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MAKING UP PERSONHOOD: AN ETHNOGRAPHIC STUDY OF SPECIAL EDUCATORS  
AND INTELLECTUALLY DISABLED ADULTS IN INDIA

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## **Abstract**

This dissertation examines the relational context between special educators and intellectually disabled adults in Pune, India. It analyzes how special educators intervene in the lives of intellectually disabled people to shape or make up their personhood. This study is based on 15 months of ethnographic research within institutions such as vocational centers, workshops, and residential facilities in India that cater to intellectually disabled adults who do not necessarily communicate using conventionalized speech-based language and often require support with activities of daily life. Within these institutions, special educators and intellectually disabled adults often spent a considerable amount of time together participating in activities such as working, resting, and having fun. In this context, special educators noticed and interpreted gestures, facial expressions, behaviors, and utterances of intellectually disabled adults and decided what these meant. Further, based on their interpretations, they also decided what intellectually disabled people could in these institutions and even who they were as people. In doing so, they constructed the personhood of intellectually disabled people, shaped their own expertise as people who understood and “knew” intellectually disabled people, and maintained order and achieved workflow within these institutions.

I use the concept of “intervention” to analyze the ways in which special educators interacted with intellectually disabled people because most of these interactions, despite being creative, were top-down and hierarchical in nature, wherein special educators called the shots and intellectually disabled people often did not have much space to provide their feedback. I examine how special educators intervened in the domains of communication, work, fun, and sexuality. In doing so, they made up intellectually disabled people as people who could

communicate (in limited and interpretable ways), work (under supervision and on repetitive tasks), have fun (in a consumption-oriented manner), and be sexual and romantic (with direction and within limits). This dissertation is divided into two parts. The first half of the dissertation examines how special educators intervened in the lives of intellectually disabled adults on an everyday basis within institutions by communicating with them and occupying them, through productive work as well as activities of fun. In the second half of the dissertation, I shift attention from everyday interventions and consider the ways in which special educators (some of whom were also parents of intellectually disabled people and founders of institutions) imagined and implemented long term and future oriented life projects for intellectually disabled people. Across the dissertation, I engage with the articulations of intellectually disabled people that were either ignored or rejected by special educators. While the interventions made by special educators were often generous and created opportunities for intellectually disabled people, the personhood shaped through the interventions was narrow or restricted because it was often limited to these institutions, did not capacitate or develop intellectually disabled people's skills, and did not offer them many choices regarding what they could do.

In examining the hierarchical yet often responsive interventions made by special educators, this dissertation challenges western, rational, and individualistic models of personhood, adulthood, and expertise and offers an alternative that is enacted relationally through the interpretations and actions of multiple actors. It also traces lives of intellectually disabled people both within and outside institutions and offers a perspective on the marginalized and peripheral status of intellectually disabled people in mainstream Indian society. The dissertation also theorizes the concept of intervention as a complex relational practice that can be top-down as well as creative and generous at the same time.

## Introduction

### Geeta's and Sarika Ma'am's Story

Why does she like putting the glass bottle near her pee-hole? She couldn't talk and tell us what was going on...what did she exactly want? What was in her mind?... [I]t was very hard to figure that out...but I had to keep working on this because we work with *special mula* [special children in Marathi], and we are special educators.

Sarika ma'am , a special educator, and the principal of the vocational center at the Rainbow Foundation<sup>1</sup>, a non-governmental institution that provides education and vocational training to intellectually disabled adults shared this anecdote in Marathi (although as I noted, she used some words in English). She was talking about Geeta, an intellectually disabled woman, who attended the vocational center. She shared this story during a sexuality workshop that she and I had co-organized for the other special educators in Summer 2019 when I was doing my preliminary ethnographic fieldwork there. Sarika ma'am continued with the story and said that she noticed this behavior of Geeta putting the glass bottle near her "pee-hole" multiple times and was worried that she might hurt herself if the bottle broke. So, she approached other senior special educators, Geeta's parents, and the counselor who worked at the Rainbow Foundation to find a solution for Geeta to stop using the bottle. She said that she first replaced the glass bottle with plastic bottles, such as a ponds cream bottle, and kept them in front of her. However, Geeta did not want to use the plastic bottles and continued using the glass bottle. Sarika ma'am became more worried and wanted to get to the bottom of this. Since Geeta was non-verbal, Sarika ma'am

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<sup>1</sup> The names of all the individuals and organizations in the dissertation are anonymized to safeguard confidentiality unless mentioned otherwise.

could not ask her and find out why she used the glass bottle. One day during an activity in which intellectually disabled people were asked to hold hands with each other, Sarika ma'am noticed that Geeta enjoyed holding hands with a young intellectually disabled man who also attended Rainbow Foundation. This prompted Sarika ma'am to wonder if Geeta liked the rough texture of his hands. She said that she noticed Geeta's expressions and body language and it looked like she was enjoying his touch. She concluded that Geeta was missing the sensation of touch in her life and proceeded to take measures through which Geeta and this young man could touch each other under her supervision. When Geeta's foot hurt, Sarika ma'am asked the young man to give her oil massages. When Sarika ma'am organized group trips to the mall, she asked him and Geeta to hold hands. She ended the anecdote saying that Geeta no longer used the glass bottle.

This was not the first time I had observed special educators attending to, interpreting, and subsequently responding to the behaviors of intellectually disabled people. In Geeta's case, Sarika ma'am went through the process of noticing Geeta's behavior of using the glass bottle, worrying about it, interpreting it as unsafe, offering Geeta a plastic bottle which is rejected by her, responding to this rejection by re-interpreting the behavior as denoting Geeta's fondness for rough textures or hardness, and eventually deciding that Geeta and the young man should hold hands.

The sexuality workshop was held on my last day of preliminary fieldwork. I started doing ethnographic fieldwork at Rainbow Foundation in June 2019. When I began this research, I was interested in exploring the ways in which special educators supervised and regulated the sexuality of intellectually disabled people. The year before, in Summer 2018, I had interviewed special educators in Kolkata and Wada, a village three hours from Mumbai, about their views on intellectually disabled people's sexuality. During these interviews, special educators talked about

intellectually disabled people's sexuality in terms of problem behaviors, such as public masturbation, that had to be regulated and managed in socially appropriate ways. I was intrigued by how openly they talked to me about matters of sexuality and wanted to learn more about how sexuality emerged as a problem area within institutions that catered to intellectually disabled people. This led me to Rainbow Foundation in Pune. I found out about Rainbow Foundation through Tathapi Trust (original name), a non-governmental organization where I worked as a research consultant before moving to the United States for my graduate studies. My colleagues at Tathapi Trust had conducted sexuality awareness workshops with Rainbow Foundation and encouraged me to conduct my fieldwork there.

When I approached the administrative head at Rainbow Foundation and told her that I wanted to conduct research on sexuality (or *laingikta*, the Marathi translation of the word), she granted me permission to observe their vocational center, which catered to people over 18 years of age. She also asked me to write an article with my research findings for their annual report and do a sexuality education workshop with the special educators at the end of my fieldwork period. During my fieldwork, I came to realize that my previous findings about special educators viewing sexuality exclusively in terms of problem behaviors were reductive and did not get to the heart of what was happening between special educators and intellectually disabled adults. Most intellectually disabled adults at Rainbow Foundation did not use conventionalized language to communicate. Interactions between special educators and intellectually disabled adults, and even among intellectually disabled adults, did not take the form of organic back-and-forth, in the sense that when educators asked questions to intellectually disabled adults, they often did not receive verbal or quick answers. Or when special educators asked intellectually disabled adults to do a task, they would often have to repeat their instructions to get them to do the task.

Intellectually disabled adults also often used gestures, facial expressions, or repetitive phrases and utterances to express themselves. Further, intellectually disabled adults required support with everyday tasks, such as eating, bathing, and transportation. I observed that in addition to teaching basic mathematics, languages (English and Marathi) and providing vocational skills in canning, file making, baking, and clothes stitching, special educators played a large role in their lives by assisting them with activities of daily living. They helped them with washing up and using the toilet, reminded them to take their medication, and accompanied them during meals. Indeed, intellectually disabled adults spent a considerable amount of time in these institutions learning, working, exercising, resting, and participating in extracurricular and recreational activities.

In the absence of conventional communication, I observed special educators interpreting peoples' unconventional linguistic cues (e.g. utterances and non-linear sentences) and non-linguistic cues (e.g. actions and behaviors). They developed communicative and semiotic repertoires based on familiarity and caregiving routines. On an everyday basis, special educators made sense of what intellectually disabled adults needed and desired and eventually decided what they could or could not do in various domains of life. While special educators concerned themselves with matters of sexuality, it was not the only domain of their interest. I observed them being involved in the domains of communication, learning, occupation, and recreation. For instance, special educators constantly talked to intellectually disabled adults and made confident claims about what they were saying in return. They also made decisions about what intellectually disabled adults should be doing with their time in these institutions and valued them in specific ways depending on whether they could do productive work. Further, special educators also made available opportunities for intellectually disabled adults to socialize and participate in activities of fun and enjoyment. Moreover, these domains were not always separate: for instance, when



Sarika ma'am decided that Geeta would enjoy holding hands with the young man during their mall outings, she created both recreational and (perhaps) sexual opportunities for her at the same time. Further, not only did special educators make day-to-day decisions in the lives of intellectually disabled people, some special educators, in collaboration with other stakeholders, such as parents, were also invested in planning the long-term futures of intellectually disabled adults. For instance, Sarika ma'am and Geeta have known each other for 20 years and Sarika ma'am is intimately involved in making decisions about where Geeta lives, what she does with her days, and who she spends her time with. Special educators emerged as intimate stakeholders in the lives of intellectually disabled adults whose decisions significantly shaped their life trajectories.

Thus, for my dissertation research, instead of focusing exclusively on the domain of sexuality, I re-framed my research inquiry and decided to expand its scope beyond sexuality to examine domains such as communication, occupation, and recreation. While sexuality was still going to be an important domain for me to investigate, I decided not to lead with it and instead chose to focus on how special educators acknowledged, categorized, and assessed behaviors and actions of intellectually disabled adults, whether as sexual or otherwise. Drawing on disability anthropology and disability studies scholarship, I wanted to examine how, within institutions, such as vocational centers, workshops, and residential facilities, special educators made sense of intellectually disabled adults' nonnormative cues, how they came to "know" their needs, desires, and personalities, and how, based on these, they shaped specific life-paths for them. The research questions for my dissertation changed and now I wanted to know: How did special educators make up intellectually disabled people as persons? In turn, how did special educators make themselves up as experts through their work with intellectually disabled people? Before delving

into what I mean by “making up” people, a concept I borrow from philosopher of science Ian Hacking (2007), I first examine anthropological scholarship on personhood in India to set up the stakes of my dissertation within the Indian context.

### **Who Is a Person in India?**

According to anthropologist Janet McIntosh, “We are born human beings but personhood does not attach to all humans; rather, it is something to be attained or imputed” (McIntosh 2018, 1). McIntosh states that while all societies may not have a term for personhood, “all of them have beliefs and ideologies about the qualifications necessary to be classified or treated as a full person in the world ( McIntosh 2018, 1). In her words, personhood is, “a quality thought to be constituted throughout the life course through rituals, exchanges and interactions, moral bearing, and so forth”. (McIntosh 2018, 1). In McIntosh’s view, while everyone is born a human being, personhood is a state that is attained or conferred through social, religious, and interpersonal practices, which may differ from one society to another.

Much of the classical anthropological scholarship on India adopts a comparative approach and set up a binary between Western and Indian societies. This literature claims that people in India are made up through collective social categories, such as, caste, gender, religion, and community (Mookherjee 2013). Louis Dumont (1980) in his seminal text *Homo Heirarchicus: The Caste System and its Implications* frames the caste-system as the central axis of social organization in India. He proposes that while at their core, western societies value equality and organize themselves around the individual, caste-based society in India is based on hierarchy which is maintained on the principles of the separation of the pure and the impure. In line with Dumont, Shweder, Mahapatra, and Miller (1987) also argue that given that the Indian

society is organized around a rigid caste hierarchy, Indians reject ideas of equality, autonomy, and independence, and value hierarchical relationships, dependencies, and paternalism. Thus, there exists a classical anthropological perspective that states that Indians are embedded in the rigid and hierarchical caste system that imputes differential worth to people born into different castes.

On the other hand, classical anthropological literature has also conceptualized the Indian person as a highly relational being. For instance, McKim Marriot (1976) suggests that Indian people are “dividuals”. Unlike the Western “individual”, who is an indivisible and bounded person, the dividual is made of substances, such as, blood, food, and money, that are transmitted from one person to another through social relationships and transactions. Busby (1997) draws on Marriot’s concept of the dividual but adds an important caveat. She argues that Indian people are internally whole but permeable. By focusing on the axis of gender, she illustrates that while gender in India is defined by fixed and stable bodily differences, it is also actualized in the ability to transact in specific ways. To be a man, one must not only have a penis but also effectively transact semen. Busby articulates an Indian as a “bounded, but permeable, fluid person, connected to others through the flow of substances”( Busby 1997, 275).

More recent scholarship on Indian personhood has challenged generalizations about Indian personhood. Arjun Appadurai (1988) critiques Dumont’s assertion that the Indian society is rigidly hierarchical. He argues that Dumont frames Indians as “natives”. Natives, according to Appadurai, are those who are not only confined in terms of their mobility but also their intellectual and moral abilities. In Appadurai’s analysis, by framing Indians as natives, Dumont freezes Indian personhood and ties it to essentialized and totalizing socio-cultural categories. Anthropologist Mattinson Mines (1988) also critiques the consensus that Indian

society is hierarchical in nature with no room for individualism. Based on 23 life histories in southern India, Mines demonstrates that Indians are active agents with personal goals and desires that lead them to make decisions and take responsibility for their lives, even if it means rebelling against caste and family norms. Medical anthropologist Sarah Lamb (2018) in her ethnographic research with Rural Bengali women explicitly makes an argument against the binary set up between Western individual personhood and Indian relational personhood and states that values of relationality and individuality are often intertwined with one another in India. By focusing on the concept of “maya” which translates to worldly attachments, Lamb demonstrates how ageing Bengali rural women saw themselves as both relationally enmeshed with others but also as separable and unique individuals, who tried to extract themselves from worldly relationships or “maya” through practices such as eating separately as they grew older. Thus, recent scholarship has taken a more nuanced approach to Indian personhood framing it as simultaneously hierarchical, relational, and individualistic. The Indian person is a complex being who is simultaneously hierarchically bound, relationally produced, and yet an individual. Social categories, such as, caste, gender, religion, and disability exercise great influence on one’s status in the Indian society. Not all Indians are equal persons. Further, relationships, especially those forged through institutions, such as, marriage and family, shape people’s social roles in Indian society.

In the larger normative Indian society, upper-caste, upper class, non-disabled, married, Hindu men occupy positions of most status and power, both within domestic and public spheres. Where does this leave disabled, particularly, intellectually disabled people? Disability studies scholars in India have deliberated on what it means to be a disabled person in India. They have discussed how disabled people in India have been approached through the religious lens as either

“holy” or as sufferers or karma, wherein their disability is seen as a consequence of sins of their previous life (Miles 1995; Ghai 2002). Anita Ghai (2002) also discusses how disabled people are infantilized in India and are seen as needing protection or charity. This charity or pity model, she argues, inspires people to donate food, clothes, and money to shelters and organizations that work for disabled people. However, this does not mean that disabled people and their families do not negotiate with social institutions, such as, kin and the state for them to attain social roles, opportunities, and even rights.

Veena Das and Renu Addlakha (2001) discuss how families of disabled women secure somewhat normative futures for their disabled daughters by strategically negotiating and blurring the distinction between the domestic and public sphere. They present a case study of a family arranging their daughter’s marriage under civil law, instead of a social and religious marriage, thereby circumventing kinship networks who wrote her off as not worthy of marriage. Thus, these families engaged in the strategic work of making their child a person. James Staples (2005) in his ethnographic work on masculinity and personhood within a community of leprosy-affected people in South India explores how men with leprosy develop child-like relationships with foreign donors by surrendering their masculine role in this relationship while simultaneously asserting their masculinity while dealing with younger men within their own communities.

This scholarship is significant because it tells us that despite being marginalized within Indian society, disabled people and their families find ways to exercise their agency within their constrained environments. However, most of this literature does not focus on intellectually disabled people. The exceptions to this are Vaidya (2016) and Ghosh and Banerjee (2017) who examine how families become the main site of assistance and support for intellectually disabled people in urban as well as rural India. Further, Mehrotra and Vaidya (2008) focus specifically on

rural intellectually disabled men and demonstrate that while intellectually disabled men in rural Haryana do not have the same status as non-disabled men, they are absorbed into domestic and work spheres by doing traditionally feminine chores, such as, cooking, cleaning, and fetching water that contribute to the household and village economy. Thus, disability studies scholarship in India has analysed diverse social roles and relationships that pertain to disabled people in India. In particular, these scholars have examined the ways in which the family plays a big hand in shaping the life trajectories of disabled people, especially intellectually disabled people. However, this scholarship has not examined how intellectually disabled people live in urban India and the role that institutions and institutional stakeholders, such as, special educators, play in shaping these lives.

During my fieldwork, I observed that many intellectually disabled people were absorbed into the domestic sphere, wherein they contributed to the household by doing chores such as washing and drying utensils, folding clothes, and assisting with cooking. Within the domestic sphere, intellectually disabled people sometimes had close relationships with their parents, siblings, and extended relatives, wherein they spent time with each other over activities such as eating, watching television, and chit-chatting. Across class backgrounds, families also shared with me that they never excluded their intellectually disabled family member when they went out to restaurants, holidays, or family events, such as, marriage ceremonies. However, intellectually disabled people did not inhabit independent social roles in urban Indian society, especially in the public sphere. With a few exceptions, they often did not go to mainstream schools or colleges, did not get married or have children and did not have paid jobs. To the best of my knowledge, I never saw them going for movies, hanging out at tea stalls, or going for walks by themselves. Whenever they went out, they were accompanied by their families or special educators. Thus,

intellectually disabled people often lived limited or restricted lives and did not participate in most mainstream social, cultural, and interpersonal activities on their own terms. The terms of their participation were usually decided by either their families or institutional stakeholders, such as special educators.

Intellectually disabled people often did not exhibit normative language, behaviours, and comportment. To explain what I mean by normative, I draw on the concept of Crip Linguistics (Henner and Robinson 2023) which frames normative language as that which reduces language to speech sounds and written systems representing speech sounds, often at the cost of excluding different ways of languaging, such as, touch, drawing, or gesture. Not having access to normative language, behaviours and comportment led to their systematic exclusion from institutions, rituals, and interactions that are part of social, cultural, and political life in urban India. They were often pushed out of mainstream schools for not being able to keep up, were considered unsuitable for marriage (given their assumed lack of understanding and ability to contribute to the household), and often quit their jobs, because of instances of bullying and being overwhelmed with their workload <sup>2</sup>.

Considering that most intellectually disabled people were excluded from normative social life, institutions, and networks, social categories, such as, caste, gender, and religion did not shape their personhood in the same way as other Indians. For instance, even though intellectually disabled people from upper-caste backgrounds, such as Geeta, could go on vacations to Indian and foreign locations with their families, their intellectual disability shaped the fact that they

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<sup>2</sup> Workplace bullying and harassment is increasingly becoming an issue as the corporate sector in India has started collaborating with NGOs to hire people with learning disabilities, ADHD, and so-called “high functioning” autism. (Sreeradha Basu and Brinda Sarkar, “India Inc embracing neurodiversity”, *The Economic Times*, April 14, 2024, <https://tinyurl.com/yw4wfekb>)

could not access many other privileges that come with their caste location. They were unable to attend reputable mainstream private schools, have well-paid jobs, or inherit and manage property. Further, unlike upper-caste urban women of their background and age who were expected to be married and have children, there were no societal expectations for intellectually disabled women, such as Geeta to marry or reproduce. On the other hand, while intellectually disabled people from lower caste and class backgrounds were disadvantaged because their families were often poor, their intellectual disability shaped their life trajectories in such a manner that they were not exposed to systematic discrimination in higher education institutions, while seeking jobs and apartments for rent, or in the marriage market. Similarly, although the contemporary Indian society is highly Islamophobic, I did not observe Muslim intellectually disabled people within special education institutions being treated any differently by their special educators, although they had to follow Hindu rituals in most of the institutions I visited (during prayer time and festivities) given that these institutions were founded and run by dominant caste Hindus. Thus, being intellectually disabled somewhat insulated them from being shaped by social categories in the same way as others.

However, this does not mean that social categories did not affect their personhood at all. If intellectually disabled people belonged to upper to upper-middle class and Brahmin or other dominant caste backgrounds, they were more likely to attend private institutions which charged a fee for attendance, such as Rainbow Foundation and Udaan, which were two of my field-sites. In contrast, intellectually disabled people who came from poorer families and/or minoritized caste backgrounds were more likely to attend government aided institutions which did not charge them a fee, such as Sankalp, which was another field-site of mine. This influenced the opportunities presented to them. For instance, Rainbow Foundation and Udaan organized overnight picnics



and hikes which were partially paid for by the families of intellectually disabled people. In contrast, programming at Sankalp did not include any recreational activities which would involve families bearing major expenses. This made the everyday life of people who attended Sankalp more bound by a routine that focused on vocational activities that occurred within the institution. Families of intellectually disabled people from privileged backgrounds could afford private medical care and access rehabilitation experts for their children. This was not a possibility for those who came from poorer families. Further, gender also shaped the personhood of intellectually disabled people. Women faced more scrutiny than men from special educators when it came to their clothing. Special educators would constantly ask them to adjust their clothes, so that their bra-strap was not showing. On the other hand, special educators regulated men more when it came to behaviors which they interpreted as “sexual” or “masturbation”. Thus, although social categories shaped the lives of intellectually disabled people, these categories did not absorb them fully and affected their lives on a different scale and in different contexts. Further, other categories, such as their diagnosis affected their lives too (although many people did not have a specific diagnosis). For instance, having diagnoses, such as, “Down syndrome” and “autism” set them apart from their families, making them into specific kinds of individuals with specific idiosyncrasies and needs, and not just relational beings who exist in and through their relationships with their families. Additionally, factors such as the significance of disability one had also interacted with other social identities, sometimes to the effect of reducing the impact of the other social identities. For example, Bilal, a young Muslim man at Sankalp workshop had a milder form of intellectual disability (he did not have a specific medical diagnosis) compared to his peers which made him one of the most productive members of the workshop and a favorite among the special educators. This was despite that fact that some of

these special educators and higher administrators harbored and sometimes shared their anti-Muslim sentiments with each other and me.

Special educators too occupied a complicated position in Indian society. Social categories and identities such as gender, class, and caste shaped their lives and affected their self-perception. Most special educators that I interacted with were young and middle-aged Hindu women who were married and had children. Given this, they were expected to fulfil multiple domestic responsibilities along with their jobs. Special educators from upper-caste and upper-middle class backgrounds often had access to caste-class privileges, such as, economic security, domestic workers to support them at home, and access to English language education. In contrast, special educators who belonged to marginalized class and caste backgrounds often faced more financial strains and had to manage their domestic responsibilities without any support. Despite these differences, across diverse social identities, special educators perceived themselves as people who did a low-paying and low-status job which was under appreciated by administrators, parents of intellectually disabled people, and their own families. Further, they shared with me that their work was undervalued because the larger society was ignorant about the group of people they worked with and understood them in derogatory terms as *vedi loka* (crazy people in Marathi). Thus, although special educators themselves exhibited normative comportment, language, and behaviours, they perceived themselves as being underappreciated and maybe even stigmatized given their close association with a nonnormative group of people.

Within this larger social landscape, aside from familial homes, institutions, such as, special schools, vocational centres, and residential facilities emerged as segregated spaces in which intellectually disabled people in urban areas spent a considerable amount of their time often over long periods of time. In these institutions, special educators were their main

interlocutors, who did the relational work of constructing or “making them up” as people. Thus, even though everyone’s personhood is made up through social categories and relationships, intellectually disabled people (and by extension, special educators) existed on the peripheries of Indian society, where they did not occupy social identities, roles, and institutions in the same way that non-disabled people did. This makes it important to make note of how their personhood was differently “made up”.

### **The Work of Making Up: A Ruptured and Leaky Process**

I draw on as well as depart from Ian Hacking’s concept of “making up people” (2007) to frame the ways in which special educators shaped intellectually disabled people. By making up people, Hacking refers to, “the ways in which a new scientific classification may bring into being a new kind of person” ( Hacking 2007, 287). For instance, Hacking analyzes how the emergence of the medical category of autism gave rise to completely novel ways of experiencing oneself and one’s interactions with families, friends, employers, and counselors for those diagnosed as autistic. According to Hacking, making up people does not only involve the process of categorizing or classifying. It also involves the individuals who receive the classification, the institutions that legitimize the classification, knowledge about the classification, and experts who have the qualifications to legitimize the classification.

Hacking also proposes the concept of “the looping effect” (Hacking 2007, 286) as a necessary implication of the process of making up people, which he articulates as, “the way in which a classification may interact with the people classified”. By this he means that while classifications may be applied in a top-down manner by scientific and medical authorities, those who are classified also respond to being categorized, sometimes by resisting the connotations of

these classifications. For instance, people categorized as homosexual resisted the negative connotations of this label and eventually effected change which led to homosexuality no longer being defined as a disease. Thus, according to Hacking, individuals made up through such classifications do not remain static. Instead, they are “moving targets” (Hacking 2007, 293), ever changing due to the changing dynamics between the classification, the individuals classified, knowledge systems, and expert opinions.

Hacking was interested in medico-scientific classifications, such as, multiple personality disorder and autism in his theorization of “making up people”, which are conferred impersonally by experts who do not share deep relationships with the individuals who receive the classification. In my dissertation, I take up Hacking’s term “making up people” and apply it to a very different context. Special educators at my field-sites were not medico-scientific experts in the same way as psychiatrists and medical doctors. They interacted with intellectually disabled people daily within institutional settings, in which they occupied positions of relative authority. Within these settings, special educators “made up” intellectually disabled people by imputing meaning to their behaviors, based on which they made decisions regarding what they could do and who they were as people. Thus, the “making up” of people in my field-sites was much more hands-on and happened through everyday interactions. Special educators made claims about intellectually disabled peoples’ academic and vocational performance, friendships, and rivalries, and even their feelings or mood on a particular day by noticing and interpreting their speech, behaviors, and actions.

This process of “making up” which took place through everyday interactions also involved special educators using enduring categories or classifications. These categories had explanatory power and were used by special educators to make sense of intellectually disabled

people and to assign them social roles. However, these categories, (i.e., special mula), were often different from medicalized, generalizable, scientific categories, such as, “autism”, which Hacking discusses in his work. Although as I write about this in detail later, administrators and educators at urban institutions asked families of intellectually disabled people at the time of their child’s admission to take their children to government hospitals to undergo medical testing (usually involving an IQ test) to receive the government’s disability certificate. As such, most of the intellectually disabled people that I interacted with at my field-sites did have a disability certificate which stated that they had government recognized disability status. Further, some individuals, not all, also had a medical diagnosis, such as “autism” and “Down syndrome”. However, these medical terms were less prevalent than the non-medical categories that emerged within these institutions.

For instance, the category, special mula used by special educators across institutions to refer to all intellectually disabled adults was not a medical or scientific category and did not involve the formal process of diagnosis. All intellectually disabled people had to do to be a special mula was to attend these institutions. The category was neither strictly local (given that it included the English word special which was derived from the western field of special education) nor strictly globalized (given that it used the word for children in Marathi). Special educators used the category of special mula to set intellectually disabled people apart from “normal” people (normal was a word of their choice for non-disabled individuals). The word special framed intellectually disabled people as innocent, loving, caring, and obedient- all things that made them different from normal people, whose rational and intellectual abilities were seen as corrupting influences. On the other hand, the word *mula* (children) framed intellectually disabled people as forever children. During many discussions with me, special educators shared with me

that while special mula physically and even sexually developed at the same pace as their “normal” peers, they lagged when it came to their mental capacities. This line of thinking also became evident when special educators sometimes used the term mental age, from the field of psychological testing, to describe the intelligence of some of the individuals by saying things, such as, “he is 21 years old, but his mental age is that of a 4-year-old”. The term special mula, thus, established intellectually disabled people, even the adults, as people with mental deficits or limitations that made them unable to do things that “normal” people do, such as, go to mainstream schools and colleges, have paid jobs, and get married and have children. However, it is the same deficits that also made them innocent, loving, and caring, in ways that normal people, due to their intellectual capacities, would never be. Thus, intellectually disabled adults were never really adults. They were always chronologically out of time as “unfinished adults” (Kafer 2013, 54) who could not occupy normative personhood in social, economic, and political domains (although there were some exceptions who did paid work, got married, and even voted). Further, by framing intellectually disabled adults as special mula, special educators justified their own behavior of constantly scrutinizing, supervising, and overseeing intellectually disabled adults.

Aside from special mula, special educators used other categories which were local and emerged from specific institutional goals and values. For instance, at Sankalp, a government-aided workshop which valued productivity, discipline, and orderliness, special educators categorized those intellectually disabled people who could do productive work (such as sewing) as *changli mula* (good children in Marathi) and *kaam karnari mula* (children who work in Marathi). Those who could not do such work, and thus, ended up spending most of their sitting were classified as *basnari mula* (children who sit in Marathi). Finally, as stated before, while

formal medical diagnosis was not especially important in the institutions I worked at, considering that the institution's programming was in no way affected by individual diagnosis, special educators sometimes made use of diagnostic or medicalized categories to describe specific individuals. In discussions with each other, me, parents, and administrators, such as principals and trustees, special educators used categories such as "Down syndrome", "autism", and "cerebral palsy" when talking about the behaviors, personalities, or even physical traits of specific individuals. For instance, special educators would sometimes point to a person with Down syndrome and say to me, "he is very tidy and clean because he has Down syndrome". Thus, special educators used categories of diverse kinds while talking to and talking about intellectually disabled adults and these categories shaped the ways in which intellectually disabled adults came to be viewed and eventually treated within these institutions.

Not only did special educators categorize intellectually disabled adults, but they also used the category of "special educator" in English to talk about themselves. They would share with me how as special educators, they were different from mainstream teachers, who did not need to anticipate and interpret the diverse needs of their students, because their students could verbalize their needs. Further, in categorizing themselves as special educators, they also distanced themselves from parents of intellectually disabled people, who according to them just coddled and isolated their children at home, not providing them with the exposure they needed to develop. For instance, during the sexuality workshop, many educators shared how often parents got agitated when their children received phone calls from their classmates. Special educators thought that calling each other was a normal part of being teenagers for everyone, including intellectually disabled adults. Thus, special educators positioned themselves as people who had a unique role to play in the lives of intellectually disabled adults- as people who understood what

they needed or who they were, sometimes even better than their parents. Although special educators sometimes distinguished themselves from parents by talking about the training they have received in order to do their current jobs (either through formal degrees in special education or on-the job training at institutions), most special educators stated that it was the experience (*anubhav* in Marathi) that had they gained from working with many different kinds of special mula at the same time that set them apart from parents, who only knew their own child. Thus, special educators saw themselves as people who did important and unique work, despite their expertise not always being valued by other stakeholders. Patience, empathy, innovation, and quick thinking were common qualities listed by special educators as essential for being good special educators. Thus, not only did special educators “make up” intellectually disabled adults through their daily interactions during which they relied on categories, they also made themselves up as hands-on and experienced experts through the category of “special educator”.

Lastly, Hacking imagined making up people as a seamless and circular process as follows: people either fit their classification seamlessly or they did not and resisted the classification. This was not the case in my field-sites. The process of making up people was ruptured, leaky, and uncertain. While special educators made up intellectually disabled adults as people who felt, desired, and needed specific things, intellectually disabled adults did not always mirror these claims in their behaviors or actions. For instance, although Sarika ma’am was convinced that Geeta did not use the glass bottle anymore, there was no certainty about this fact. It is possible that Geeta still used the glass bottle in her privacy, away from the supervision of Sarika ma’am. In another example, while all the special educators shared with me that all special mula were innocent, loving, and obedient, I observed intellectually disabled adults often acting in ways that were not apparently innocent or loving, such as, scolding each other, getting into



fights, and refusing to listen to the orders given by special educators. Thus, while special educators attempted to shape or make up intellectually disabled people in specific ways, these attempts were not always seamless.

Further, unlike the examples that Hacking provides of homosexual individuals and high-functioning autistic individuals, who banded together and collectively resisted the negative connotations of their classifications, thereby changing these classifications themselves, the intellectually disabled adults I interacted with did not have the power to effect such change. Considering that most of these individuals did not use conventionalized language and depended on special educators for their day-to-day existence within these institutions, there was acute asymmetry between the educators and intellectually disabled adults, making it nearly impossible for them to collectivize and resist the ways in which special educators made them up as people. However, this does not mean that intellectually disabled adults were always obedient. They routinely expressed themselves in ways that did not fit the categorization and claims of special educators. In this dissertation, I trace the ways in which special educators made up intellectually disabled people and themselves in an uncertain, leaky, and ruptured manner and hold on to the ways in which this process of “making up” was indeed imperfect. Next, I shift to examining the concept of intervention, which I use throughout the dissertation to analyze the ways in which special educators made up intellectually disabled adults, and in turn, made themselves up as well.

### **Special Educators as Interventionists**

Bucholtz and Hall (2005) argue that identities are intersubjectively rather than individually produced and emerge through interactions rather than being assigned in a priori manner (587). According to these authors, while macro sociological categories such as, gender and race are

significant, identities emerge through the more temporary interactional positions, roles, and orientations (such as, evaluator, engaged listener, and so on) that people assume during interactions, which may accumulate over time to forge ideological associations and may eventually shape how and in what ways people interact (591). In resonance with Bucholtz and Hall, in this dissertation, I illustrate that special educators made up intellectually disabled adults and themselves as persons through relational interactions within specific institutional contexts. Specifically, I propose that special educators interacted with intellectually disabled people as “interventionists” in order to make up their personhood.

The Oxford English Dictionary (OED) defines intervention as ‘stepping in’, or interfering in any affair, so as to affect its course or issue<sup>3</sup>. Intervention is a “troublesome word, particularly for anyone trained in anthropology” (Redfield 2018). The term has been associated with top-down colonial, humanitarian, and medical projects in the domains of military action, surgery, public health, and psychiatry (Redfield 2018; Yates-Doerr et al. 2023). Thus, the concept of intervention often carries a negative subtext of powerful (often colonial and imperial) stakeholders taking action and making decisions about marginalized groups. However, intervention is also a contested term and can mean different things for different disciplines. For instance, in the field of design, intervention is a “constitutive element of its practice” (Redfield 2018), which essentially means that to design, one must intervene. Further, while interventions may often be designed in a top-down manner, their practice can sometimes be more interactive and collaborative (Yates-Doerr et al. 2023). For example, although anthropologists have done significant research that highlights the ways in which global health interventions often serve

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<sup>3</sup> Oxford English Dictionary, s.v. “Intervention (n.)”, accessed July 13, 2024, [https://www.oed.com/dictionary/intervention\\_n?tab=meaning\\_and\\_use#125537](https://www.oed.com/dictionary/intervention_n?tab=meaning_and_use#125537)

military goals of surveilling and controlling specific populations, take the form of “magic bullet” laboratory-based solutions which ignore structural issues, and can be based on deterministic, de-contextualized models, various scholars have also demonstrated how some interventions when implemented or appropriated by local actors can become locally meaningful, anti-imperial and non-western in nature (Yates-Doerr et al. 2003). Drawing on these authors and the OED, I frame interventions as top-down practices of stepping in or interfering that are enacted by relatively powerful actors (special educators) while interacting with intellectually disabled people, who are a marginalized group. However, in resonance with these authors, I also approach the interventions made by special educators as complex and sometimes surprising actions that result in different outcomes depending on the larger context of who is making the intervention, under what circumstances, in what way, and to what end.

I view special educators as interventionists because they occupied positions of power as experts who could figure out, understand, and know intellectually disabled people. However, their interventions were often complicated actions which also included them engaging with the nonnormative behaviors, gestures, and actions of intellectually disabled people. However, these engagements were never horizontal or equitable because these were always followed by top-down and unilateral decisions about what intellectually disabled people thought, felt, needed, what they could or could not do, and who they were as people. Going back to the opening vignette, Sarika ma’am engaged with Geeta’s behavior of putting the glass bottle near her genitals and interpreted it as dangerous. However, instead of asking Geeta any follow up questions about this behavior, Sarika ma’am unilaterally came up with the decision to provide her with a plastic bottle. When Geeta rejected the plastic bottle, Sarika ma’am came up with another solution- that of Geeta holding hands with a young intellectually disabled man. She

made this decision because she had noticed Geeta enjoying herself when she held hands with this young man during a group activity. While I do not intent to dismiss nonnormative cues such as facial expressions as valuable signals of communication, what I want to point to here is the certainty and confidence with which Sarika ma'am framed her solution of handholding as the right one based only on her own interpretation of Geeta's facial expressions.

Did Geeta truly like holding hands with the young man? Did she stop using the glass bottle? These were not questions that informed Sarika ma'am's relational practices. Special educators called the shots about what these cues meant and what needed to be done next. It is this top-down, asymmetrical and certain nature of interactions initiated by special educators that lends well to the framework of interventions. It was through these asymmetric interventions that special educators made up intellectually disabled people as persons. However, despite being asymmetric, these interventions were complex: intellectually disabled people were not entirely absent from these interactions. They were constructed as unequal participants given that special educators often engaged with them by noticing, interpreting, and responding to their cues. In turn, it was through these interventions that special educators also made themselves up as experts who did the important work of attending to, interpreting, and responding to the needs and desires of the special mula they worked with. As Sarika ma'am said in the opening vignette, "... what did she exactly want? What was in her mind?... [I]t was very hard to figure that out...but I had to keep working on this because we work with special mula, and we are special educators".

Before proceeding, I want to address the anthropological concept of facilitation and make a case for why despite its relevance and influence on my analysis , I do not use the term and instead opt for the concept of intervention. Don Kulick and Jens Rydström use the concept of facilitation in their book *Loneliness and its Opposite* (2015) while describing the systematic

ways in which trained sexual advisers actualize the sexual desires of their cognitively disabled clients. Their book provides a model of sexual facilitation in which cognitively disabled people participate in a multitude of sexual activities by seeking assistance from caregivers and professionals. Based on the Danish model of sexual advisers, the authors advocate for more strategies that, “facilitate disabled people’s capacity to engage in a range of social and emotional relations with other people” (2015, 20). Kulick and Rydström frame facilitation as a set of relational practices, which include communicating with cognitively disabled people about their sexual desires and collaborating with them to provide them support for the realization of these desires.

More recently, Matthew Wolf-Meyer in his book *Unraveling: Remaking Personhood in a Neurodiverse Age* (2020) approaches facilitation more expansively, beyond the domain of sexuality, and argues that all personhood is facilitated through relationships with other humans, non-humans, technologies, and institutions. To make his case, Wolf-Meyer compares conventionalized spoken and written language with facilitated communication (FC), a technology used most often by disabled people who do not communicate normatively through speech. While using FC, support persons provide physical assistance to disabled people as they produce their messages, usually by typing them out on a communication device such as a keyboard. In the recent years, FC has been debunked by its detractors for not authentically representing disabled people’s voices and instead being a vehicle for non-disabled support persons to project their own thoughts on to disabled people. According to Wolf-Meyer, this line of criticism assumes the subject to be a liberal individual who expresses themselves independently through speech without any support. However, he argues that speech-based individually produced language and FC-based language co-produced by two people have more in

common than what meets the eye. Both are tools that facilitate people to express themselves and become social persons in the process. However, the facilitative nature of speech-based individual language is invisibilized and taken-for-granted and that of FC is apparent (and critiqued) because it involves more than one person and uses a visible communication tool.

Kulick and Rydström (2015) and Wolf-Meyer (2020) use the concept of facilitation to demonstrate how sexual personhood and communicative personhood emerge through relationships with other people and technologies. On this point, I draw from these authors as special educators too made up intellectually disabled people and themselves as persons by building relationships. However, this is the extent to which I draw on the concept of facilitation because these scholars frame facilitation as a collaborative practice that capacitated disabled people to communicate and actualize their thoughts and desires. This is where the special educators I observed diverge from the framework of facilitation as they did not collaborate with intellectually disabled people. Special educators were not particularly interested in learning what intellectually disabled adults needed or wanted and then making these things happen, unlike the sexual advisers in Denmark, who acted on the expressed desires of their clients. Special educators often projected their own or their institution's worldview on to intellectually disabled people and did not make systematic attempts to understand what intellectually disabled people were feeling or trying to say. Further, none of their relational practices were aimed at helping intellectually disabled people develop or grow. Instead, special educators focused their energies on keeping intellectually disabled people occupied or busy within these institutions. Even when they interacted with intellectually disabled people beyond these institutions, special educators continued interacting with them through interventions. For instance, as I analyze in detail in Chapter 4, Sarika ma'am and Geeta's relationship continued beyond Rainbow Foundation, as

Geeta started living with Sarika ma'am and her husband on a part time basis. Despite this new arrangement, Sarika ma'am did not make any attempts to collaborate with Geeta or develop her skills in a systematic manner. Instead, Sarika ma'am continued intervening in her life by making top-down decisions about what she needed and felt.

Considering these differences, I suggest that special educators were not facilitators. Instead, I use the term intervention to encapsulate their relational practices. While special educators engaged with the gestures, behaviors, and actions of intellectually disabled people, they did not treat them as rational, independent people who could decide what was best for their own life. Special educators did not treat them as people who knew what they wanted to communicate, how they wanted to spend their time, or who they wanted to spend their time with. Thus, despite engaging with their cues, special educators intervened in their lives based on their own ideas of what works best in the given situation. I suggest that while the interventions made by special educators made up intellectually disabled people into persons, this personhood was limited. For one, this personhood was limited because of its temporary and segregated nature. It often did not extend beyond these institutional spaces and did not substantially change the perceptions or practices of the larger society regarding intellectually disabled people. Further, special educators did not capacitate intellectually disabled people with skills, tools, resources, or relationships in a substantial or a long-term manner. For instance, staying occupied with sewing at Sankalp workshop did not help anyone get paid assignments or jobs related to sewing beyond Sankalp. Finally, while some relationships such as the one between Sarika ma'am and Geeta were long-term, most interactions between special educators and intellectually disabled adults were limited to the institutions.

This is not to say that the interventions made by special educators were not creative or experimental or that these did not make possible opportunities for intellectually disabled people. I am also not suggesting that special educators were always in a position to facilitate more responsive, less top-down opportunities. As I will describe in later chapters, special educators were often under the supervision of administrators and faced pressures from parents. However, I want to pay attention to the specific modalities of interventions and trace how these affected the kinds of people both intellectually disabled people and special educators could be in these institutional spaces. At the core of this dissertation are questions about nonnormative personhood, adulthood, and expertise. How do intellectually disabled adults who do not communicate through conventional language and whose inner worlds appear to be opaque, emerge as people in the institutions that cater to them in India? What are the limits to the kinds of personhood and adulthood afforded to intellectually disabled adults through the interventions made by special educators? How do special educators frame themselves as knowing experts who make sense of intellectually disabled adults and make decisions on behalf of them? What are the social, medical, and legal categories that special educators create or use to classify them? What are the social roles and life-trajectories afforded or denied to intellectually disabled adults when special educators anticipate their desires, needs, and capabilities? These were some of the questions that led me towards doing my dissertation fieldwork, which involved a multi-sited ethnography of institutions, such as vocational centers, workshops, and residential facilities that cater to intellectually disabled adults in the state of Maharashtra in India, with a focus on the city of Pune.

In this dissertation, I chose to focus on intellectually disabled adults instead of children. Most of the intellectually disabled people I encountered in these institutions were people over 18



years of age, and thus chronological adults. While it is normative to interpret and make decisions on behalf of children, intellectually disabled adults, seen as special mula, are uniquely positioned as adults who are infantilized and supervised by other adults. By specifically attending to intellectually disabled adults, I want to challenge linear and normative ideas of development that culminate in heteronormative, financially independent adulthood and demonstrate how nonnormative adulthoods that do not follow the same linear trajectory of development also exist. At the same time, I also want to highlight how by being boxed as special mula intellectually disabled adults were restricted to limited social roles, spaces, and opportunities.

Further, I want to make clear the kind of data I was unable to gather during my fieldwork. While I conducted interviews with family members, such as, parents and siblings, which are analyzed in the dissertation (with Chapter 5 being focused on a parent-led workshop), I did not spend much time with intellectually disabled people at their homes, a space where they spent a lot of their time as well. The main reason for this was that I set out to do my dissertation research with a focus on special educators and how they constructed intellectually disabled people as persons within institutions. Given this, my key interlocutors were special educators. They were the ones through whom I contacted families, instead of trying to get in touch with them independently. However, I soon came to realize that special educators often had complicated and even resentful feelings towards parents of intellectually disabled people. As such, I was hesitant about engaging with parents as key interlocutors as I feared offending or losing the trust of my special educator interlocutors in the process. Thus, I was unable to trace if intellectually disabled people's life within institutions shaped their life at home or vice-versa. Despite this, the "home" kept showing up in different ways in the institutions where I conducted fieldwork. For example, special educators at Sankalp would write daily reports in intellectually disabled people's diaries

for parents through which they were informed about the events at the workshop, in case there was a problem, or if something specific had to be sent the next day to the workshop.

Additionally, as mentioned above, special educators also painted parents as antagonists who refused to cooperate with them by not sending their charges regularly to the workshops or not paying the fees on time. This demonstrated the ways in which special educators saw these institutions and the work they did within them as valuable, even if the parents did not. In the dissertation, I will highlight these moments as moments of connection between the home and the institution.

### **Terminology and Language**

It is important to clarify terminology and language before proceeding. I use the term intellectually disabled adults to refer to the people who attended the vocational centers, workshops, and residential facilities where I conducted fieldwork. Currently, intellectual disability is the term used by policymakers, psychiatrists, disability professionals, and academics to refer to a multitude of conditions that affect intellectual functioning, such as learning and problem solving and the ability to perform everyday activities without assistance. While I use the term intellectually disabled in this dissertation, almost none of my interlocutors used it, preferring the term special mula. Thus, in the dissertation, I switch between these two terms and use special mula whenever I quote my interlocutors or present their perspectives because the term special mula carries specific connotations of intellectually disabled adults being framed as innocent, loving, child-like, and in need of protection and supervision. Special educators also used medicalized terms such as mentally retarded (MR), slow, and autistic to describe specific individuals. While the terminology of mental retardation and slowness has problematic and

offensive connotations, I use these terms verbatim as used by my interlocutors to demonstrate the conceptual frameworks in circulation in my field-sites. Finally, for stylistic reasons I will sometimes label/term intellectually disabled adults (which becomes too cumbersome to both write and read) as attendees while talking about their position within their institutions.

Further, I will be referring to the teachers and trainers at these institutions as special educators. Across institutions, these individuals referred to themselves as special educators (in English) during conversations with me. Even the other stakeholders I interviewed, such as administrators, parents, and disability professionals, referred to them as special educators. However, while I use the term special educator, I also attend to the different terms used for special educators in different institutions. For instance, at one of my field-sites, Sankalp, special educators were called *maushi* (the marathi word for maternal aunt) and at another field-site named Udaan, they were called ma'am. At both field-sites, special educators were addressed as maushi and ma'am in second person as well as referred to as maushi and ma'am in third person by others, such as, their attendees, colleagues, and administrators. I use these terms whenever I quote my interlocutors to remain as close to what was being said during conversations as well as when these terms are relevant to the larger conceptual argument or the ethnographic context. For instance, while special educator was the term that educators used for themselves while differentiating themselves from other stakeholders, such as parents, administrators, mainstream teachers, and disability professionals, such as physiotherapists and psychologists, maushi and ma'am were local terms that circulated within institutions that helped establish the social worlds within these institutions. For instance, maushi at Sankalp helped establish kin-like relations between the special educators and intellectually disabled adults. On the other hand, ma'am established a hierarchy between the special educators and intellectually disabled adults at Udaan

and granted respect to the special educators. Further, ma'am also helped create a middle-class, college-like environment within Udaan given that teachers are often referred to as ma'ams in many mainstream colleges in urban India. Most of my conversations, whether during participant observation or interviews, took place in Marathi or Hindi. In the dissertation, these conversations have been translated into English. However, whenever certain phrases or words are conceptually significant in Marathi or Hindi, I retain them in the original language and provide a translation in English.

Following disability studies scholar Simi Linton (2006), I recognize that the term special education and all the terms arising from it, such as special children and special educators are problematic as they have euphemistic connotations that obscure the reality that neither intellectually disabled people nor their education are actually considered special. Despite this, I hold onto this category because I take seriously the work that the category of special education does in India, and I ask how intellectually disabled people and educators are made up as “special” through the use of the category. Having addressed the terminologies, I provide a brief overview of laws, policies, and schemes that pertain to intellectually disabled people to examine how the Indian state defines intellectually disabled people and their legal rights and entitlements.

### **Disability in India: Legal Personhood of Intellectually Disabled People**

According to the 2011 census, the population of India was 1.2 billion, out of which approximately 26 million people, around 2.2% of the population were estimated to be disabled (however, there is an understanding that these numbers are underestimates)<sup>4</sup>. Of these, 1.5 million people were classified as having mental retardation (the category used in the 2011

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<sup>4</sup> The 2021 census in India was postponed due to COVID-19. It is yet to take place.

census). Currently, the Department of Empowerment of Persons with Disabilities, which falls under the Ministry of Social Justice and Empowerment oversees laws, policies, and schemes that pertain to disability on the level of the Indian government.

Historically and currently, the Indian state has variously taken up disability as an issue of welfare, charity, development, and more recently, rights (Ghai 2002; Mehrotra 2011; Ghosh and Ghosh 2016). Post independence, the Indian government set up the National Council for Handicapped Welfare. This government body was comprised of rehabilitation experts, who adopted a biomedical view of disability, and viewed disability as a disease in need of cure and correction (Mehrotra 2011). The 1980s saw a perspectival shift from welfare to development and rights (Mehrotra 2011). The United Nations made disability their focus by declaring 1983-92 as the Decade of Disabled Persons and 1993-2002 as the Asian and Pacific Decade of Disabled Persons. Additionally, the 1980s saw the rise of identity politics with the emergence of the feminist and Dalit activist (marginalized caste based) movements in India. These developments provided an opportune platform for disabled communities to lobby and protest for the passing of the Persons with Disabilities (Equal Opportunities, Protection of Rights, and Full Participation) Act in 1995 (here forth referred to as the PWD Act). In recent years, the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2008 led to the formulation of the Rights of Persons with Disabilities (RPD) Act in 2016. The RPD Act came into being through the political actions of representatives of different impairment groups who form the disability- rights movement in India. Some of these activists approach disability as a matter of rights (Friedner, Ghosh and Palaniappan 2018). On paper, the RPD Act (2016) adopts a rights-based discourse and emphasizes the values of respect, dignity, individual autonomy, inclusion, and accessibility for disabled citizens. However, people with intellectual disabilities

are often not a part of these advocacy efforts and are usually represented by their parents, who act on their behalf as their advocates (Vaidya 2016)

The RPD Act defines a person with disability as someone with long term physical, mental, intellectual, or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others. While the older disability law, the PWD Act from 1995 had listed 7 disability categories, the RPD Act (2016), expanded the list to include 21 conditions, including cerebral palsy, specific learning disabilities, autism spectrum disorders, and multiple disabilities. Importantly, while the PWD Act (1995) used the term “mental retardation”, the RPD Act (2016) uses the more politically and socially appropriate term “intellectual disability”, which it defines as a condition characterized by significant limitation both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior which covers a range of every day, social and practical skills. While the RPD Act (2016) uses rights-based language, it still medicalizes disability by granting benefits or entitlements to disabled people based on a medical diagnosis of their impairment status (Friedner, Ghosh and Palaniappan 2018). Under the act, disabled people are entitled to governmental schemes and benefits only if they qualify as having a “benchmark disability” which is defined as a person having no less than 40 percent of a specified disability as certified by a medical government authority, who provides them with a disability certificate. If an intellectually disabled person has a disability certificate, in theory, they can access free education in government-aided special schools and vocational centers, a disability pension of Rs. 1000 per month after the age of 18 years, and life insurance. While I did not have many conversations with parents of intellectually disabled people about the process of getting a disability certificate, the few conversations I had revealed that the testing process involved medical professionals asking intellectually disabled

people to read letters from the alphabet and numbers to assess their intelligence. Most of the intellectually disabled adults I worked with in Pune had “benchmark disabilities” and their families had procured disability certificates for them.

Aside from the RPD Act, The National Trust for Welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 is also very significant for intellectually disabled people and their families. Under this act, voluntary organizations and parent groups can register themselves to gain recognition and credibility as institutions that work with this population. Further, the National Trust Act also has a guardianship clause for people with autism, cerebral palsy, mental retardation, and multiple disabilities as they are viewed as not being capable of making their own decisions. Recently, during the consultation process for the RPD Act, there were tensions between disability rights activists and parent advocates of intellectually disabled people over the question of legal capacity of intellectually disabled people (Vaidya 2016). While activists demanded that all disabled individuals have a right to full legal capacity, parent advocates argued that their children did not have the capacity to genuinely exercise their legal rights and would thus be exploited if left completely to their own devices. Thus, questions of personhood, guardianship, and legal capacity are issues with high stakes when it comes to defining the legal rights of intellectually disabled people in India.

During my fieldwork, I met many parents of intellectually disabled adults who told me that the special educators at special schools and vocational centers often helped them figure out these complicated and messy government procedures, by directing them to specific government hospitals to get their child assessed for a disability certificate and filling out their forms and applications for disability pension and legal guardianship. As mentioned earlier, I did not have too many conversations in the field regarding disability certificates and guardianship, but

conversations with administrators, educators, and families revealed that many intellectually disabled adults in the urban institutions where I conducted fieldwork had disability certificates, but the parents often did not have legal guardianship. Further, intellectually disabled adults at the only rural institution I examined, the Ananda Foundation, did not have disability certificates (something I discuss in depth in Chapter 5 in terms of the different socio-economic and cultural realities of rural India). While this is an estimation on my behalf, most of the intellectually disabled adults were not under the formal guardianship of their parents and this did not seem to affect theirs or their families' lives to a great extent. In 2016, the Ministry of Social Justice and Empowerment also launched their Unique Disability Identity Card (UDID) project, which aims to create a national digital database of people with disabilities in India, by issuing unique disability identity cards through a digital portal. Even disability certificates, which previously could be granted manually, can now only be granted online through the UDID portal. This has proven to be a difficult transition for many parents of intellectually disabled people I met (who do not have adequate digital literacy) and thus often depend on special educators to help them navigate this digital platform. Thus, special educators and families of intellectually disabled adults were not entirely distinct actors whose paths never crossed- instead, they worked together to procure legal certifications and entitlements for intellectually disabled adults.

Finally, the Indian government also passed the Rehabilitation Council of India Act in 1992, which led to the formation of the Rehabilitation Council of India (RCI), the governing body that regulates and standardizes the training of personnel and professionals in the fields of rehabilitation and special education. According to the RCI's vision document for the years 2020 to 2030, at present there are 60 RCI approved courses operational in the fields of rehabilitation and special education and 120, 781 RCI approved special educators. Even the recent National



Education Policy report stresses an urgent need for more special educators who possess the skills required to understand the specific needs of disabled children (NEP 2020,22). Despite increasing involvement from the Indian state, special education in India is a vast field with multiple institutions that often lie outside governmental regulation. For instance, Rainbow Foundation was a private institution that did not hire RCI trained special educators. Instead, they provided on-site training through workshops for its new recruits. In contrast, Sankalp, a government-aided workshop where I conducted fieldwork had special educators who were either RCI trained or had received training in specific vocations such as sewing and bookbinding from Industrial Training Institutes (ITI). This dissertation will consider both governmental and non-governmental institutions that cater to intellectually disabled adults to get a fuller picture of their life-trajectories in both types of spaces.

### **Situating Intellectual Disability within Anthropology of Disability/Disability Anthropology**

While disability has increasingly been a subject of anthropological research in the West and in India, intellectually disabled people continue to be underrepresented in this scholarship. Earlier anthropological scholarship that focused on disability in the West often focused on stigma, integration, and social exclusion (Edgerton 1967; Ablon 1984; Groce 1985). Scholars also experimented with auto-ethnographies and biographies (Zola 1982; Murphy 1987; Frank 2000) to explore the lived experiences of disabled people. Except for Robert Edgerton (1967) whose pioneering study *The Cloak of Competence: Stigma in the Lives of the Mentally Disabled*, which examined the ways in which people with mild mental retardation navigated the world of employment, housing, dating and sex, and recreational activities, most of these older studies did not examine the lives of intellectually disabled people. More recent anthropological scholarship

that addresses disability in the United States has addressed the ways in which disability intersects with other social dimensions, such as race and class to produce very different life experiences and opportunities for poor Black disabled people (Ralph 2014).

Indian scholarship on disability is shaped by western discourses of disability identity, rights, and stigma. Many researchers have accepted the category of disability, applied it to the Indian context, and commented on its culturally and historically specific meanings. According to various scholars, in the Indian context, disability has been viewed as a lack, deficit or limitation. Images of deceit, mischief, and devilry have also been associated with disabled people (Ghai 2002). As mentioned earlier, disabled people are also viewed as “holy”, “sufferers of karma”, and infantilized as subjects of charity and pity (Miles 1995; Ghai 2002). More recent scholarship regarding disability in India has taken up themes such as disability and the Indian nation-state (Mehrotra 2011; Friedner Ghosh and Palaniappan 2018), the intersection of disability and gender (Ghai 2002; Addlakha 2008; Goyal 2017), the lives of disabled individuals in relation to changing socio-economic structures and policies (Friedner 2015; Chaudhry, 2015), deaf sociality and deaf spaces (Friedner 2015; Kusters 2017), as well as how social practices such as begging shape the masculinity of disabled men (Staples 2011).

Anthropologists in cross-cultural contexts have addressed intellectual disability mostly in the context of kinship, family, and care and demonstrated the ways in which they gain their personhood through their familial relationships of care (Rapp and Ginsburg 2011; Hart 2014; Rutherford 2020; Sargent 2018; Sargent 2021). This is often the case because intellectually disabled adults are not rational, independent, autonomous subjects and often depend on others, especially close family members, for their everyday care (Kittay 2011). Both Rapp and Ginsburg (2011) and Sargent (2021) engage with the ways in which the presence of disability leads to the

re-configuration of the structures of kinship and family. While Rapp and Ginsburg examine how a disabled child with atypical needs in the United States may unsettle conventional familial and kinship roles, expectations, and structure, Sargent examines how mothers of children with Down Syndrome develop a “moral orientation” of acceptance. Further, both Rutherford (2020) and Hart (2014) talk about how parents, through their relationships of care and love, learn to look at their children’s nonnormative cues as being meaningful and translate them for others.

Even in India, the few studies that focus on intellectually disabled people have been through the lens of familial care. Shubhangi Vaidya (2016) in her ethnographic work on autism in urban India illustrates that families are the most significant resource for people with intellectual disabilities. She argues that people with intellectual disabilities often require life-long care and assistance and in the absence of state sponsored services and provisions, this support is provided by families, especially mothers. In line with Vaidya, Ghosh and Banerjee (2016) focus on mother-daughter relationships in rural Bengal, wherein mothers looked after the physical and emotional well-being of their disabled daughters. The authors state that the mothers’ claim that they can communicate with their non-verbal daughters illustrates that care is relational and not passively received by the disabled children. They also argue that in recognizing their children as having likes and dislikes, despite being non-verbal, personhood for the disabled child emerges in these caring relationships.

Even at my fields-sites, special educators often said to me that being caring was an important quality for their job. The interventions made by special educators were often caring in nature. They would feed intellectually disabled adults, stand beside them until their parent or guardian came to pick them up in the evening, and ask them about their families’ well-being. Special educators would also lovingly address intellectually disabled adults as *bala* (baby in

Marathi), *beta* (son in Hindi), and *beti* (daughter in Hindi). Finally, special educators also often insisted that special mula were innocent and caring people precisely because they were not “normal”. Thus, the analytic of care showed up in various ways at these institutions: as a quality that defined both the special educators and intellectually disabled people and in the care work performed by the educators. Drawing on this scholarship that highlights the role of care practices in the shaping of intellectually disabled people, I will make note of the ways in which care shows up either in discourses or practices of special educators. However, I will not be using the analytic of care to examine the relational context between special educators and intellectually disabled people. While special educators often repeated to me that having a caring disposition was an important part of their job, on most occasions, I observed special educators making their interventions in a seemingly pragmatic or un-caring manner, wherein they needed to get things done swiftly without time to spare to even talk in an affectionate manner. Further, while special educators often called intellectually disabled people caring and innocent, they also categorized them in other ways, as productive, helpful, or problematic. Finally, while special educators did feminized care work such as cooking for and feeding intellectually disabled people, they also did bureaucratic work such as maintaining attendance records and writing monthly reports- work which cannot be as easily slotted as care work. Considering this, I choose not to use the analytic of care and instead use the framework of interventions to describe and analyze the creative and innovate interpretive work and decision making performed by special educators.

### **Reframing Special Educators as Relational Experts**

Disability studies scholarship from the United States has approached special educators and other experts that work with people with intellectual disabilities in a critical manner (Erevelles 2000;

Adams et al. 2000; Davis and Watson 2001; Baglieri et al. 2011). In particular, these scholars have pointed to the ways in which children experience segregation in special education programs which leads to their exclusion from mainstream society. Mike Gill (2015) and Wilson et. al (2011), specifically address the ways in which disability professionals who work in institutional settings surveil and regulate the sexuality of intellectually disabled adults. This work is significant because it showcases how being categorized as needing “special” programs inherently excludes people from mainstream society. Further, within these segregated institutional environments, institutional stakeholders, such as special educators can control the most private and intimate aspects of people’s lives, including their sexuality. In India too, these institutions are segregated from mainstream society and set up intellectually disabled people for a future in which they can never fully assimilate into mainstream society on equal terms as their non-disabled or “normal” peers. Further, within these institutions, special educators do have a final say on many aspects of their lives, including matters of sexuality. In this dissertation, I draw on this disability studies scholarship that points to the structural inequalities faced by intellectually disabled people who inhabit institutions of special education. Whenever relevant, I also point to the ways in which special educators exercise their authority over intellectually disabled people’s lives.

However, I also take a step back and examine how special educators establish their authority over intellectually disabled people in the first place. I do the same by viewing special educators as experts. Along with calling themselves caring, special educators also framed themselves as people who understood and knew intellectually disabled people. By conducting an in-depth analysis of the relational work they perform within institutions, I ask: Do the interventions made by special educators make them into experts? If so, for whom? Further, what

does this expertise allow them to do? According to anthropologist E. Summerson Carr, “across its many domains, expertise is both inherently interactional, involving the participation of objects, producers, and consumers of knowledge, and inescapably ideological, implicated in the evolving hierarchies of value that legitimate particular ways of knowing as ‘expert.’ ” (2010, 17)

Carr argues that expertise emerges in real-time communicative practices that are articulated within institutions that are shaped by specific ideologies. Carr establishes that becoming an expert involves taking a deliberate stance and establishing a register or a linguistic repertoire which may include technical terms, prosodic practices, facial expressions, and gestures. In her theorization, Carr de-links expertise from ideas of objective technical skills and academic credentials and brings it within the realm of social practices and relationships. Finally, Carr argues that expertise not only creates a relationship between a “special kind of person” and a “special thing” (i.e., between the experts and the specific object or subject of expertise); it also creates a relationship between two types of people: “experts and laities” (2010, 22). In other words, the bestowal of expertise creates a distinction between those who claim to know and those who do not. Drawing on Carr’s analysis, this dissertation traces how special educators make themselves up as experts through their social interactions, by saying certain phrases, making specific facial expressions, and adopting certain authoritative styles of communication. Further, by conducting a multi-sited ethnography that explores very different institutional settings, I examine how special educators made themselves up as experts in different ways depending on their institution’s larger objectives and vision.

Further, Carr also points to the importance of institutional recognition when it comes to the establishment of expertise. According to her, institutions play a major role in grounding and naturalizing expert practices. It is not enough for professionals to understand their practices as

expertise without receiving support and validation from institutions. To this point, I examine how the expertise of special educators was contested and never a fully achieved state. While the institutions within which they worked gave them titles (such as that of a special educator), their expertise was often questioned by higher administrators, other disability professionals who associated with these institutions, such as, psychologist and psychiatrists, as well as the parents of intellectually disabled people. Further, there were differences among the different special educators regarding their expert status. While some more experienced special educators, such as Sarika ma'am who was able to start her own organization were recognized as experts by their colleagues and some of the parents, other younger, less experienced special educators were not.

Further, during my preliminary fieldwork at Rainbow Foundation as well as my dissertation fieldwork later, I noticed that most of the special educators were women from middle to lower-middle class backgrounds. Most of them did not have formal degrees in special education. They would often talk to me about how neither parents nor higher administrators took their recommendations seriously. Further, they would also tell me that their jobs did not pay them a lot, with their salaries ranging between Rs. 12,0000 (USD 144) to Rs. 30,0000 (USD 361) a month. Thus, although special educators were in positions of power relative to intellectually disabled adults, they did not have power in relation to other non-disabled stakeholders. It was through their everyday interventions with intellectually disabled adults, instead of high status or high salaries, that they made up their own expertise often only in their own and each other's eyes.

Thus, instead of approaching special educators as institutionally recognized, powerful experts who regulated and controlled intellectually disabled adults, I build on anthropological scholarship that examines undervalued and underpaid feminized professions, such as, social

work, nursing, and elder care (Ibarra 2002; Bolton 2005) and demonstrate how special educators too occupied complicated positions- as both powerful and relatively powerless stakeholders. Most of their interventions did not extend beyond these institutions because even when educators tried to advise or influence parents, they were often not listened to (aside from parents taking their advice while procuring disability certificates for their children). To be clear, this does not mean that I will not attend to the ways in which special educators regulated or controlled intellectually disabled people. Instead, I complicate the relational context between the two groups and delve deeper into how special educators occupied a complex position as people who performed feminized, undervalued work and yet produced their authority over intellectually disabled adults by making claims about understanding them in a distinct manner because of their interventions within institutional settings.

### **The Ethics of Doing Anthropological Research with Intellectually Disabled People**

From the inception of this project, I struggled to figure out the place of intellectually disabled people within it. Were they my interlocutors or was I exclusively focusing on non-disabled stakeholders, such as special educators, and documenting the ways in which they interacted with intellectually disabled adults? How was I supposed to observe cues, interact, and write about them, given that they were not the traditional rational, speaking, autonomous subjects of anthropology? (McKeanry and Zoanni 2018) I was hesitant about framing intellectually disabled people as my interlocutors because I did not want to reproduce the same epistemic hierarchies that are ever present in their lives, wherein other people claimed to know what they were feeling, thinking, and saying. When I started fieldwork, I was certain that I would not represent intellectually disabled people, and instead focus only on the ways in which special educators



engage them and make decisions about them. However, the more time I spent doing fieldwork, I realized that it was even more problematic to not address intellectually disabled people at all. This was because intellectually disabled adults articulated and expressed themselves in many, often nonnormative, non-linear ways. Special educators did not always attend to these nonnormative expressions. Further, intellectually disabled adults would also interact and engage with me. Over time, I developed friendly relationships with some of them. Thus, in my well-intentioned attempt to not misrepresent them, I was erasing intellectually disabled people's agentic expressions, and only framing them as passive recipients, which was far from what I witnessed during fieldwork.

To situate intellectually disabled people in my dissertation not just as recipients of other people's actions, I turned to *The Cambridge Journal of Anthropology* which published a special issue on cognitive disability in 2018 that grappled with very similar questions of how intellectually disabled people are recognized, known, and constructed as persons. The special issue also addressed some of my questions and anxieties about the relationship between anthropology and cognitive disability. In the introduction to the special issue, Patrick McKearney and Tyler Zoanni (2018) propose that cognitive difference or variation threatens the basic anthropological assumption of the "psychic unity of mankind" (3) that frames all humans as roughly having the same cognitive capacities that are realized in culturally and historically specific ways. They write that a serious engagement with the radical difference presented by cognitive disability may lead anthropology to challenge this assumption and ask new questions about traditional anthropological concepts, such as: do cognitive differences manifest in diverse ways in different cultural settings or do cognitive variations precede cultural or social classifications and meanings? (McKearney and Zoanni 2018) These scholars argue that cognitive

differences present limitations and constraints that often cannot be overcome or resolved through social transformation. They challenge traditional anthropological assumptions about personhood and posit that people with cognitive disabilities present a generative opportunity for anthropologists to re-think their ideas about whether all people are equal.

The articles within this special issue also present innovative ethnographic approaches to people with intellectual and cognitive disabilities. McKearney (2018) through his ethnographic research at L'Arche, a community group home in the U.K. explores how carers of intellectually disabled people are trained to notice the charismatic and surprising agency of intellectually disabled persons. At L'Arche, intellectually disabled people are understood as actively affecting their carers through their actions, which are not intellectual in nature, but more emotional and relational. In this framework, intellectually disabled persons are not looked at as rational subjects. It is precisely the lack of their cognitive capacities that is seen as providing them with this exceptional affective agency that moves the carers and makes a difference to their lives. While McKearney ascribes affective agency to his respondents, Zoanni (2018) proposes that his research subjects have unique signatures. His ethnographic research in Uganda revealed that there are many intellectually disabled people who may not have a voice, but because of certain patterns of behaviours and people's responses to them, a distinct signature of their being emerges. This signature, according to Zoanni, is an imprint. It may not always be easy to read or recognize, but it does make people with intellectual disabilities socially legible. Finally, drawing on fieldwork based in Dutch residential care homes, Driessen (2018) proposes that her research participants with dementia should be viewed as appreciating subjects rather than being characterized as lacking function or not being subjects at all. She demonstrates that people with dementia take active pleasure in bathing, dancing, and daily care. She states that the carers

carefully create conditions for pleasure. But she argues that pleasure is a relational achievement, and the residents need to actively surrender to those conditions before pleasure may occur.

Aside from this special issue, Stacy Simplican (2015) in her book, *The Capacity Contract*, also addresses the thorny question of intellectually disabled people's agency, specifically in the context of politics. Her basic query is: can people with intellectual disabilities be political participants? If yes, on what terms? She critiques perspectives that depend on measurement as a tool as it allows only two options- either people with intellectual disabilities participate on the same terms as everyone else or they do not participate at all. Instead, she argues that we need to re-think our definition of politics. Based on ethnographic work with people with intellectual disabilities, she presents humour, dance, and alliance as three modes of being political. For instance, dance is political to her as it is a human expression that does not require speech, but it can disrupt normative settings and provide an avenue for people to "contract" with each other in a non-cognitive way. Instead of forcing intellectually disabled people to fit into the mould of rational political actors, Simplican urges us to value the innovative ways in which they are already engaging with the political.

Across these ethnographic texts, these scholars move beyond the independent/dependent binary and suggest affective, relational, and embodied approaches to engage the personhood and agency of intellectually disabled people. In these ethnographies, intellectually disabled people emerge as charismatic, surprising, and appreciating subjects who engage the world through their nonnormative actions. These authors urge us to take their actions seriously and to not dismiss them simply because these do not appear to be rational and autonomous. In resonance with the authors, I too made the decision to attend to the nonnormative expressions and articulations of intellectually disabled adults in my field-sites and decided to approach personhood more

expansively. Instead of ignoring them or not writing about them at all, throughout my dissertation, I address the different ways in which intellectually disabled adults interacted with each other, special educators, and me (and vice versa) and how it was such interactions that made up personhood in a relational manner. Further, I also note how there were many occasions on which I did not understand what intellectually disabled adults were saying to me. While my anxieties about misrepresentation do not disappear, instead of avoiding writing about intellectually disabled people, I write about them in a reflective (almost hesitant) manner, with the intention of highlighting their agency and demonstrating the ways in which they occupied space and time in these institutions.

### **Why Pune?**

As of 2017, the state of Maharashtra had 92 government approved institutions in the fields of special education and rehabilitation, which is more than any other state in India. I selected the city of Pune as the primary site of my research as it is a pivotal center for institutions that address intellectually disabled people; events and activities occurring in Pune affect the rest of India. Coined the “Oxford of the East” by Jawaharlal Nehru, the first Prime Minister of India, Pune is a site of numerous educational institutions, including special schools and vocational centers. It also houses two national universities that provide degrees in special education. Pune is also the location of numerous residential homes, parents’ associations, and support groups that focus on intellectual disability, which made it an ideal site to do my ethnographic research.

Further, I conducted my ethnographic research from August 2021 to September 2022, in the immediate aftermath of the COVID-19 pandemic. In fact, the omicron wave hit India in January 2022, which interrupted a fieldtrip to Karkamb, a village approximately five hours from

Pune. Considering that I was navigating fieldwork during a precarious and unpredictable time, I decided that I wanted to return to a semblance of stability and routine at the end of my fieldwork, which for me was my family home in Pune. Thus, the decision to work in Pune was also shaped by my own vulnerabilities and preferences in the backdrop of COVID-19. Moreover, Pune is also where I had my first job as a consultant and sexuality trainer at Tathapi Trust, a non-governmental organization that focused on questions of sexuality and health. When I was working at Tathapi Trust, they had initiated a project on intellectual disability and sexuality (*matimanditva ani laingikta* in Marathi). While I did not work on the project, I witnessed my colleagues doing training and awareness sessions for special educators and parents of intellectually disabled people, many of whom came from villages to attend these workshops on weekends. They also invited professionals, such as psychiatrists and special educators to conduct expert workshops, published magazines with perspectives from educators and parents, and sexuality training booklets in Marathi. I was initiated to the world of intellectually disabled people and various stakeholders in their lives in Pune and thought it would be the ideal site to explore this further during my PhD fieldwork. Indeed, my contacts at Tathapi Trust introduced me to some of my key interlocutors, who I will talk about later in the methodology section. Thus, I had long-term personal and professional connections with Pune which allowed me to pursue multiple ethnographic routes, meet with diverse interlocutors, and establish relationships of trust and comfort with them.

In the midst of COVID-19, anthropologists Gökçe Günel, Saiba Varma, and Chika Watanabe introduced the concept of “patchwork anthropology” (2020) to re-configure what counts as legitimate anthropological knowledge by acknowledging that researchers, especially those who do not occupy the same positions of privilege as unattached, single white men, have

full lives and responsibilities outside academia, which affect the ways in which they do fieldwork. One of their challenges to traditional assumptions around fieldwork is the strict distinction between the “field” and “home”. I draw on this line of thought to challenge this strict binary between field and home and position Pune as an ideal primary site for this research, not simply because of its affordances as a city which caters to institutions and events that pertain to intellectually disabled people (although that is an important factor to consider) but also because of the safety, socio-cultural familiarity, and connections it afforded me because of my relationship with it.

### **Dissertation Fieldwork Methodology**

The findings presented in this dissertation are based on a year of ethnographic fieldwork conducted between September 2021 to August 2022. The three field-sites I examine in-depth in the rest of the chapters are: 1) Udaan, a newly registered, non-governmental, home-based vocational and arts center in Pune, 2) Sankalp, a reputed government aided workshop in Pune, and 3) Ananda Foundation, a newly registered, non-governmental workshop in Karkamb, a village in the state of Maharashtra. My preliminary fieldwork with Rainbow Foundation led me to Udaan. Udaan was founded by Sarika ma’am, who was the principal of the vocational center at Rainbow Foundation during my fieldwork period. Soon after I returned to the United States after my fieldwork in Summer 2019, Sarika ma’am quit Rainbow Foundation because she wanted to start her own organization with her husband, Sahil Patel. Sahil sir was the music teacher at Rainbow Foundation. Udaan, unlike Rainbow Foundation, was home-based and founded with the vision of providing fun and pleasurable experiences for intellectually disabled adults. When I found out that Sarika ma’am and Sahil sir had founded their own organization, I

was excited to learn more about their work and asked them if I could conduct participant observation at their organization, to which they agreed. From August to December 2021, I conducted participant observation at Udaan.

Sankalp was a well-known organization in Pune, which had both a special school and a workshop. Special educators, including Sarika ma'am at the Rainbow Foundation had told me about its existence in 2019. When I returned for my dissertation fieldwork, after conducting fieldwork at Udaan for three months, I wanted to examine a government-aided, formal vocational center and thus reached out to educators at Sankalp. I had to first undergo an interview with Mr. Sathe, a trustee at Sankalp, wherein he asked me about my research purpose, methods, and ethics. Once he was convinced of my intentions, I was permitted to conduct fieldwork at Sankalp workshop, where I conducted ethnographic fieldwork from April to August 2022.

Finally, I connected with Asha and Jayant Lokhande, the founders of Ananda Foundation through Tathapi Trust which as I mentioned above is a non-profit organization that worked on issues of gender, health, and sexuality. Jayant and Asha, who were parents to Smriti, a young intellectually disabled woman with Down syndrome, would often lead Tathapi's parent awareness workshops on the topic of sexuality. My ex-colleagues from Tathapi Trust as well as a friend of mine who works in the non-profit world in Pune introduced me to them in the Summer of 2019 thinking that they would be ideal interlocutors considering my research interests at the intersection of intellectual disability and sexuality. While I interviewed them once in 2019, I had to return soon for the United States. However, I kept in touch with them and soon found out that they too, much like Sarika ma'am and Sahil sir, had started their own organization named Ananda Foundation by the end of 2019. However, they had left Pune and set up the organization

in Karkamb, a village in Maharashtra. I visited Ananda Foundation in January 2022, in the thick of the Omicron wave of the COVID-19 pandemic. I could only stay in Karkamb for three days before the workshop shut down due to a suspected COVID-19 outbreak. However, I kept in touch with Asha over texts and Whatsapp video calls, tracking their organizational and familial journeys closely. Incidentally, Smriti had been a student at Rainbow Foundation special school and even attended the vocational center for a while, which was overseen by Sarika ma'am. Thus, the three field sites, while distinct, were connected to each other. Indeed, during my dissertation fieldwork period, I met with intellectually disabled adults who had been students at Rainbow Foundation in 2019 who were now either at Udaan or Sankalp. While I do not know why people transitioned from Rainbow Foundation to Sankalp, many people transitioned from Rainbow Foundation to Udaan because they were now over 25 years of age and had passed the age cut off for Rainbow Foundation and many parents knew of Sarika ma'am from her days as the principal of the vocational center at Rainbow Foundation, making the transition to Udaan a familiar next step.

Aside from doing participant observation at these three sites, I conducted a focus group with the special educators at Sankalp workshop, multiple interviews with Sahil sir and Sarika ma'am at Udaan, and multiple interviews with Asha between 2019 and 2023. I also conducted in-depth interviews with parents of intellectually disabled adults who attended Udaan and Sankalp. It was special educators at these two institutions who referred me to specific parents because they considered them to be cooperative. I conducted four parent interviews in their homes and one interview within the premises of Sankalp (this was an interview with Sunita, who was a parent as well as a *madat-nis* or helper/assistant at Sankalp). I also interviewed administrators, such as the principal of Sankalp special school and the superintendent of Sankalp



workshop and disability professions, such as a psychologist and a psychiatrist, who were both affiliated with Sankalp. While I interviewed the administrators and psychologist within the premises of Sankalp because they came there to work every day, I travelled to the psychiatrist's clinic to interview him, because he visited Sankalp only once a month to offer his consultation services, during which time he had a packed schedule. I conducted the focus group and interviews in Marathi, Hindi, and English and had them professionally translated to English. Aside from Udaan, Sankalp, and Ananda Foundation, my three primary field-sites, I conducted short term participant observation and interviews at a few other institutions in Pune: namely Srushti (a vocational center that focused on occupation) and Asha residential facility (a parent-run residential home).

I also visited Sahavas, a respite care facility, for a week in November 2021, an institution where I had conducted fieldwork in Summer 2018. Sahavas is in Wada, a village three hours away by car from Mumbai. Sahavas, unlike my other field-sites which are vocational centers, was meant for residential purposes, and catered to significantly and multiply disabled people who had high support needs. I also interviewed the owner of café Khushi, a café in Mumbai where the servers, cooks, and cashiers are people with intellectual disabilities. Here, I had the opportunity to have short conversations with some of the employees at the café. Finally, I made a week-long trip to Dehradun, to visit Latika (original name retained upon consultation with the founders), an organization that provides services, such as testing, early intervention, special educational, and vocational training to intellectually disabled people across different age-groups and follows a rights-based perspective in their work. I visited these other centers because I wanted to learn more about the kind of opportunities and personhoods made available to intellectually disabled adults in India, particularly in case these differed widely from the

institutions on which I focus. For instance, Sahavas respite care center provided residential facilities to significantly intellectually disabled adults and special educators there often had to do challenging care-work (such as bathe residents every morning). Meanwhile, the founders of both Latika and Café Khushi were invested in a rights-based model of disability and trained its staff to follow very different conventions of communication, wherein they did not talk on behalf of intellectually disabled people and never talked about them in front of them, which was unlike any of the institutions I focus on in this dissertation. While I will not be focusing any of the chapters on these field-sites, I refer to ethnographic findings from these sites whenever their specific institutional context is of relevance. While many of the findings I document in this dissertation apply to most of these organizations, I also make it a point to discuss some of these institutions as counterexamples when I make larger arguments about institutions in India that cater to intellectually disabled adults.

During my participant observation, I spent time at each field-site observing everyday routine. Considering that Udaan was a relatively new organization, they needed my help with everyday activities. Thus, I contributed by managing their social media accounts on Facebook and Instagram, writing work emails in English, painting diyas during peak Diwali season, and doing errands when guests, such as prospective trustees came over. One of my major contributions to Udaan was organizing an arts exchange event between Udaan and a special school in New York over zoom, wherein the intellectually disabled adults from Udaan performed a Djembe (West-African percussion instrument) drum circle. In contrast, Sankalp workshop was a much more formal organization where both educators and intellectually disabled adults had set roles. Thus, I did not actively contribute much at Sankalp and spent most of my time sitting on a chair or on the floor, scribbling my notes. Finally, though I only spent two whole days at Ananda

Foundation, I had previously helped edit Asha and Jayant's book about their parenting journey in 2019, when I met them briefly during my preliminary research trip. Given my long-term collaborative relationship with Asha, I was encouraged to actively participate in the vocational activities and interact with both the educator and the intellectually disabled adults. Across all three field-sites, I paid attention to the everyday relational context between special educators and intellectually disabled adults. I made note of the ways in which special educators communicated with their attendees, the vocational tasks carried out at the institutions, and moments of rest, leisure, and celebrations. Given that many intellectually disabled adults did not use conventionalized language, I observed not only verbal cues but also nonverbal cues, such as, gestures, body language, and facial expressions. Across all my field sites (not just the three primary field-sites) intellectually disabled adults expressed themselves through nonnormative and nonverbal cues, and while I never knew with certainty what these cues meant, I made efforts to respond through verbal and nonverbal cues.

Finally, it is important to mention that the different institutions were not only different when it came to their organizational structure and location, but also when it came to the socio-economic backgrounds of both the special educators and the intellectually disabled adults. While Udaan, co-founded by Sahil sir and Sarika ma'am, took fees from its attendees (approximately Rs. 3000 [USD 36] per month) and thus catered largely to people from middle to upper-middle class backgrounds, Sankalp, a government-aided institution, did not charge a fee for most of its attendees and thus catered predominantly to lower middle class to lower class attendees. Finally, at Ananda Foundation as well, most of the attendees came from poorer families and they were paid a daily stipend of Rs. 20 (USD 0.24). While Sahil sir and Sarika ma'am as well as Jayant and Asha could be classified as upper-middle class, most of the special educators at Sankalp

were middle class government employees. These class differences, as I will examine later in the dissertation, affected both the decisions that special educators could make as well as the services that intellectually disabled people received. In brief, while Sarika ma'am and Sahil sir's as well as, Jayant and Asha's class position allowed them to take certain risks (such as quit their jobs and set up these institutions and make so-called "bolder" choices regarding what intellectually disabled people could or could not do), the special educators at Sankalp would often come across as being more rule following because they had to answer to higher authorities and could not afford to lose their jobs. Further, while at Udaan, Sahil sir and Sarika ma'am had enough capital to organize activities, such as picnics and overnight hikes, at the other institutions, the poorer intellectually disabled adults received more repetitive vocational training. Despite these differences, these institutions also shared certain features, especially when it came to the problems they faced, such as absenteeism or retaining their attendees. I often heard from administrators, special educators, and a few parents about how parents pulled their charges out of these institutions. The reasons I was given were varied: parents could not pay for transportation, could not pay the fees, or often felt that their children no longer needed to go to the vocational center/workshop and could just stay at home. These problems were exacerbated when these institutions re-opened after their closure during the COVID-19 pandemic because many families had suffered financial losses during this period and were less willing and able to spend money on these institutions. Thus, although all the institutions had some long-term attendees, they had also lost many of their older attendees and were attempting to actively recruit. This made the population of these institutions somewhat unstable.

## **Positionality**

My privileged positionality as a non-disabled, Brahmin (upper caste) Hindu, Maharashtrian cis woman shaped my research experiences. From this position, accessing organizations for fieldwork purposes was a relatively smooth process. Further, being a PhD student from University of Chicago also worked to my advantage. During fieldwork, I had to manage relationships with both special educators and intellectually disabled adults, often at the same time. Considering that most of the special educators were women, my positionality as a cis woman, who could communicate with them in Marathi, helped me establish amicable relationships with them. Over time, they felt comfortable enough to discuss their family and work life with me. They would also ask me questions about my personal and work life. For instance, given that most of the educators were married and I was not, they would often lightly tease me about my status and give me advice about married life. Thus, my positionality made it relatively easy for me to relate to and establish trust with special educators. However, unbeknownst to me, special educators, especially those who belonged to different class and caste backgrounds, may also have been hesitant about sharing many aspects of their life with me because of my drastically different life trajectory.

While establishing a rapport with special educators, despite our class and caste difference was relatively effortless, establishing a rapport with intellectually disabled adults, while simultaneously respecting the authority of the special educators in charge proved to be a much more challenging endeavor. For instance, special educators would often talk about intellectually disabled adults in front of them. Further, they would also ignore what appeared to me to be active attempts at communication from intellectually disabled adults if they were engrossed in a

conversation with me. There were many instances in which intellectually disabled adults would come up to educators to complain to them about a peer or simply share a piece of information which they would ignore because they were talking to me. While these conversations made me uncomfortable, I did not question the judgment of the educators, thus further reinforcing the hierarchical relational context within these organizations. I was also introduced as Shruti *tai* or *didi* (elder sister in Marathi and Hindi respectively) by the educators to intellectually disabled adults (even to those who were older than me) which led to further widening the social gap between us.

Indeed, when I started my fieldwork, many intellectually disabled adults treated me as an authority figure by asking for my permission when they left or entered the rooms and complaining to me about their peers. However, over time, I was able to communicate in a more informal manner with them, especially when I was not in conversation with special educators. Given that intellectually disabled adults had diverse communication styles, personalities, and gender and age backgrounds, I had different levels and kinds of relationships with different individuals. For instance, it was easier for me to interact with women who used verbal language and who were also eager to engage me (either by sharing facts about their families or asking me about my life). In contrast, there were men at both Udaan and Sankalp who did not talk much, or only talked to the educators, who I was unable to interact with much. While I was unable to challenge the hierarchical communication initiated by special educators, I made proactive attempts on my side to acknowledge and respond to nonnormative cues articulated by intellectually disabled adults. For instance, whenever I perceived someone communicating with me through gestures and body language, I would make attempts to respond by gesturing, nodding, and making facial expressions.

## **Chapter Outline**

Across the chapters, I analyze the different ways in which special educators noticed and interpreted intellectually disabled people's needs and desires and subsequently made decisions that impacted their lives. In Chapter 1, I explore how special educators intervened in the domain of communication to make up intellectually disabled adults as communicative beings. I start with a focus on communication because special educators and intellectually disabled adults spent entire days together in these institutions during which communication was key and foundational to special educators intervening in the lives of intellectually disabled people. I examine Sankalp workshop and Udaan vocational and arts center, which are different from each other in terms of their organizational structure and values, and demonstrate how in both these institutions, special educators constantly talked to intellectually disabled adults and found messages in their nonnormative utterances, behaviors, and actions. Special educators, in both organizations, interpreted their unconventional and non-linguistic cues (such as behaviors and actions) and linguistic cues (such as utterances and non-linear sentences) and saw them as communicative signals. They talked as if they understood their attendees and made confident claims about what they were saying. In doing so, special educators made up intellectually disabled people as communicative beings whose thoughts and feelings were known to them. Aside from listing the different ways in which special educators talked to intellectually disabled adults, by ordering, instructing, praising, scolding, and chatting with/to them, I also analyze the different categories, such as, "good child" or "problem child" that special educators used to make sense of intellectually disabled people's behaviors. Throughout the chapter, I demonstrate that by constantly talking to intellectually disabled people, interpreting their nonnormative behaviors

and utterances, and subsequently making interventions by categorizing them as specific kinds of people, special educators made up intellectually disabled people as communicative beings. I also demonstrate special educators gave intellectually disabled adults a limited form of communicative personhood, as they viewed them as uncomplicated people whose thoughts are easy to access.

In Chapter 2 and Chapter 3, I shift my focus from the domain of communication and look at the ways in which special educators intervened in the lives of intellectually disabled people by keeping them occupied in diverse ways. In Chapter 2, I focus exclusively on Sankalp workshop to demonstrate that while special educators attempted to make up intellectually disabled people as productive workers by keeping them occupied in productive and busy work (*kaam* in Marathi), not all intellectually disabled people could participate in work in the same way, either because they could not or did not want to. Many people, instead of doing work (*kaam*), simply sat, or napped for hours. While sitting or napping were not valued activities in the eyes of authorities such as special educators, I demonstrate that passing time by sitting, napping, or chatting in non-linear ways, instead of doing productive work, was also a form of occupation. I use the Indian concept of “timepass” (Jeffrey 2010) to talk about the less so-called productive forms of occupation that occurred at Sankalp. Throughout the chapter, I illustrate how special educators attempted to keep intellectually disabled people occupied in various activities through the day and in the process made them up as people who when asked or prompted could look after themselves, help their peers and people in positions of authority, and perform chores. Despite this emphasis on work (*kaam*), I show how intellectually disabled adults (and special educators) also used the institutional space to rest, relax, have spontaneous interactions- all of which were also valuable ways of occupying their space and time within the organization.



In Chapter 3, I transition from Sankalp, with its institutional emphasis on productivity and busy work, and focus on Udaan, a relatively new, home-based, vocational and arts center in Pune which prioritized the values of fun, pleasure, and enjoyment. I demonstrate how instead of busy work, special educators at Udaan kept intellectually disabled adults occupied by creating fun experiences for them, such as, dancing, singing, watching television, and organizing picnics and overnight trips. I draw on South-Asian anthropological scholarship on *mazaa* (Anjaria and Anjaria 2020), the Hindi and Urdu word for fun, to demonstrate that enabling fun and pleasurable experiences, can lead to the creation of “new worlds,” (Anjaria and Anjaria 2020, 234) and new social opportunities for intellectually disabled adults. In this world, intellectually disabled adults were made up as fun people who experienced pleasures and indulged in fantasies. Further, I also consider the issue of teasing or “making fun” as it came up repeatedly at Udaan. Moments of joy and teasing often co-existed, overlapped, but sometimes diverged—especially if it led to feelings of upset and hurt. By talking about practices of “making fun” and their ability to charge the atmosphere with negative or uncomfortable feelings, I want to make note of how complicated scenes of fun and laughter are, depending on who is in charge, who gets to say what, and at whose expense.

Thus far, this dissertation examines how institutional stakeholders, such as special educators, intervene in the lives of intellectually disabled adults by communicating with them, categorizing them, and occupying them on a day-to-day basis. In the next two chapters, I shift my focus to more long-term interventions and examine how institutional stakeholders, some of whom are also parents who have founded institutions, imagine, plan, and implement long term life-projects ( Reynolds Whyte 2020) for intellectually disabled adults. What are the futures imagined and actualized for intellectually disabled people in India? How are these intellectually

disabled adults' futures intertwined with the futures of institutions? What are the constraints that institutional stakeholders may face when implementing life projects for intellectually disabled adults? I address these questions in Chapter 4 and Chapter 5.

In Chapter 4, I continue focusing on Udaan and examine how the co-founders, Sahil sir and Sarika ma'am intervened in the lives of Geeta and Swarup two of their oldest intellectually disabled attendees, to implement a long term romantic and sexual companionship for them within the premises of Udaan. I demonstrate that by noticing and interpreting their behaviors as denoting attraction for each other, teasing them about their supposed romantic feelings, referring to them as husband and wife despite them not being married, and subsequently making interventions, such as, asking them to spend time together wherein they could kiss and touch each other, Sahil sir and Sarika ma'am made up a playful sexuality for Geeta and Swarup. This sexuality was playful because it was imagined through fun practices such as make-believe and teasing and did not have legitimacy outside the social world of Udaan. The sexual personhood imagined at Udaan was not only playful but also public, because Sarika ma'am and Sahil sir deliberated on what Geeta and Swarup felt and could do with each other and supervised their physical intimacy. Throughout the chapter, I demonstrate how Sahil sir and Sarika ma'am's life-project for Geeta and Swarup, although limited, made possible romantic and sexual opportunities for them.

In Chapter 5, the final chapter of the dissertation, I shift my focus to Ananda Foundation, the only parent-run, rural institution I encountered and trace how the institution's journey (from the inception of its vision) was intimately tied to Smriti's journey, the young intellectually disabled daughter of Jayant and Asha, the couple who run the organization. This chapter is an outlier on many levels. For one, the data for this chapter is based not only on participant

observation at Ananda Foundation which was unfortunately cut short due to COVID-19, but also on an analysis of the book that Jayant and Asha wrote in 2010, and that I helped translate and proofread in 2019, that chronicled the vision of their life-project. Their life-project involved both setting up the organization and their daughter's future within the organization: as someone who both works and enjoys sexual companionship within this space. Secondly, instead of focusing on non-kin actors, this chapter examines what happens when parents, based on their experiences of raising children with intellectual disabilities, become institutional actors. Lastly, unlike the other organizations that are based in Pune, an urban center in Maharashtra, this chapter traces Jayant's and Asha's journey which starts from Karkamb, a village in Maharashtra, where Asha was born and raised, takes a long detour at Pune for their daughter Smriti's medical care and education, and ends up back in Karkamb to set up Ananda Foundation.

Despite these differences, this chapter is connected to the rest of the dissertation because, like in the rest of the chapters, I examine how Jayant and Asha (both kin and institutional stakeholders) intervene in the lives of intellectually disabled adults, including their own daughter's. However, unlike the other chapters, I demonstrate what happens when an urban intervention such as a vocational center is introduced within the rural context of Karkamb, wherein people have never heard of an institution of this nature and already have social roles and life-plans for their intellectually disabled adult children which do not align with sending them to the Ananda Foundation. Within this context, I note the ways in which Jayant and Asha re-imagine their life-project for both the vocational center and their daughter's future by responding to the realities and needs of Karkamb residents. They do so by abandoning their vision of a vocational center and transforming their organization into a social home for intellectually disabled adults who need food and shelter during the day. Further, they also move away from

their vision of their daughter finding sexual and romantic companionship within the vocational center and work towards providing her with an alternative personhood of a “happy single working girl”.

Across the chapters, I examine the ways in which special educators, through their interventions, create opportunities, however limited and imperfect, for intellectually disabled adults. In the conclusion, I emphasize the fact that while I recognize the work special educators do in making up the personhood of intellectually disabled people, it is limited, and just one of the possibilities. What would happen if one seriously considered paid employment, marriage, parenthood, and participation in public life, such as casually hanging out at tea stalls without supervision as real possibilities? These possibilities are rooted in (liberal) ideas of disability rights, facilitation of autonomy, and capacitation of skills, which run counter to the relationships I explore in this dissertation. In the conclusion, I make space for considering and imagining those possibilities while acknowledging that these are liberal ideas. Further, I also spend time considering other non-liberal ideas of personhood by asking questions, such as: what possibilities would be created for intellectually disabled people if there was an exclusive focus on providing them with care and seeing them as recipients of care? I consider these diverse possibilities in the conclusion to illustrate that what I present in the dissertation is just one of the pathways to personhood for intellectually disabled people.

## **Interlude I: Two Life Stories**

In this interlude, I introduce two young women with intellectual disabilities named Smriti and Prachi and I discuss their families, socio-economic contexts, and life trajectories. I have chosen them for the interlude because the two life stories have many similarities as well as differences. Smriti and Prachi belong to different class and caste backgrounds and have different diagnostic journeys which shape their life stories differently. However, both share many experiences as well, such as the interventions at home their families come up with to make their lives better, their interactions with medical professionals, and their family's decision to move them from mainstream to special schools. I chose these stories because in both cases the families discuss how valuable institutions of special education and special educators have been for their children's development.

### **Smriti's Story**

The narrative that I present in the next few paragraphs is based on the book *Amche Anokhe Prayog* in Marathi or *Our Unique Experiments* in English, a book co-authored by Asha and Jayant, Smriti's parents<sup>5</sup>. The book chronicles their life experiences with a focus on how their life transformed after Smriti's birth. The viewpoints, anecdotes, and events highlighted here directly reference the book, including some direct quotes from the book (translated into English). The story presented here gives insights into what Jayant and Asha chose to share about Smriti's life trajectory from their own perspective.

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<sup>5</sup> The name of the book and the people mentioned in it are changed to protect the anonymity of the writers.

Smriti was born in 1994 in Solapur, a city located in the south-western region of the state of Maharashtra in India. She was born to Asha and Jayant Lokhande. At that time, Asha was a high-school teacher and Jayant was a journalist at a Marathi newspaper. When Smriti was born, both Sujata and Jayant were ecstatic, because they had always wanted a daughter. On the third day after her birth, Smriti suddenly “got fits”. She was immediately moved to a children’s hospital a few miles away from the maternity hospital where she was born to be placed in an incubator. After settling Smriti in an incubator at the children’s hospital, Jayant returned to Asha’s hospital. A day later, Asha’s gynecologist and a renowned pediatrician took Jayant aside and said, “Your daughter is not normal. She is mentally retarded. See, I suggest that you forget the baby”. Jayant was shocked when he heard this and asked the doctor, “What do you mean by forget the baby?” His reply was, “It means, stop medication!”.

Jayant refused to listen to this advice. However, he also decided to keep this information from his wife, who was still recovering in the hospital. He told Asha that Smriti had jaundice, which is why she had to be taken to the incubator. In her first year, Asha saw that Smriti was developing slowly, but she thought it was because of her jaundice. When Smriti turned one, Jayant thought it was time for Asha to know the truth about Smriti. But he wanted Asha to hear it from a doctor. On 14<sup>th</sup> January 1995, the family travelled to Pune to meet a renowned pediatrician, Dr. Abhyankar, to do some medical tests. Dr. Abhyankar told them that Smriti was a “mongol baby”. He told them that she had a life-long retardation. He said that while her capacity is less, it can be developed well. He also shared with them that Smriti did not have any heart health issues and that such children are born music lovers. After the two-hour session with Dr. Abhyankar, Asha emerged from the doctor’s clinic with a resolve to give Smriti the best possible life. The very next day, Jayant and Asha went to a counselor in Pune and made Smriti

undergo the 21 Trisomy diagnostic test and the Intelligence Quotient (IQ) test to confirm that she indeed had Down syndrome. Over the next few years, the couple visited multiple speech therapists, physiotherapists, and ophthalmologists to manage her eye health, speech, and motor development.

On the front of her education, Jayant and Asha decided against sending her to a special school- the term commonly used in India for segregated spaces of education and training for people with intellectual, learning, or developmental disabilities. They enrolled Smriti in a mainstream school. Asha, being a teacher, channeled her professional expertise into developing Smriti's capacities to read, write, and talk at home. For instance, Asha developed a daily ritual wherein she would narrate the day's events to Smriti in the form of a story. While initially, Smriti just listened, eventually she started participating by talking. However, despite Smriti having learned how to read, write, and communicate using a few words, after 4<sup>th</sup> grade, she could no longer keep up with the academic load of the school. Neither Jayant nor Asha wanted to send Smriti to a special school in Solapur since they were unimpressed with the quality of support and training provided in these institutions. Thus, in 2003, the Lokhandes decided to move to Pune, a bigger and more urbanized city, in search of a good special school for Smriti. One of Asha's cousins, who worked at Sasson Hospital (the leading government hospital in Pune) informed them of Rainbow Foundation, a school that catered to "slow learners". They reached out to the Rainbow Foundation, wherein the in-house psychologists assessed Smriti's IQ. Her IQ was 63, which indicated a mild mental retardation. Rainbow Foundation had two wings for children under the age of 18 years.

Sparrow, the first wing, worked more like a regular school but catered to children who needed extra support to appear for their academic examinations, such as children who had

received a diagnosis of dyslexia or dysgraphia- learning disabilities that affect people’s abilities to process language or numbers. Peacock, the second wing, catered to children who were assessed by the school as not being capable of engaging in academics. Instead at Peacock, the focus was on music, arts, and vocational training. While the Lokhandes wanted to send Smriti to Sparrow, the special educators at Rainbow Foundation explained to them that Peacock might be a better fit for Smriti. While initially crestfallen, they agreed to the arrangement and Smriti joined the Peacock wing of Rainbow Foundation, where she participated in music, dance, and theatre events, attended picnics, and learned functional academics (a syllabus that focused on teaching students how to use language in daily conversations, basic reading and writing skills, and mathematics for day-to-day transactions). Meanwhile, Asha became pregnant in 2000. This time around, she visited Sassoon Hospital in Pune to undergo the pre-natal screening test to make sure that the fetus did not have Down syndrome. Having found out that the baby was “normal” (in Jayant’s and Asha’s words), they went ahead with the pregnancy and had their second daughter, Sunaina. At 18 years of age, Smriti shifted to the vocational center affiliated with Rainbow Foundation. However, she missed her teachers from the school and did not like the environment and expectations of the vocational center. She eventually left the center and decided to stay at home. However, while Smriti was at home, Jayant and Asha also planned to build a workshop of their own, where Smriti could eventually become a teacher herself.

I first met Smriti, Asha, and Jayant in 2019. By the end of 2019, they had built an organization called Ananda Foundation in Karkamb, a village within Solapur district. Karkamb was where Asha grew up and her father offered her a plot of land there to build an organization of her own. At present, the Lokhandes live in Karkamb, except for Sunaina who pursued her higher education in Pune and decided to stay back to do a master’s degree in psychology. At



Karkamb, Smriti, now a 28-year-old, actively participates at the Ananda Foundation workshop and spends time with her extended family, many of whom live in nearby villages.

### **Prachi's Story**

Prachi was born in 2004 to Sunita and Ramesh Mankar in Pune. Sunita was a domestic worker and Ramesh was an office boy. Prachi was born in Sunita's seventh month of pregnancy. Sunita was feeling unwell and swollen but did not have any labor pains. She went to Sassoon hospital where the doctors said that the baby was having convulsions, so they needed to induce labor. Prachi did not cry when she was born. She was also underweight. The doctors decided to keep her in the incubator for a few days. After eight days, Prachi could return home. But Prachi would cry day and night, which had Sunita and Ramesh worried to no end. One of Sunita's cousins also had a baby around the time Prachi was born. Sunita realized that Prachi was not developing at the same pace as her cousin's baby. For instance, Prachi could not hold her neck up at six months unlike her cousin. She could only do it at the age of ten months. However, Sunita did not give up. She and her husband had seen other *apang* (handicapped in Marathi) children in their neighborhood and how they were neglected, and they did not want the same for their daughter<sup>6</sup>.

Sunita wanted her daughter to be able to sit and walk like other children. To teach Prachi to sit without support, Sunita would sit on the floor with her legs spread out making *chapattis* (round flat breads) and make Prachi sit in between her legs. While Prachi could not sit without her mother's support, she would laugh and giggle, which made Sunita very happy. Later, she started placing soft pillows on the floor and placing Prachi on them. Eventually, Prachi started

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<sup>6</sup> During the interview, I was unable to ask Sunita how, whether, and at what point she knew that Prachi was *apang* (handicapped), but from her interview transcript, it appears that she knew early on that Prachi was *apang* or shared similarities with other children in their neighborhood who were considered to be *apang*.

sitting without support at the age of one and a half years. Sunita and Ramesh would also sit on the floor and make Prachi practice walking while holding the wall. With practice, Prachi started walking at the age of two and half years. Ramesh would also bring sand and put it in a tub of water and have Prachi stand in it to make her legs stronger. Sunita and Ramesh figured things out by watching television shows about the topic. They did not consult medical experts until Prachi turned seven.

Sunita enrolled Prachi and her younger sister, Pragati, who was a year younger to her, in an *Anganwadi* (a child-care center run by the Indian government where children can access food, pre-school education, and basic health care services). Prachi did not have teeth for a long time, so the teachers at Anganwadi would tell Sunita to grind the food in a mixer and give it to her. Prachi even started attending school with her sister Pragati. However, when Prachi was in the fourth grade, around seven or eight years old, the teachers at the school said that she could not keep up with the studies and that she should enroll in a special school, meant for *matimand* (Marathi term for mentally retarded, literally translates as mentally slow) children. Around the same time, Sunita also took Prachi to Sasson Hospital and asked the doctors to examine her. They did check-ups on her and told her that Prachi's brain does not have enough blood supply. They also made Prachi read numbers and repeat letters, but she could not do that. They issued her a disability certificate which said that she had 75% disability. Prachi's teachers at her school told Sunita to take her to Sankalp, a special school that was close to an apartment complex where Sunita worked as a domestic worker. Sunita asked the woman she worked for if she could take a day off to take her daughter to Sankalp. The woman asked her to not worry, wrote down the address of the school for her, and asked her to go immediately. She knew of Sankalp because she

would buy *diyas* (earthen oil-lamps) and lanterns made by their students at Sankalp during Diwali season.

When Sunita and Prachi arrived at Sankalp, the in-house psychologist, Mr. Patil, who examines new arrivals immediately gave Prachi admission. However, he said that given Prachi was so young, Sunita would have to accompany Prachi for the first couple of months for at least two hours. Sunita could not afford to spend this time at Sankalp because she had to work every day to financially support her family. Unable to attend Sankalp and unable to keep up with the pace of her current school, Prachi stayed at home from the age of 7 to 12 years. When she turned 12 years old, Prachi got her periods. She started throwing tantrums and beating people up around her. She also refused to wear menstrual pads. Feeling helpless, Sunita returned to Mr. Patil and asked if Prachi could join Sankalp school. Mr. Patil said that if Prachi had joined when she was younger, she would have progressed a lot by now. Now, there was a big gap according to him. Despite saying this, he agreed to admitting Prachi in the school. According to Sunita, the teachers at Sankalp school taught Prachi everything. Now Prachi knows how to bathe by herself and put her own pad on during periods. While she did not talk before, now she talks with her peers at Sankalp.

During the COVID-19 pandemic, Sunita lost her job as a domestic worker. The teachers and administrators at Sankalp helped their family out by providing them with kits of rice, wheat, and oil. Prachi was distraught during the pandemic years because she could not go to school. Post lockdown, in 2021, when Prachi returned to school, Sunita applied for a job as a *madat-nis* (helper or assistant in Marathi ) at Sankalp. Prachi's teachers recommended her to the administrators, and they agreed to give Sunita a job at Sankalp workshop. Sunita's job at the workshop includes accompanying the attendees on the bus, sewing dusters (the

production/commercial activity at the center), and assisting the women attendees at the center with toileting and changing pads. Her second daughter is in the 11<sup>th</sup> grade at Symbiosis college, a reputed private institution in Pune. Her husband now drives his own rickshaw and picks up Prachi every day after school. According to Sunita, everyone at home, including Prachi, helps with household chores (such as cooking and cleaning), which makes it possible for her to do her job. She is very happy with her new job because she gets to be near Prachi. Prachi turned 18 years old in 2022 and was about to leave Sankalp special school and transition to the workshop in July 2022. Sunita was excited about this because she wanted Prachi to learn how to sew, an activity of focus at the vocational center. (Based on an interview with Sunita Mankar held in May 2022 on the premises of Sankalp workshop, her workspace).

## Chapter 1: Making Up People Through Communication

### Introducing the Two Field-sites

#### *Site 1. Sankalp Trust, Pune*

On my first day of fieldwork in March 2022 at Sankalp, a government aided workshop that caters to intellectually disabled adults over the age of 18 years, I was assigned by the workshop's superintendent, Mr. Borse, to special educator Sandhya *maushi's* (Marathi word for maternal aunt) men's sewing section. Upon my arrival, she introduced me as Shruti tai (Marathi word for elder sister) to everyone. Having finished the morning routine of prayers and physical exercises, Sandhya *maushi* proceeded to call each person to the front of the room to introduce them to me. She asked each person, in Marathi, to tell me their name, what they liked doing, and where they lived. While some people answered the questions, when someone did not answer the questions, Sandhya *maushi* would step in and answer on their behalf. When Ramesh, a young man who did not speak much came up to the desk and did not answer Sandhya *maushi's* questions, she looked at him encouragingly and said, "You love drawing, and you love helping at home". He nodded and left before the next person arrived.

#### *Site 2. Udaan, Pune*

On a busy weekday in September 2021 before Diwali, the Hindu festival of lights, I was sitting along with Sonali ma'am, a special educator, and a few intellectually disabled adult attendees on the floor of the crafts room at Udaan, a relatively new arts and vocational center, painting *diyas* (oil-lamps) at breakneck speed. When Sarika ma'am, the founder of Udaan, came into the crafts room to find something in the cupboards, Sonali ma'am complained to her in Hindi that two

attendees named Gopal and Vishal were working very slowly. Sarika ma'am smiled and asked them to work fast, before leaving the room. Soon after it was time for lunch. Vishal refused to leave with the others and continued painting. Sonali ma'am pleaded with him to go eat by saying, "You worked fast only today, go for lunch now." Vishal continued painting without looking up. Then she looked at me and said, "I said before he was working slowly, right? So now he does not want to go." All three of us left for lunch after a little while.

Across my field-sites, such as Sankalp, Udaan, and Ananda Foundation, I observed special educators attending to, interpreting, and consequently making claims about intellectually disabled adults' silences, behaviors, facial expressions, and body language. Intellectually disabled adults within these institutions most often did not use conventionalized language to communicate. Their language, behaviors, and comportment did not fit into the ideal of a rational, speaking, coherent person. While some mainly used verbal language (usually Marathi, sometimes Hindi), some others mainly used gestures and facial expressions, and still others used an integrated combination of verbal language and gestures. Very few people always used linear sentence structures using speech. They would usually not respond through verbal language even if they were being explicitly addressed, they would repeat specific phrases or gestures in a seemingly sporadic manner and would often not follow instructions or do things promptly when asked. Conversations within these institutions did not take the form of normative turn-taking.

During my fieldwork, I was often unsure about what intellectually disabled people meant when they said or did something. I would not know how to respond to their cues and would usually awkwardly nod, smile, or repeat their gestures politely. However, I almost never observed special educators looking hesitant or tentative. Instead, as described in the vignettes above, they often engaged with their non-linguistic behaviors and actions and linguistic

utterances and non-linear sentences, or lack thereof, and saw these as communicative signals. For instance, Sandhya maushi filled in for Ramesh when he was silent and claimed that he loved drawing and helping at home, and Sonali ma'am interpreted Vishal's refusal to have lunch as an effect of her complaining about his slow work. In both these examples, I was not sure about the claims made by the special educators. Did Ramesh actually like drawing and helping at home? Was Vishal genuinely upset about Sonali ma'am's remark about the pace of his work? However, these were not the kind of questions that special educators occupied themselves with. Instead, they engaged the behaviors, actions, gestures, and silences of intellectually disabled people by intervening through making confident claims about what intellectually disabled people meant, thought, liked, disliked, and even who they were as people. In doing so, special educators made up intellectually disabled adults into communicative beings, who could be interpreted and known by them. Further, they also made themselves up into experts who were able to interpret and know intellectually disabled people.

The special educators that I worked with did not make any clear and decisive statements about whether intellectually disabled people possessed language. In fact, their statements regarding intellectually disabled people and their capabilities were often contradictory. For instance, sometimes they would say that while *special mula* (special children) could not talk through words, they could talk through gestures, facial expressions, and signs. However, they contradicted this statement by also saying that while special mula could not talk, they understood everything (*bolu nahi shakat pan samajh aahe* in Marathi). At other times, special educators would evaluate intellectually disabled people on a case-by-case basis. For instance, they would point to a specific individual and say that he or she can talk very well and at the same time point to someone else and say that he or she cannot talk at all. Thus, special educators did not have a

rigid, unchanging view about what counts as language and whether intellectually disabled people possessed it. They also oscillated between making general claims about all intellectually disabled people and more specific claims about particular individuals. However, in sometimes framing intellectually disabled people as people who could “understand everything”, special educators approached them as people who knew and understood things (at least to some extent) but did not have the ability to articulate their thoughts or feelings through speech.

Henner and Robinson (2023) critique mainstream approaches to language which understand language as being limited to conventional speech and do not consider other modalities, such as gestures, drawings, icons as legitimate language. Within this framework, people either have language (in the form of ordered speech) or do not and are thus languageless. They attribute this kind of thinking to specialized educators and speech therapists whose work involves viewing disabled people’s language as having deficits which need to be corrected. Their framework, which they term as crip linguistics, is significant because it suggests that no language, however unconventional, is disordered or bad. Unlike the specialized educators and speech therapists in the United States who often have formal training based on which they make systematic plans to correct or change disabled people’s language, special educators in India did not actively attempt to change intellectually disabled people’s language by trying to correct it or by making them use speech. As stated before, educators often attended to their nonnormative cues and even considered them to be a form of talking through gestures and expressions. However, they followed this up with top-down interventions by making confident claims about what intellectually disabled people meant through their cues. Special educators brought order to their apparently disordered, nonnormative expressions in the well-ordered form of their voicing, recasting, and uptake of disabled people’s’ communication. In doing so, they made up their own



epistemic authority. When it came to matters of language, special educators took charge and called the shots. However, intellectually disabled adults were not completely absent. Instead, special educators made them up as unequal conversational participants through the interactions they had with them.

### **Making Up a Narrow Personhood**

In vocational centers and workshops in India, special educators usually worked with more than ten intellectually disabled adults at the same time. Moreover, they also did production work (the term used within institutions to refer to vocational activities, such as, sewing dusters and painting diyas, that resulted in products that were later sold for profits) and fulfilled other work duties, which were different depending on the organizational context, but nonetheless took up a lot of their time. For instance, special educators often cooked lunch for themselves and some of their attendees at Udaan. At Sankalp, special educators stitched purses which were presented as souvenirs or gifts to important guests such as funders and trustees during their visits. It was within these constrained contexts that special educators communicated with intellectually disabled adults wherein they often did not attend to each person individually by sustaining a long conversation with them. Even when they had the time, special educators did not dwell too long on what intellectually disabled people meant to say. They also did not ask them any follow-up or clarifying questions during these interactions. Instead, they preferred to spend their spare time chatting with each other, calling their families, or browsing the internet on their phones. In these institutions, where time was often of essence and special educators were doing multiple tasks at the same time, they usually quickly attended to, interpreted, and made decisions about what intellectually disabled people meant when they said or did something (or even when they did not

say or did not do something), leaving little space for ambiguity. In doing so, they made up intellectually disabled people as easy-to-read or transparent persons, whose thoughts, feelings, and preferences were (uniquely) accessible to them.

It was through communication that special educators organized the social worlds of these organizations, within which intellectually disabled adults were assigned chores and social roles. As I describe in-depth later in the chapter, special educators intervened in the domain of communication by instructing, prompting, praising, scolding, filling-in-the blanks, and chit-chatting with intellectually disabled people. By communicating in these ways, special educators made up the personhood of intellectually disabled people. This personhood was limited or narrow. By this I mean that, although special educators thought that intellectually disabled people understood things to a certain extent and had desires and needs, they made them up as people who did not have a complex subjectivity, could not exercise choices and could not articulate their own thoughts and feelings. Special educators constructed them as people who were knowable and transparent, as people whose interior thoughts and feelings could be accessed and interpreted by them.

Further, special educators shaped intellectually disabled people's personhood in relation to the limited contexts they were familiar with. For instance, special educators saw them in relation to their families and the institutions within which they existed and made their communicative interventions by referencing these contexts. Special educators also saw most of them as people who could not make decisions about how to live their lives within these institutions and therefore constructed them as people who constantly and repeatedly needed to be told what to do. Finally, special educators did not construct all intellectually disabled people in the same manner: some people were expected to be more reliable and capable than others. Some

intellectually disabled people who ostensibly had milder disabilities and were able to perform tasks, chores, and social roles as expected were approached in different ways in that more was expected from them, than those who were considered to be significantly disabled and were unable to say and do things in somewhat normative ways.

By communicating in these ways with intellectually disabled people, special educators also organized everyday life at these organizations. For instance, they often repeatedly instructed intellectually disabled adults to get them to perform specific tasks. They subsequently praised and scolded them depending on whether they fulfilled those tasks. Further, when special educators chatted with intellectually disabled adults in an informal tone and even joked with them and each other, they contributed to making the atmosphere in these institutions livelier and more animated.

As mentioned in the introduction, special educators also intervened in the lives of intellectually disabled people by using categories which made up them as specific kinds of people. While these categories did not come up when special educators communicated with intellectually disabled adults, these often came up in the discussions they had with each other, higher administrators, and me. Categories that applied to all intellectually disabled people such as *special mula* as well as more specific categories that applied to particular individuals, such as *changli mula* ( good children in Marathi) and helper-type slotted intellectually disabled adults as specific kinds of people, which helped educators decide what they could or could not do within these institutions. While these categories aided special educators in making sense of intellectually disabled people's behaviors and skills and helped them in organizing institutional life, intellectually disabled people were given a narrow form of personhood through these categories. For instance, these categories often framed them as having particular and

anticipated/known personality traits (such as innocent and loving) and did not afford them a complex personhood, wherein they could be more than one thing at a time.

Although noticing, interpreting, and making assumptions about an interlocutor's thoughts or feelings can be a common feature of most communication, the stakes were high when it came to special educators doing the same with intellectually disabled adults, because of the highly unequal and hierarchal relational context between the two groups. In most cases, intellectually disabled adults did not possess the linear, rational, and conventional linguistic capacity to respond to or challenge the communicative interventions made by special educators. Thus, through communication, special educators decided what intellectually disabled people said, felt, and thought, what they should do nor do not, and who they were as people. While their influence was often but not always limited to these institutions, intellectually disabled adults spent considerable amount of their time daily in these spaces, often over many years. Aside from their homes, vocational centers and workshops were important, and likely, the only site of consistent social interaction for them. Therefore, it is important to attend to how special educators intervened in the domain of communication within these institutions and how that shaped both their and intellectually disabled adults' personhood as well as the larger social world of these institutions.

While anthropological studies have considered how parents of people with intellectual and developmental disabilities "learn to look" (Rutherford 2020, 1464) at their children in novel ways based on the intimacy they establish with them and take joy in "noticing and celebrating these small moments of responsiveness" (Rutherford 2020, 1470) as well as "radically translate" (Hart 2014, 288) their children's' inner world for others, not much work has been done on how institutional actors similarly notice and translate moments of responsiveness and

unresponsiveness demonstrated by intellectually disabled people. In this chapter, I document and analyze such communicative practices and their consequences. Importantly, this chapter will also set the stage for the subsequent chapters as the communicative practices, social categories, and understandings of personhood that I outline here will be discussed throughout the rest of the dissertation.

### **Framing Special Educators' Communication as Leaps-Of-Certainty**

On one slow and hot April afternoon in Anisha maushi's section at Sankalp, Virat, an older intellectually disabled man in his 40s came up to me and said "thank you" in English before returning to sit on the carpet on the floor. I was just sitting on a chair next to Anisha maushi looking into my notebook. I had not even interacted with or talked to Virat. Anisha looked up from her sewing machine, puzzled, and said in Marathi, "Why did you say thank you to her?" I looked puzzled too and said, also in Marathi "I did not do anything!" Anisha smiled and said in Marathi, "You come here now, there is an attachment", (using the English word attachment).

Special educators often made claims such as this one wherein they claimed to know the hidden meaning behind the actions of intellectually disabled adults that seemed to puzzle or confuse me. "How do you know?" was a question I often asked them. The question often evoked amusement among special educators, who would shrug and give me various answers, such as: you observe them over time, you pay attention to their gestures and expressions, or you just learn from experience (they would use the word *anubhav* in Marathi). They would never give me a "scientific" or "rational" sounding answer. Scholarship in linguistic anthropology (Goodwin 2004; Green 2014; Green 2022; Rutherford 2009; Rutherford 2021) has considered the ethical stakes of communication between disabled and non-disabled actors across linguistic differences

and inequalities. Both Goodwin (2004) and Green (2022) demonstrate that what matters for communication to transpire is less a shared linguistic system and more a desire or willingness to communicate. Rutherford (2021) specifically addresses the ethical stakes of communicating with significantly intellectually disabled people who appear to be opaque. She claims that caregivers and therapists communicate with intellectually disabled people from a space of faith or belief. Rutherford (2021) writes that caregivers and therapists often talk with disabled people, “as if they understand them, without knowing if they do” ( Rutherford 2021, 140-41), because their communication is based in faith that, “through the right medium, they will be able to reach their disabled interlocutors and see deeply into their minds” ( Rutherford 2021, 141)

Similarly, in a blog piece from 2009, Rutherford talks about the speech therapists who engaged her atypically communicative daughter Millie in myriad ways and states that, “ Millie’s therapists surround her with talk and find messages in every sound or move she makes. Akin to the therapists and caregivers who communicated with Millie, special educators in the field-sites I visited also constantly talked to intellectually disabled people and found messages in their gestures, expressions, and silences. They too talked as if they understood them, without knowing that they did. However, I do not use the term “faith-based” communication while discussing special educators. While talking to me or each other, special educators never framed their communicative strategies as emerging from faith. Instead, what was striking about the special educators was that they made their claims in a confident and certain manner, leaving no room for ambiguity, uncertainty, or feedback from intellectually disabled people<sup>7</sup>.

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<sup>7</sup> Unlike the therapists and caregivers who worked with Millie, the special educators I engaged with did not have access to Facilitated Communication (FC) or specialized communication systems and training.

In the rest of the chapter, I examine how this certainty-based communication of special educators transpired at Sankalp and Udaan. I begin with listing the various communicative strategies adopted by educators, such as instructing, praising, scolding, filling-in-the-blanks, and chit-chatting. I then move to the different modes of talk adopted by them, wherein they talked to, talked at, talked on behalf of, and talked about intellectually disabled adults in front of them. After having looked at communicative strategies and modes of everyday talk, I shift to examining the social categories that special educators adopted to describe intellectually disabled adults and demonstrate the effects of these categories on their everyday lives within the organizations. Wherever relevant, I also situate myself as a conversational actor vis-à-vis both special educators and intellectually disabled adults and examine how my presence also shaped communicative contexts.

While I examine only Sankalp and Udaan here, I observed special educators communicating similarly across most of my field-sites. I only consider these two organizations here because I spent most of my fieldwork period doing participant observation in these two spaces which gave me sufficient time to observe communicative relationships over a longer period and learn more about the life stories of both the special educators and some of the intellectually disabled attendees. Also, given how different Sankalp and Udaan are in terms of their vision and structure, I wanted to juxtapose these two sites and point to the similarities and differences between the communicative strategies as well as the social categories used by special educators at the two institutions, based on which they relationally made up the personhood of intellectually disabled people. It is significant to study this because the communicative strategies and the social categories used by special educators shaped the kind of people intellectually

disabled people could be within these spaces, the expertise of special educators, and everyday life and workflow within these institutions.

### **Sites: Juxtaposing Drastically Different Organizations**

In this chapter, I consider two of my field-sites, Sankalp *Udyog Kendra* (‘work center in Marathi) and Udaan, next to each other. While both are in relatively affluent neighborhoods of Pune, Sankalp workshop (workshop was the preferred term that circulated within the institution), founded in 1978, is government-aided and based in an older bureaucratic looking building, and Udaan is a home-based, non-governmental, vocational and arts center founded in 2019. Both organizations cater to intellectually disabled people over 18 years of age. While Sankalp caters to around 100 intellectually disabled adults, at Udaan, around 15 to 20 people attend regularly. Sankalp workshop carries out the production activities of weaving and sewing industrial dusters, bookbinding, and paper-shredding. It has long term contracts with corporations and private hospitals and both educators and intellectually disabled people here follow an everyday routine to fulfill these production activities. Given that Sankalp is government-aided, most intellectually disabled adults do not have to pay a fee to attend the center<sup>8</sup>. Thus, the center caters to attendees from diverse socio-economic, religious, and caste backgrounds. Further, Sankalp has a long-standing tradition of celebrating Hindu festivals and rituals on its premises on a regular basis. This is the case because the workshop is managed by Sankalp Trust, which was founded by Mrs. Iravati Damle, an upper-caste (Brahmin) Hindu woman who believed that religious festivals were an important social experience for everyone and *matimand mula* ( the term for mentally

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<sup>8</sup> The only intellectually disabled adults who pay a fee at Sankalp belong to the care group, which is a section funded by Sankalp trust and not the government and caters to people over 45 years of age, who aged out of the government cut-off for receiving aid. I have an in-depth discussion about the care group in the next chapter.



retarded children in Marathi) should have the opportunity to participate in festivities, just like everyone else<sup>9</sup>. Finally, Sankalp is gender-segregated and traditional about its views regarding gender and sexuality. Men and women have separate sections (except for the care group) and wear uniforms, which for men is a full pant and formal shirt, and for women is a salwar kameez with a *dupatta* (a long flowing garment) that covers their chest. In fact, special educators often order attendees to adjust their dupattas so that they cover their chests or ask them to pull their shirts down in case they ride up. At Sankalp, productivity, discipline, and following traditions were priorities for both special educators and intellectually disabled adults<sup>10</sup>.

In contrast to Sankalp's formalized, bureaucratic, production-oriented, and traditional set-up, Udaan is a home-based, informal vocational and arts center. People here participate in activities like painting diyas (during Diwali season), making festive snack items, and learning and performing the Djembe, a West-African drum played with bare hands. Udaan does not have long-term contracts with companies or hospitals and instead sells its products (dijas and snacks) through informal social networks and in a seasonal manner (Hindu festive season is usually a busy time at Udaan). Udaan was founded by Sarika ma'am and Sahil sir, a married couple, who had wanted to build a vocational and arts center where, in their words, intellectually disabled people could have the experience of going to college like their "normal" peers. They wanted to create a space where intellectually disabled people too could enjoy life. No one at Udaan wore uniforms and men and women were encouraged to socialize with each other. Sahil sir and Sarika

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<sup>9</sup> I learned about Mrs. Damle's views from her autobiography which is in the form of a book and published by Sankalp Trust. The special educators and administrators at Sankalp implored me to read this book and referenced it during conversations with me. I do an in-depth analysis of her perspectives and work at Sankalp in the next chapter. I am unable to cite this work as it would compromise the anonymity of the institution.

<sup>10</sup> Sankalp workshop is formally registered as an Udyog Kendra which translates to a work center in Marathi and Hindi. Udyog Kendras in India are traditionally small-scale government and non-government enterprises that focus on handicrafts and encourage self-sufficiency as a value, both on the level of the enterprise and the employees.

ma'am often organized overnight picnics, hikes, and sleepovers at Udaan, which was the same space as their home. While some of the special educators at Sankalp vocational center had a bachelor's degree in special education, all of them had degrees from Industrial Training Institutes (ITI) in specific vocations, such as sewing and bookbinding. At Udaan, no one had any formal education or training in the field of special education. While Sahil sir was a music teacher, Sarika ma'am and Sonali ma'am, the two special educators, had received in-house training at Rainbow Foundation, the institution where both had worked before Udaan, which I introduced in the introductory chapter as the institution where I conducted my preliminary fieldwork in 2019.

Despite these differences, special educators from both Sankalp and Udaan said that what mattered much more than their training was their on-the-job 'experience' (anubhav in Marathi and Hindi). Most special educators told me that they knew nothing about special mula when they first started their jobs. They told me that they did not know how to talk to them or understand much of what they said or did. But they said that over time, with guidance from their senior colleagues, they learned how to interact with them. For instance, Pushpa maushi, the youngest special educator at Sankalp once shared with me that when she had just started working there, she feared Irfan, one of the attendees, because he was supposedly very hyper. She asked Kulkarni maushi, a senior colleague of hers for help. According to her, Kulkarni maushi calmly talked to Irfan and calmed him down. Over time, she stated that she also learned how to talk to Irfan, and now she does not have any of the problems she had before. She also shared with me that when she had just started work, she did not know how to keep the special mula in her section occupied. This was when her colleagues gave her the advice of keeping them occupied through drawing, going on walks, and playing games and puzzles with them, something she felt comfortable doing now, after having spent three years at Sankalp. Thus, special educators framed

their learnings from senior colleagues and spending time with the attendees as being more important than anything they learned doing their coursework.

While most of the special educators at Sankalp received a government salary which was around Rs. 30,000 (USD \$360) per month, Sonali ma'am, the only salaried special educator at Udaan received around Rs. 12,000 (USD \$ 144) for working part-time. As I was wrapping up my fieldwork, Udaan employed a teaching assistant named Rama, who had an intellectual disability. Rama earned much lesser than Sonali (around Rs. 5000 or USD \$60) and she left Udaan after a few months of service because she was dissatisfied with her low income. The other workers at Udaan, Sahil sir and Sarika ma'am were also the founders and did not receive salaries from themselves. Udaan also had a few volunteers, who would come to the center whenever they had the time and would not be paid for their services. Finally, while Marathi was the medium of linguistic conversation at Sankalp, at Udaan, it was a mix of Marathi, Hindi, and Gujarati, because Sahil sir and Sonali ma'am, two of the staff members, were Gujarati Hindus from upper caste and upper-middle class backgrounds. On the surface, Sankalp and Udaan were as different as day and night. However, in the next sections, I will examine how relationships of communication that emerged at both organizations had more in common than not.

Both Udaan and Sankalp (and my other field-sites) were feminized workspaces, which mostly hired women special educators who spent a lot of their time not only training and doing production work, but also assisting intellectually disabled people with activities of daily life, such as feeding and using the toilet. While Sankalp came across as a more formalized institution (especially given that it was based in a government building), both institutions had a domestic quality to them. Special educators and intellectually disabled adults did not just work towards productive goals together, they also rested, socialized, and even did fun activities together.

Educators at both institutions often lovingly addressed intellectually disabled people as *bala* (child in Marathi), *beta* (son in Hindi) or *beti* (daughter in Hindi). They repeatedly shared with me that their role was to be both a mother and a teacher to special mula. Thus, kin-like relationships emerged between the educators and intellectually disabled people at both institutions. At Sankalp, the special educators were addressed as *maushi* (maternal aunt in Marathi) reinforcing their maternal role in intellectually disabled people's lives. While at Udaan, special educators were addressed as *ma'am*, which was not a kin-term, the fact that the institution was literally based in Sarika *ma'am* and Sahil *sir's* home gave it an informal, home-like texture, wherein people watched television together and the women educators cooked for everyone else during lunch time.

The kin-terms also extended to me<sup>11</sup>. Special educators at Sankalp asked the attendees to call me *Shruti tai* (the Marathi word for elder sister). Similarly, at Udaan, I was addressed as *Shruti didi* (the Hindi word for elder sister). This was the case even though many of the attendees at both organizations were either my age or older. I contend that these kin-terms helped establish the relational and communicative asymmetries between educators and intellectually disabled adults, wherein special educators occupied the role of maternal and teacher-like figures and intellectually disabled adults were seen not as normative adults but rather infantilized as special children. Importantly, these kin terms also shaped the conditions of possibility for communicative intimacy, wherein educators could perform a form of “linguistic care work” (Henner and Robinson 2023, 28) wherein they calibrated and oriented themselves to receive and respond to nonnormative communication from intellectually disabled adults. I next move to

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<sup>11</sup> Male teachers were called *sir* across organizations. Kin terms were not used for them. This also denotes how despite being feminized workspaces, men who worked here were granted more professional respect.

examining the communicative strategies of special educators at both Sankalp and Udaan to provide a picture of everyday interactions.

## **Communicative Strategies of Special Educators**

### *Instructing and Prompting*

Giving intellectually disabled adults instructions and repeated prompts to carry out tasks or chores was one of the most frequent communicative strategies used by special educators. I use the terms instructions and prompts together because while special educators would start with providing an instruction or an order, they would often repeat the instruction in the form of verbal and physical prompts ( by rewording their instruction or modelling the behavior they want done) until either their attendee did the task, or they gave up on the attendee doing the task. Providing instructions was the favored mode of communication when special educators were working towards getting things done. For instance, at both Sankalp and Udaan, educators instructed intellectually disabled adults to do chores for the organization as well as for them. At Sankalp, attendees were often called upon to fetch water for the educators or clean their spoons after lunch. At Udaan, educators regularly instructed attendees, especially the men, to move heavy furniture while cleaning up the organizational space (which was also Sahil sir's and Sarika ma'am's home) or lift and carry heavy bags of production related materials from a rickshaw to the organization. Further, given that Sankalp was more traditional and regulated, special educators here instructed and prompted intellectually disabled adults, especially women, to take care of their appearance and to groom themselves to look more socially appropriate and modest. Special educators would ask women to adjust their bra-strap and pull down their kurtas and ask men to tuck in their shirts and comb their hair.

To me, instructing appeared to be a deeply unequal intervention because intellectually disabled adults were never consulted about whether they wanted to do a particular task. However, instruction was a significant mode of person-making and institution-building at both these sites. Special educators, at both organizations, shared with me that they made special mula do chores for their own selves and others because they wanted to teach them to become “independent”, a word special educators used in English. Special educators wanted them to be able to take care of themselves and help around their own homes with household chores. However, during my fieldwork period, I never observed intellectually disabled adults becoming independent enough to do these tasks without receiving explicit instructions and prompts from educators. Instead, through instructions and prompts, special educators made up intellectually disabled people into people who, when given clear instructions, could look after themselves and do chores for others. Further, instructing kept the organizational flow running: tasks were completed and everyday routine was maintained. In turn, through instructing, special educators also made up their own authority and got tasks done.

Aside from instructing intellectually disabled people to do chores around the institution and work on their appearance and grooming, special educators also gave explicit and repeated instructions and prompts while doing vocational activities. For instance, on a busy day before Diwali in October 2021, Sonali ma’am and Vinit, an ever-smiling young male attendee, sat next to each other in the crafts-room of Udaan wrapping homemade chocolates in fancy gift paper. Sonali ma’am gave instructions to Vinit during each step of the activity. Through words and gestures (which was her doing a simulation of the activity with her hands in the air) she prompted him to place the chocolate in the center of the paper, to put it on the silver side, not the green side of the paper, to place the side of the chocolate that was engraved face-down on the

paper, to fold the paper properly so that the chocolate was no longer visible. She had to repeat her instructions each time Vinit tried his hand at the activity, as he would usually miss one of the steps. After Sonali ma'am had prompted Vinit for some time with words and gestures, she took a chocolate and wrapping paper and started doing the activity next to him. She also continued providing a verbal commentary of what each step entailed as she did the steps herself. Vinit, in turn, would respond non-normatively, with smiles, saying words such as "done" (in English) once done with a step, and repeating movements after her. Further, when Sonali ma'am saw that Vinit had not wrapped his chocolate properly, she took it from him and smoothed the wrapping paper more evenly. Vinit repeated her actions with his own hands.

While it is common in an educational or training setting of any kind to provide instructions and prompts, what stood out to me was the fact that intellectually disabled adults were often not expected to respond in normative ways. Vinit responded by repeating Sonali ma'am's actions and expressing himself through facial expressions or monosyllabic statements, such as "done." Further, while special educators, as mentioned above, stated that they wanted special mula to become "independent", they also contradicted this statement by often sharing with me that, realistically, they did not expect many of their attendees to finish most vocational tasks by themselves. Educators across institutions shared with me how they had to "polish" (said in English) the work done by special mula. For instance, they would tell me that while special mula did the first layer of painting on diyas, it was usually followed by the special educators applying the final coat of paint before packing the diyas up for final sale. Pushpa, the youngest special educator at Sankalp who oversaw the arts and crafts section, would showcase the artwork that she and her attendees had made together and tell me that while the attendees would do some preliminary coloring with her support, she would do most of the painting or crafting on her own.

Thus, instructing during vocational activities was not necessarily something special educators did in the hopes that they would one day be able to stop doing this. Instead, as they shared with me, they viewed most intellectually disabled adults as people who would always require support in the form of explicit and repetitive instructions. Further special educators also shared with me that the goal of their institutions was to keep intellectually disabled people busy or occupied. I almost never observed special educators coming up with systematic plans or projects for improving intellectually disabled people through these vocational activities. Thus, by intervening through instructions and prompts, special educators made up a “pragmatic personhood” for intellectually disabled adults, wherein (ideally) they could groom themselves and do chores and vocational activities with support. This pragmatic personhood was limited because special educators usually did not provide intellectually disabled people with choices, wherein they could decide whether and what kind of activity they may want to do. Further, this kind of personhood did not offer intellectually disabled people with opportunities to exist in ways that did not involve doing some form of work, either for themselves or for others. Finally, the pragmatic personhood constructed by special educators was not geared towards skilling, developing, or capacitating intellectually disabled people; it was concerned with keeping them occupied and ensuring that the institutional routine and objectives are achieved. Within these institutions, intellectually disabled adults could remain “unfinished adults” (Kafer 2013, 54) as they did not need (and were not capacitated) to fulfill the tasks or roles required of a normative and independent adult in mainstream society.

However, I note that not all intellectually disabled people were constructed as people who needed constant instructions and prompts. Special educators had higher expectations from some individuals who they considered to be reliable workers or exceptionally skilled at vocational



tasks. For instance, Bilal, a quiet male attendee in Sandhya maushi's sewing section at Sankalp would usually sew multiple dusters with no instructions. She often referred to him as a *guni mulga* (gifted boy in Marathi) when she spoke to me. At Udaan, Swarup, a young male attendee was always called upon by the educators to do chores, which he completed without many repeated instructions. He was known as the helper at Udaan and considered an important member of the institution. Both Bilal and Swarup were framed as reliable and capable, and educators had higher expectations from them when it came to their performance of chores and vocational tasks. Thus, the expectations of special educators set up the conditions of pragmatic personhood for intellectually disabled people. While most intellectually disabled adults were made up as people who would always require support with tasks and vocational activities, some of them were made up as expectational people who were skilled and reliable at carrying out tasks without much external support.

### *Praising and Scolding*

Special educators would also intervene by using the communicative strategies of praising and scolding intellectually disabled adults for their actions. For instance, Sandhya maushi at Sankalp regularly asked attendees to clap for each other, no matter how big or small their achievement was. On the same day, she asked attendees to clap for Darshan, because he successfully folded a batch of dusters, as well as Prakash, because he would soon be flying on a plane for the first time in his life to participate in the qualifying rounds for the Special Olympics. Similarly, at Udaan, co-founder Sahil sir appreciated Swarup, one of the intellectually disabled attendees for properly opening and laying out a bundle of heavy mattresses by saying in Hindi, "You opened it properly, *shabash!*" (good job). Words and gestures of praise punctuated a day of seemingly mundane activities (such as folding dusters and making envelopes) and appeared to lift the spirits

of special educators as well as the attendees, who would usually respond with a smile when they received praise.

On the flipside, special educators would also scold intellectually disabled adults for being too slow with the production/commercial activity they were doing (such as painting diyas or folding dusters) or for doing something they considered to be disruptive, such as, talking too loudly or annoying a peer. Much like instructing and prompting, praising, and scolding were also communicative strategies that while hierarchical and unequal, structured life at both the organizations. Later in the chapter, I discuss how those who were praised were often categorized as “good” while those who were scolded were understood as being “problematic”.

#### *Filling-in-the blanks*

Special educators across my field-sites also used the communicative strategy of “filling-in-the blanks” wherein they made claims about intellectually disabled people’s seemingly unresponsive behaviors, especially when they did not answer when they were asked questions or when they did not do the task that was asked of them. The opening vignette of the chapter is illustrative of this strategy. In this example, Sandhya maushi filled -in-the-blanks for Ramesh when she asked him to introduce himself to me. After he did not respond to her prompt for a while, Sandhya maushi jumped in to answer on his behalf by saying that he liked drawing and helping at home. Another instance of filling-in-the-blanks occurred in Kumud maushi’s women’s sewing section at Sankalp when two of her attendees, Saheli and Smita, who were twin sisters, appeared to be unresponsive to her instructions. When she asked them to fold a stack of dusters, they folded one or two dusters, and then stopped and sat apparently doing nothing. After prompting them for a while, Kumud maushi turned to me and said, “their parents must have scolded them at home today, that is why they do not want to work”. While I did not ask Kumud maushi how she knew

that Saheli and Smita had been scolded at home, it is significant to note that she interpreted their unresponsiveness and apparent lack of enthusiasm to fold dusters as a sign of familial discord. In both examples, special educators showed a familiarity with the familial context of their intellectually disabled attendees, with Sandhya maushi commenting on how Ramesh liked helping at home and Kumud maushi making the claim that Saheli and Smita were scolded at home. I most often noticed special educators using the communicative strategy of filling-in-the-blanks with me as I was the outsider who was not familiar with their attendees or their idiosyncrasies. However, I also saw special educators filling-in-the-blanks while talking to each other about specific intellectually disabled individuals, especially those who appeared to be quiet or unresponsive. By filling-in-the-blanks, special educators made up intellectually disabled people as people whose silences or so-called unresponsive behaviors could be interpreted by them. In turn, they also made themselves up as experts who were both able to speak on behalf of intellectually disabled people and decode the reasons for their unresponsiveness because of how familiar they were with them. I understand filling-in-the-blanks as a communicative intervention that was directed towards me rather than intellectually disabled people themselves (unlike instructions, prompts, praising, and scolding) and was enacted in the service of helping me understand the interactions that occur at these institutions.

### *Chit-chat*

In March 2022, during my second week of fieldwork at Sankalp Trust, I was asked by the center's administrative head, Mr. Borse, to observe Kulkarani maushi's section. Kulkarani maushi was a special educator with twenty years of experience at Sankalp and oversaw one of the two women's sewing sections. In between formal activities, such as morning prayers, which were followed by physical exercises, Kulkarani maushi joked and chit-chatted with the girls. In one

instance, she addressed everyone and said in Marathi , “What did you do during vacations?” (by which she was referring to the two-year break caused by the COVID-19 pandemic during which time the center was shut). While most of the girls did not respond to the question, one of the attendees, Anjali, responded by turning her hand into small circles. Seeing this, Kulkarni maushi laughed and said in Marathi, “You were just making *laadus* ( a round sweet Indian delicacy ) for two years?” and went back to sewing dusters.

This example demonstrates the ways in which special educators used light-hearted chit-chat and jokes to engage with intellectually disabled adults as they spent their days next to each other. Special educators would often initiate conversations with intellectually disabled people by asking them questions about their families, their routine at home, what they did when they had to stay back home during the days when the centers were closed due to COVID-19 restrictions, and so on. While only a few attendees responded using normative language, special educators would continue carrying out this uneven dialogue, by interpreting and subsequently making interventions in the form of confident claims about nonnormative signals, such as, Kulkarni maushi’s claim that Anjali meant to say *laadus* when she made round circles with her hands. By interpreting non-normative cues and responding to them by organizing them within an orderly turn-taking structure (in the form of questions and answers), Kulkarni maushi “repaired” (Schegloff 2007) the conversation and kept it going, instead of letting it come to a halt. By repair, I refer to the set of conversational practices used by co-interactions to make certain, “that the interaction does not freeze in its place when trouble arises, that intersubjectivity is maintained or restored, and that the turn and sequence and activity can progress to possible completion ” (Schegloff 2007, xiv). While this understanding of repair applies to normative conversations wherein both the speaker and the listener can initiate repair until both parties are

on the same page regarding the messages being exchanged during conversation by using strategies, such as, reformatting sentences, deleting words, or replacing phrases (Kitzinger 2012), I observed special educators performing conversational repair in a different manner. The work of repair done by special educators did not result in the maintenance and restoration of intersubjectivity. Rather, it involved special educators taking creative leaps with their interpretations with little regard for whether their interpretations accurately reflected what intellectually disabled people meant to say. Their repair work was a complex communicative intervention that was aimed at keeping the light-hearted chit-chat ongoing to create an informal and convivial atmosphere within these institutions.

Unlike instructing, prompting, praising, or scolding, chit-chatting was less concerned with getting things done or with how intellectually disabled people worked or acted at these centers. Instead, it was a more informal mode of communication directed towards intellectually disabled people that took account of the fact that these people had lives outside the centers (with their families at home). Further, though it did not look like conventional work, special educators had to do creative and innovative work while chit-chatting by coming up with topics of conversations that may be of interest to intellectually disabled people and then interpreting and making claims about their responses.

In short, special educators intervened in the domain of communication by using diverse communicative strategies. Through these strategies they made intellectually disabled adults do their chores or production work, let them know if they did something well or badly, passed time in a light-hearted manner, and inquired about their lives beyond these organizations. However, these communicative strategies gave a limited form of personhood to intellectually disabled adults. Within these interactions, intellectually disabled people received significantly more than

they gave. To expand, while intellectually disabled people received instructions, prompts, praise, and scolding from special educators, there was very little space for them to respond or provide any form of feedback to their educators. Even during the chit-chat sessions, special educators initiated the topics of discussions, decided which cues meant what, and the flow of the conversation, including when to end it. What if intellectually disabled people wanted to do other vocational activities? What if scolding did not have the effect of making them do the task at hand? What if Anjali meant something else and not laadus when she gestured? These possibilities were not entertained by the special educators as they made up their personhood in a certain and confident manner, without leaving any space for ambiguity, complexity, or feedback from intellectually disabled people. Special educators confidently constructed intellectually disabled people as uncomplicated beings and approached them as people who were easy to understand, interpret, and know. Further, they also understood them as people who, given their intellectual limitations and deficits, could not be autonomous and independent and required constant supervision and scaffolding in most aspects of their lives, including informal conversations. Finally, special educators approached them as people whose relationships were restricted to their families and their institutions and built connections with them by referencing these relationships. While my intention is not to dismiss the work that special educators did in making their communicative interventions, I want to point to the fact that intellectually disabled people were not given many possibilities regarding who they could be, what they could do, and the kinds of relationships they could have.

## **Different Forms of Talk Used by Special Educators**

### *Talking To, Talking At, and Talking on Behalf Of- All at the Same Time*

When special educators communicated with intellectually disabled adults, it was difficult to distinguish whether they were talking to them, talking at them, or talking on behalf of them.

When educators instructed intellectually disabled people, it appeared as though they were talking at them in a top-down manner. However, in most other conversational contexts, given that intellectually disabled adults often did not respond in a conventional manner when special educators addressed them, it often looked like the educators would talk to, talk at, and talk on behalf of them at the same time. For instance, on the same day as Kulkarni maushi claimed that Anjali made laadus at home, she also saw Rujuta, another attendee of hers, napping while sitting on the floor. Upon noticing this, she used a louder voice than her usual one and playfully said in Marathi, “See, Rujuta, everyone is saying that you are old!”, and then looking at everyone, she said, “Look, she is sleeping!” In response to this, Rujuta woke up and many of the other attendees looked at her and laughed out loud. In reality, none of the other attendees had said that Rujuta was old. However, Kulkarni maushi talked on their behalf, claiming that they did. Given that she used a louder-than-usual voice and addressed everyone from her chair, while everyone else was sitting on the floor, it added to the image that she was talking at them, in a top-down manner, without much interest in listening to what they had to say.

However, Kulkarni maushi’s comments also elicited responses among the girls. When she asked others to look at Rujuta sleep, most of them turned towards Rujuta and laughed out loud, which also gives the impression that she did indeed also talk to them. Thus, all three modes of talk often co-occurred in many scenes of communication. The example also illustrates that not

all talk at these organizations was oriented towards productive work. Educators also liked to crack jokes and be playful when they communicated with intellectually disabled adults.

Considering how non-linear and even creatively interpreted these interactions were, it was often difficult to apply normative conversational standards to these interactions, wherein there might be more organic or seamless turn-taking (such as when the special educators and I talked to each other). Further, despite the asymmetries between special educators and intellectually disabled adults, there were moments during which intellectually disabled adults also responded to cues from special educators. They were not just passive recipients of communication initiated by special educators, as exemplified in the above example of the attendees in Kulkarni maushi's section laughing when she joked and said, "Look, she is sleeping!".

#### *Talking about Them in Front of Them*

Whereas it was difficult to tease apart whether educators would talk to, talk at, or talk on behalf of intellectually disabled adults, special educators at both Sankalp and Udaan, as well as most of my other field-sites, would regularly talk about them, in their absence and in front of them<sup>12</sup>.

This was an everyday occurrence, especially triggered by my presence as a researcher, because

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<sup>12</sup> I want to mention Latika here, as a counterexample to my other field-sites when it came to communication practices. Latika is a voluntary organization that works with intellectually disabled people in Dehradun, India and its founder, Jo Chopra, thinks and writes about respectful communication practices and even the special educators that work at Latika follow practices such as never talking about intellectually disabled people in front of them. This was the case because educators at Latika adopted a different view of personhood and dignity, which maintained that talking on behalf of intellectually disabled people infantilized them. At Latika, special educators made explicit attempts to capacitate intellectually disabled people to communicate their demands, protests, and choices. To provide an example, special educators at Latika organized a "tuck shop" which was a temporary store wherein intellectually disabled people could practice their shopping skills by purchasing packed snacks of their choice. When intellectually disabled people approached the store, the special educator in charge told them the prices of various items and prompted the trainees with questions such as, "What do you want?" Some of them responded by pointing to specific items. With others, she used more specific prompts, such as, "Do you want the chocolate?" "Do you want the chips?" Only if they did not respond to even those questions, she would make the choice for them. While the special educators at Latika were trained to capacitate intellectually disabled people to make choices, much like the special educators I met at other institutions, they also made their decisions (such as which snack to choose for their pretend customers) based on their knowledge of the person as well as an educated guess as to what they might like.



special educators would turn to me to explain the nonnormative utterances and behaviors of intellectually disabled adults. For instance, Sandhya maushi, one of the most enthusiastic and talkative special educators at Sankalp, would often share her insights about the attendees with me in front of them through statements in Marathi (with certain terms in English), such as, “Prakash is our sportsman ” (sportsman in English) or “Himesh has a physical disability , but he can understand” (physical disability in English). While special educators routinely spoke about intellectually disabled people in front of them with me, they also spoke to each other about them, especially if they were discussing a behavioral issue. Initially, I struggled with this conversational practice and would awkwardly nod and not ask follow-up questions. However, after being immersed in these organizations (and spending time at many other organizations of the same nature), I realized this deeply hierarchical practice was common across most such organizations in India and became more accustomed to it. By talking about intellectually disabled adults in front of them, special educators established their expertise, especially vis-à-vis me. I was positioned as a researcher who wanted to learn more about their work, and they were positioned as people who “knew” intellectually disabled people. Having listed the different communicative interventions and modes of talk initiated by special educators which served to make the day in the institution go by, get tasks done, construct the personhood of intellectually disabled people as well as enact their own expertise, I next move to the categories that special educators used to make sense of and make up intellectually disabled adults.

## **Making Sense of Heterogeneity Through Categorization**

### *Framing Intellectually Disabled People as Loving and Innocent*

“Each child is different” said Sandhya maushi during a focus group discussion with the five women educators at Sankalp workshop. Different versions of this phrase were repeated to me on multiple occasions by special educators at various organizations. Special educators would insist that their work is harder than that of mainstream teachers because no two special mula were alike. Indeed, I too observed how diverse intellectually disabled people were with respect to how they communicated, their disability status, as well as whether and to what extent they participated in the vocational activities that took place at these centers. While some people required little to no support and managed to do the assigned vocational activities, many others had moderate to higher support needs. However, despite recognizing and constantly repeating out loud to me that special mula were a diverse group of people, special educators also routinely categorized them in various ways. They used these categories, as I will demonstrate in this section, as explanatory models to make sense of the heterogenous, ambiguous, and sometimes troubling behaviors or actions of intellectually disabled adults. Further, they used these categories to make up their own value as people who did difficult, challenging, and low paying work. However, in using these categories, special educators reduced the complexities and heterogeneity presented by intellectually disabled adults.

Further, there was tension between discourses of sameness and difference. By this I mean that, special educators contradicted their claims that framed intellectually disabled people as distinct individuals (when they said that each child is different) when they grouped them together under categories that erased their individuality. While educators sometimes used medicalized

disability categories, especially those of “autism” and “Down syndrome” to talk about stereotypical behaviors associated with these categories, such as repetitive actions and tidiness respectively, special educators usually did not rely on such diagnostic categories. Instead, they used categories that emerged within the social worlds of these organizations, usually from observing and analyzing the behaviors of intellectually disabled people. To begin with, all intellectually disabled adults were categorized as special mula who were seen as being loving, caring, and innocent.

### *The Loving and Innocent Special Mula*

Across my field-sites, special educators would call special mula loving, caring and innocent. Instead of focusing on conventional standards of personhood, such as rationality and autonomy, educators used measures such as love and care to recognize the personhood of intellectually disabled people (Kittay 2011). For instance, Anisha maushi at Sankalp once said to me, “Our children do not know the difference between rich and poor, like normal children But when you cry, they cry”. Much like Anisha maushi here, special educators would often insist that while special mula were not as intelligent as normal people, they were very loving. Special educators saw intellectually disabled people as being innocent and empathetic people, whose lack of conventional intelligence gave them the ability to feel more than “normal” people. During my focus group with special educators at Sankalp, all of them said that special mula were very good at figuring out their moods and would always ask after them if they were in a bad mood because of something that happened at home. Thus, what special mula lacked in conventional intelligence, special educators claimed they made up through their loving and empathetic nature. Valuing intellectually disabled adults as loving people helped special educators make sense of their jobs: they too had to be loving and affectionate in return. Educators across field-sites would

share with me how they would have to keep their worries at home when they came to this job, because here, they had to be cheerful. Thus, special educators understood their own personhood as emerging in relation to and as a reflection of intellectually disabled people and framed both the groups as having a loving, sensitive, and empathetic personhood.

Special educators even claimed that the loving nature of intellectually disabled adults made this job what it was. Sandhya maushi at Sankalp said to me that she feels lucky to do this job because she gets to work with such “virtuous children” (*gunni mula* in Marathi). She continued by saying that these children help mothers at home and always listen to what is being told to them. Thus, along with innocence, intellectually disabled adults were also seen as being virtuous because of how obedient and cooperative they were. Educators even shared that they were ready to face adverse situations during their work because ultimately, no matter what, the people they worked with were loving. Sonali ma’am from Udaan, for example, shared with me the story of a former student of hers who suddenly slapped her so hard that she feared she had lost her hearing. However, she said that once he realized what he had done, he never left her side because these “children have a lot of love.” (she used the Hindi word *pyaar* for love).

In this example, Sonali ma’am used the category of a “loving child” to retrospectively make sense of the violence of being slapped. Viewing intellectually disabled adults as loving was essential for special educators to make sense of the nonnormative and ambiguous behaviors of intellectually disabled adults as well as their own professional personhood. Calling intellectually disabled adults “loving” helped them navigate their work as people who worked with individuals who are not “normal”, who were not paid much for their demanding work, and who negotiated difficult work conditions such as being hit by a student. Further, working with virtuous and loving people made them virtuous, patient, and empathetic professionals and gave them value as

well. However, in framing intellectually disabled people as loving (instead of further asking questions about what may have prompted the act of slapping), special educators also essentialized them as being fundamentally different from normal people (normal was the word used by special educators for non-disabled people). In doing so, they put them in a box wherein it was not possible for them to occupy a more complex personhood, wherein they could be both loving and angry.

Aside from making claims about special children being loving people in general, educators at both Sankalp and Udaan also categorized people in ways that aligned with their organizations' values and needs. For instance, at Sankalp, given that the organization encouraged discipline and productivity, the two categories that circulated among special educators were: *changli mula* (good children in Marathi) and *basnaari mula* (children who sit in Marathi). Those who could do productive work (such as using the sewing machine) and follow instructions properly (by doing chores when asked by the educators) were classified as *changli mula*. On the other hand, those who were unable to do productive work efficiently and were also not able to follow instructions promptly were called the *basnaari mula*. The good children also tended to communicate using more conventionalized language compared to the children who sat. Thus, obedience (ability to do things as asked), productivity (ability to do things well) and normative communication skills were the values that divided people into the categories of good children and children who sit.

These categories shaped both the opportunities made available to intellectually disabled adults as well as the social worlds of Sankalp and Udaan. At Sankalp, disabled adults categorized as the “good children” were more valued by the organization's administrations. They were called upon by the educators to give speeches during festivities or present chief guests with gifts during

the public-facing events. They were presented as the face of Sankalp. On the other hand, special educators paid comparatively less attention to those classified as “children who sat”. They did not call upon them to participate in the events and often did not pay attention to their nonnormative behavioral cues. Within Sankalp’s social world, “children-who-sat” were on the peripheries, seen more as audiences to their more valued “good” peers. As discussed in the section on communication strategies, special educators often praised those who fell in the category of good children and sometimes scolded those categorized as children who sat for not being able to complete a task successfully. However, even though those categorized as good children got the opportunity to participate more actively in the everyday organizational life of Sankalp, the role also hindered other possibilities for them. For instance, I wondered if all those known as good children liked being the center of attention at public events or if some of them may have preferred to sit and nap occasionally?

At Udaan, considering that there were much fewer attendees, around fifteen to twenty at a time, people were not categorized into groups. Instead, specific individuals were often assigned social roles. For example, Swarup, a thirty-one-year-old man, was known at Udaan as the “helper”, specifically Sahil’s helper. Indeed, from my first day of fieldwork, I noticed that Swarup would quickly follow orders to do most of the heavy lifting (literally) at Udaan. Right from picking up heavy bags of diyas up the stairs to cleaning up after a big snack making session, Swarup was the one doing it. However, although Swarup was often called upon to contribute to Udaan’s everyday functioning by doing much of the manual labor, his role as the helper also inhibited him from participating in Udaan’s other, possibly more fun activities, such as playing Djembe and watching television. Thus, although Swarup was constructed as an exceptional, reliable, and capable person, in the process, he may have lost out on opportunities to

engage in the more light-hearted and fun activities at Udaan. Thus, special educators intervened in the lives of intellectually disabled people by categorizing them to make sense of their behaviors and subsequently make decisions about their life, such as giving them specific chores and social roles. However, while these categories gave intellectually disabled people simplified forms of personhood (as people who loved and cared, as people who could obediently follow instructions, as people who helped around, or as people who did not do much but sit), it did not offer them complex forms of personhood, through which they could be more than one thing at a time. Further, special educators also approached intellectually disabled people as people whose characteristics and interiority could be interpreted and known by them. The stakes of giving intellectually disabled people simple personhood were high. For one, when those made up as good children acted in ways that were considered bad or inappropriate, they were reprimanded, often more severely than others. In one instance at Udaan, Swarup was asked to feed Geeta, a fellow attendee, but he instead chose to hang out with a male peer. This angered Sahil sir and Sarika ma'am, who publicly scolded him for not looking after his "friend"; they had higher expectations for him than for others. On the other hand, those classified as children who sat were underestimated. Special educators did not proactively intervene in their lives. Thus, being slotted into categories limited the ways in which intellectually disabled adults could behave or act, without either getting scolded or invisibilized.

### **Categorizing Behaviors as Problems**

While special educators made the claim that all special mula were loving, innocent, and virtuous, it did not mean that they never assessed certain behaviors (and subsequently certain people) as being annoying, unpleasant, or problematic. At Sankalp, Gaurish, an older man in his late 40s

was seen as having sexual problems by his special educator, Anisha maushi. She told me and the other educators that Gaurish was having “sexual problems” (her words in English) because he would often sit on a bench at the back of the room and touch himself near his genitals. This was a problem for Anisha maushi because Gaurish was touching himself in front of others in a public space in a socially inappropriate manner. A couple of months into my fieldwork, when I was more comfortable at Sankalp and would wander from one section to another during lunchtime, I visited Anisha maushi’s section. She greeted me with excitement and said that she had solved Gaurish’s problem. I was intrigued by this and when I asked her how, she pointed to the paper-shredding machine that Sankalp had recently acquired (it was a bulky and ancient-looking machine). She said that she made Gaurish use the paper-shredding machine and he enjoyed it so much that now all he wanted to do is stand by the machine and use it to shred paper. According to her, he no longer wanted to touch himself. Indeed, I often saw Gaurish standing in line behind others who were using the machine. Thus, Anisha maushi noticed Gaurish’s behavior of touching himself, interpreted it as problematic and intervened by substituting the behavior with a supposedly unproblematic behavior (of standing and shredding paper). Her solution for Gaurish’s behaviors needs to be placed within the larger institutional context of Sankalp, which was one of traditional and modest views around gender and sexuality. Within the social world of Sankalp, Anisha maushi made sense of Gaurish’s behavior as a problem that needed to be erased or diverted, because it was socially inappropriate and did not sit well with the organization’s larger cultural values.

As mentioned in the introduction, Sarika ma’am had a similar interaction with Geeta back when both were at Rainbow Foundation, wherein she noticed Geeta’s behavior of holding a glass bottle near her genitals, interpreted it as being a sexual and social problem (as well as a problem



of physical harm for Geeta in case the glass bottle hurt her). However, instead of substituting the supposed sexual behavior with a vocational activity unlike Anisha maushi, Sarika ma'am intervened by substituting the problem behavior by making Geeta hold hands with a male classmate. Sarika ma'am's intervention of handholding must be seen as being informed by her own value system which she implemented later at Udaan. Sarika ma'am, unlike the administrators at Sankalp, did not value productivity and discipline. Neither did she espouse traditional values regarding gender and sexuality to the same extent as Sankalp. At Udaan, which Sarika ma'am founded, and Geeta attends till date, fun, creativity, and friendship were the institutional priorities. Considering this, the almost playful substitution of "handholding" made sense within the social world of Udaan. Despite the differences between Anisha maushi's and Sarika ma'am's interventions, in both cases, special educators used the category of the "problem" to interpret specific behaviors as inappropriate or disruptive. Further, they made up intellectually disabled people as people who could be diverted from problem behaviors with appropriate substitutions. Finally, they made themselves up as experts who could come up with creative solutions to these problems.

### **Articulations of Intellectually Disabled People Outside the Purview of Special Educators**

While special educators often did the work of initiating conversations and making claims about what intellectually disabled adults need, want, and say, I also observed many instances of special educators rejecting the nonnormative or ambiguous cues of intellectually disabled adults.

Further, intellectually disabled adults also made conversations with me (as the outsider) as well as each other- communication that were not oriented towards the educators. By flagging these articulations or expressions here, I demonstrate that although special educators made up their

epistemic authority through communication, intellectually disabled people continued to express themselves in ways that were not captured by special educators.

For instance, Shalini, a young woman from Kulkarni maushi's section at Sankalp would often repeat the same phrase in Marathi, "Will you go to *Bal Kalyan*? I will be singing there!" The first time she asked the question looking in my direction, I awkwardly replied, saying, "I do not know!" Over time I observed her using this phrase every day (in my observation, to no one specific person in particular). For context, Bal Kalyan is an NGO that provides free-of-charge dance and music lessons for children (and intellectually disabled adults) from various minoritized backgrounds. Sankalp often made fieldtrips to Bal Kalyan. However, Shalini's use of the phrase did not necessarily correspond with an impending trip. I noticed that Kulkarni maushi would ignore her and not engage with this phrase at all. Each time Shalini would ask this question, I would shrug and smile, and feel terrible about not having a satisfying response for her.

At the end of my fieldwork period, on a day that I visited Kulkarni maushi's section, maushi had decided to spend the afternoon asking attendees to perform musical and dance numbers instead of doing any production related work. Shalini excitedly raised her hand and came to the front of the room and sang a Marathi song in a beautiful voice. When I heard her sing, it struck me that Shalini might have been sharing her interest in singing through her repeated use of the phrase, "Will you go to Bal Kalyan? I will be singing there!". Or maybe, I wondered if Shalini had once performed at Bal Kalyan and really enjoyed that performance. I am unsure what her reason for saying the phrase was but given that her utterances were repetitive and did not make any sense, no one, including her peers or educators, responded to her. In another instance in Kulkarni maushi's section, Rujuta, a non-verbal woman would often make

the gesture for “food, time, when?” While I was not sure whether she was talking to me or to Kulkarni maushi (since we would both be sitting on chairs facing the room of women sitting on the floor), I interpreted the gestures to mean that she was inquiring about lunchtime. I would respond to her through gestures by telling her how much time was left for lunch. However, Kulkarni maushi rejected her ambiguous, questioning expressions.

Thus, while special educators often attended to the cues of intellectually disabled adults they were selective about who they paid attention to and when. As I mentioned earlier in the chapters, educators were usually overwhelmed with both production work and caregiving duties for multiple people at once. Within this context, I do not mean to critique special educators or argue that they should be paying attention to these cues. But I want to point to the fact that within these challenging working conditions, highly unconventional or ambiguous cues, usually articulated by the more significantly disabled individuals, were ignored and thus rejected by special educators.

Intellectually disabled adults also directed their communication towards people who were not special educators. For instance, I was a frequent conversational partner for intellectually disabled adults at both Udaan and Sankalp. While initially, they would treat me as a person with authority, by taking my permission when they entered or left the class or complaining to me about someone else’s behavior, over time, they started having more relaxed conversations with me using both words and gestures. For instance, there were women in Kulkarni maushi’s class who would show me their nail polish or ask me to look at a nice dress they wore for a school function. Parna, an older attendee in the care group would often walk up to me and start talking about her father, brother, and nephew. People would also engage with me by complimenting me for my clothes, earrings, or handwriting (either through words or their gestures and facial

expressions). Thus, even though special educators chose to communicate with intellectually disabled people almost exclusively about work or family related events, intellectually disabled people often had varied interests and opinions that were not taken up by the educators.

Finally, I discuss an instance of a young man, Aniruddh, in the bookbinding section at Sankalp asking for my number to demonstrate how, in some instances, intellectually disabled people communicated in ways that went against the wishes and directives of their special educators. Aniruddh refused to call me Shruti tai (elder sister) and called me solely by my name. Despite his special educator, Tikekar Sir, asking him repeatedly to come work near him, he decided to sit next to me and not work, and kept asking me for my number. This made me feel very awkward. I was very unsure about how to respond. I eventually refused to share my number telling him that no one else has my number either. To date, I feel that my response was patronizing and no different from the ways educators treated them as children. However, I also did not know how else to act within the organizational space of Sankalp given that I feared that if I acted any differently (for instance, by offering Aniruddh my phone number), I would be asked to discontinue my fieldwork—I felt that there was a restricted way in which I was allowed to act. Thus, intellectually disabled adults initiated communication of diverse kinds outside the explicit purview of special educators and it was often shut down.

Interestingly, intellectually disabled adults also interacted with each other, especially when special educators were not around. For instance, Rupesh was a thin, short, non-verbal man in Sandhya maushi's section at Sankalp who never made a peep when she was in the room. However, whenever she left the room, he would turn to me or the person sitting next to him and make gestures with his hands, that I interpreted as "house", "bird", "food". I was always uncertain about what he was expressing through his gestures, but I would look at him and nod or

mirror his gestures. Sometimes his peers would also respond to his cues by smiling or nodding. While at Sankalp, special educators left their section for very short periods of time, since they were expected by the administrators to supervise them all the time, at Udaan, intellectually disabled people spent more time unsupervised (although I was always present for these interactions). During such time, those who used conventional language would often sit together and talk about things such as what they ate yesterday, ask each other to pass things, or crack fart-jokes. While the above-mentioned expressions or articulations were not the basis of special educators' claims about intellectually disabled adults, these were also occurring, in the background, on the peripheries, often when special educators were not around or engaged elsewhere.

While I do not frame these articulations of intellectually disabled adults as resistance or subversion, I think it is important to keep these in mind as we move to the next chapters of the dissertation, because while special educators made themselves up as experts in the domain of communication, which often meant that they made the major decisions in the organizations, intellectually disabled adults continued acting and expressing in ways that were not always supervised, directed, or even acknowledged by special educators. Thus, although special educators played a big role in shaping intellectually disabled adults' personhood, they did not always make decisions regarding how intellectually disabled adults existed and acted within these institutions.

Even though I only examined Sankalp and Udaan in this chapter, I observed special educators intervene in the domain of communication by using similar communicative strategies, modes of talk, and categories across different institutional field-sites in the state of Maharashtra. Within vocational centers, workshops, and residential facilities, special educators intervened by

instructing, praising, scolding, and chit-chatting with intellectually disabled people. Across these interactions, it was difficult to parse apart whether special educators were talking to, talking at, or talking on behalf of them. Further, in these interactional contexts, special educators noticed, interpreted, and made confident claims about the facial expressions, silences, gestures, behaviors, and utterances of intellectually disabled people.

Finally, special educators also used social categories to intervene in the lives of intellectually disabled people and organize the social world in these institutions. They did the same not by using any systematic or scientific seeming techniques, but through their relationships with intellectually disabled adults, which were based on co-presence, familiarity, and according to special educators, experience. By enacting all the abovementioned practices, special educators made up the personhood of intellectually disabled people. This personhood was pragmatic, knowable and transparent. Given that the communicative interventions and social categories used by special educators usually did not have a reach beyond the institution and did not capacitate intellectually disabled people to participate in social, economic, or political life in mainstream society, this personhood was also specific to the institution and segregated. Further, special educators positioned intellectually disabled people mostly as receivers and not initiators of communication, categorized them as particular types of people without giving them space to be complex beings with multiple and contradictory desires and motivations, and rejected their ambiguous cues. Considering this, the personhood they made up for intellectually disabled people was simplistic and unambiguous. Further, it was through communication that special educators also made up their own expertise as people who could interpret, categorize, and know special mula, get them to do tasks and vocational activities in a timely manner, and establish an informal environment within these institutions.

Having examined the domain of communication as a mode of person-making and institutional making and maintaining used by special educators, in the next chapter, I focus on the domain of “occupation” and demonstrate the ways in which special educators at Sankalp prioritized keeping intellectually disabled adults occupied with productive work. Based on ethnographic findings, I illustrate that while productive work was valued by the organization as an occupation, intellectually disabled adults also occupied themselves in unproductive ways by passing time (doing timepass), sitting, and napping. Although special educators attempted to make intellectually disabled people into productive workers, many did not and could not become productive and instead engaged in rest, relaxation, and sporadic social connections, which were equally vital, but organizationally devalued forms of occupation.

## **Interlude II: Occupying intellectually disabled people by making them paint diyas**

### **Why Diyas?**

On October 18<sup>th</sup>, 2021, I reached Udaan, which was also Sarika ma'am and Sahil sir's home at around 1 pm. Many intellectually disabled adults were already in the crafts room painting *diyas* (oil-lamps) because it was Diwali season, the Hindu festival of lights, and Udaan had received orders to deliver colorfully painted diyas to friends, acquaintances, and small businesses.

Swarup, Vishal, Samarath, and Prathamesh were painting diyas while Geeta sat along with them, not painting. Sarika ma'am, in a mock scolding tone, told Geeta that if she does not paint today, she will not talk to her. All the other attendees also complained to each other and me that Geeta was not painting. Soon after my arrival, Vimla ma'am, a volunteer special educator who worked at Udaan for free for a couple of hours each week and led the sports sessions on Saturday, came into the crafts room to hand gloves to those of us who were painting. Sarika ma'am spent time instructing and assisting the attendees with the process of putting on the gloves. Prathamesh put the gloves on Samarth, who asked Prathamesh to slow down because he was afraid that the gloves would tear given how long his fingers were. After everyone had their gloves on, we went back to painting. At one point, Sarika ma'am looked up from her own painting task, noticed Vishal and Tarun painting and praised them by saying, *Wah* and immediately said in Hindi, "Listen Vishal, keep the pink color bottle's cap on the newspaper here. Otherwise, the color will spoil everything. And once you are done, put the caps back on the bottles. Otherwise, the color will dry up." Vishal obediently followed Sarika ma'am's instructions and carefully placed the cap bottle on a newspaper. Sarika ma'am left the room after an hour or so, and most of the



attendees, except for Geeta, continued to paint diyas, while chit-chatting with each other about what they ate the day before. I listened to their conversations and continued painting as well.

While the above vignette only describes the events that occurred over one morning at Udaan, it is emblematic of the kinds of work intellectually disabled adults did in institutions such as special schools, vocational centers, workshops, and residential facilities in India. Across my field-sites, keeping intellectually disabled adults busy was an institutional priority. When I visited different institutions to figure out which ones I should focus on for my dissertation fieldwork, what struck me most was that across almost all institutions, intellectually disabled adults were tasked with painting diyas. What was it about this specific activity of painting diyas that appealed to so many institutions? I was curious about finding the answer to this question and I asked special educators and administrators if they knew anything about the history of institutions that catered to intellectually disabled adults and why certain activities such as painting diyas became popular.

Even though none of the educators could answer my question, special educators had their own theories about the popularity of painting diyas. Sarika ma'am from Udaan and Asha from the Ananda Foundation said that painting diyas taught intellectually disabled people many skills, such as fine-motor skills, concentration, and finesse. Sonali ma'am at Udaan also said that painting diyas was an inexpensive and hence low-stakes activity, which made it perfect for these institutions. In her words, "The small basic diyas are still available for Rs. 1 (USD 0.012) per unit at the old market in Pune. If they break, it is not a big deal. It is much harder with chocolates or soaps because the raw material is more expensive". Further, all the special educators also said that it was difficult to mess up with diyas, which further added to its appeal. Even if intellectually disabled people did an imperfect job, special educators said that they could always

apply the finishing touches. Finally, most special educators also believed that intellectually disabled people really liked painting diyas because of the colors used in the activity, which made it an enjoyable experience. Thus, special educators framed painting diyas as an activity that was inexpensive, low-stakes, easy-to-do, enjoyable, and effective at skilling.

I must admit that I personally enjoyed painting diyas during my fieldwork at Udaan. I would spend hours almost every day in the month of October 2021, sitting on the floor and painting . On one occasion, I even took diyas back home with me because Udaan received an unexpectedly large order, and they needed all hands-on deck to finish the order on time. I found the process of painting meditative and relaxing. I enjoyed watching the brown diyas take on a new form when I painted them in various colors. However, while pleasurable, the activity was also very taxing. My body would ache at the end of each day after sitting on the floor, hunched over, and painting for hours. While I do not know if intellectually disabled adults enjoyed painting diyas as much as I did or as much as special educators claimed that they did, I noticed that the activity of painting diyas created a festive atmosphere of socialization and laughter. At Udaan, it was a group activity that special educators and intellectually disabled adults worked on together, while talking and cracking jokes. While I could not visit the Ananda Foundation during the Diwali season in 2021, Asha, the founder of the institution, informed me that the institution's diya painting sessions that year were a huge success because she rented out a room in the main village of Karkamb and invited non-disabled children and teenagers to join intellectually disabled adults in the diya making activity. People turned up in big numbers and with great joy. Thus, according to special educators, painting diyas made possible many things at once: learning new skills, working, and hanging out with friends and strangers.

Painting diyas also marked institutional time. It was not a regular activity that occurred all through the year. It took place for a couple of months during the Hindu festive season, which was between September to November in Maharashtra. During these months, other activities took a backseat and painting diyas became the main occupation for everyone. People also worked a lot more during this time. For instance, at Udaan, attendees worked for multiple hours, volunteers and caregivers chipped in, and special educators worked late into the night to finish their quota of diyas for the day. Further, painting diyas also shaped the institutional space. All the rooms at Udaan smelled of paint during the festive season. People's hands and clothes would be covered in colorful paint. Rooms were reorganized in such ways that there was space for people to dip and coat diyas into tubs of acrylic paint before proceeding to sit on the floor on carpets to paint them in various colors and gift wrap them to send them off to the customers. Thus, diyas marked highs and lows in time at these institutions and shaped the space in such a manner that people's bodies as well as the objects were oriented towards this one activity.

## Chapter 2: Occupying Time and Space: Kaam and Timepass as modes of being and doing at Sankalp workshop

### Introduction

March 7, 2022, was my first day of fieldwork at Sankalp workshop, an institution that catered to intellectually disabled people over the age of 18 years in Pune. The superintendent of Sankalp workshop, Mr. Borse, decided that I should spend my first day in the men's sewing section. Special educator Sandhya *maushi* (Marathi word for maternal aunt) oversaw this section. Upon my arrival at around ten in the morning, Sandhya *maushi*, who was sitting at her desk on a plastic chair, introduced me to the section as Shruti *tai* (Marathi word for elder sister). Next, she asked two men to sweep the floor and lay out the carpet. After this, she called Akash, a young man, to come to the front of the class to lead the morning prayers and physical exercises. After doing jumping jacks, toe-touches, neck rolls, Sandhya *maushi* asked everyone to wind down with breathing exercises. Having completed this routine, everyone settled into their positions. While most men sat on the floor, Sandhya *maushi* and a couple of other men sat on benches in front of sewing machines.

Sandhya *maushi* introduced me to all the intellectually disabled men in her sewing section by asking each person to come up to her desk in the front of the room. She then proceeded to ask them their names, what they like doing, and where they live. While some people answered the questions, Sandhya *maushi* also did the work of prompting and filling-in-the-blanks when I could not understand someone's speech or when someone did not answer the questions. For instance, when Ramesh, a young man who did not speak much came up to the desk and did not answer Sandhya *maushi*'s questions, she spoke on his behalf and said, "You love drawing, and you love helping at home". Sandhya *maushi* used phrases, such as, "he is our

sportsman” (sportsman in English), “he has autism” (autism in English) , or “he cannot see”, while introducing the intellectually disabled adults in her section. Tejas, a short and chirpy man, was introduced by Sandhya maushi as someone who dances very well. After the introduction, he said that he would love to dance to the song “Bodyguard” from a popular Bollywood movie with his friend Akash. Sandhya maushi obliged and played the song on the stereo, and Tejas and Akash put on an enjoyable dance performance.

Having finished the introductions and the performance, the more formal work activities of the class pertaining to sewing and folding industrial dusters began. Sandhya maushi played old Bollywood songs on the stereo all day long in the background. While she sewed, she also talked to me and the men in the class. She asked some of them to draw or use their notebook to write. Once she was done sewing a large cloth, she called upon a couple of men who were sitting on the floor to help her cut, fold, and organize the dusters into piles of ten items. While some, like Bilal, were focused on sewing dusters on the machine most of the time, most intellectually disabled people spent their time doing various things: sometimes folding, sometimes cutting, sometimes drawing, and sometimes sitting on the floor. While some people who used conventional language, like Akash and Tejas, chatted with each other and me, others sat in silence. Still others, like Rupesh, a non-verbal young man, sat quietly when Sandhya maushi was around, but started gesturing enthusiastically to me whenever she left the room to attend to some matter, by making signs for what appeared to me to be “home”, “food”, and “bird”. During lunch time, Sandhya maushi asked everyone to wash their hands and sit in two rows on the floor with their lunch boxes. Once everyone was in position, she walked around the room, checking, and commenting on what everyone had in their lunch boxes by saying things in Marathi like, “oh wow, you have brought potato *sabji* again?” (sabji is a vegetable-based dish) or “you have *chakli*

with your tiffin today as well!” (chakli is a fried savory dessert). After walking around the class and making her comments, she proceeded to have her own lunch. While sharing her food with me, she told me that although she would love to spend her lunch break with her friends, the other special educators, she was expected to oversee everyone’s lunch in her own section, in case anyone chokes or has a food allergy.

After lunch, Sandhya maushi asked everyone to walk for ten minutes to digest their food. While most paced up and down the length of the room, Darshan, a non-verbal autistic man, who I later discovered was Sandhya maushi’s favorite, snuck up to her workstation to take her phone, unlock it, and proceeded to play a specific ringtone repeatedly, while giggling and running up and down the room, much to her amusement. Once the 10 minutes were up, she instructed two people to rearrange the carpets, so that everyone could go back to their original seating positions. In the afternoon, even those who were painting and writing in the morning, worked on cutting, folding, and organizing dusters. Sanjay, a young man with sight issues, presented her with a stack of folded dusters. Dissatisfied with his folding, Sandhya maushi opened and re-folded one of the dusters. Upon seeing this, in an effort to be helpful, I volunteered to fold the whole stack. Sandhya maushi refused my help and said, “No, he has to be taught”. She took the stack of dusters and sat on the carpet in front of him and meticulously folded a few dusters. He followed her actions and proceeded to re-fold the stack of dusters in a way she found to be satisfactory. Between 2 to 3 pm, time passed slowly for me- most of the dusters were folded and except for those who were sewing, most people were sitting on the carpet on the floor. I kept checking my phone for the time, waiting for the day to be over. At around 3.45 pm, Sandhya maushi asked everyone to clean and fold the carpet and asked Ramesh to take the finished stacks of dusters downstairs, to the accountant’s office, where these were collected to be dispatched at a later time

to Tata Motors. At 4 pm, Sandhya maushi asked everyone to stand in a line and slowly exit the room to walk downstairs, where they were picked up by buses (which look like yellow school buses), shared rickshaws, or family members. Sandhya maushi waited downstairs to meet guardians and drivers and to make sure that everyone left the premises of Sankalp safely. Then she went back to her section, where she wrote a daily report about the activities of the day, which was to be submitted to Mr. Borse by the end of the month, before leaving for home at 5 pm.

### **Guntavun Thevne- Keeping Intellectually Disabled People Occupied in a Tangle**

Everyday life at Sankalp workshop looked a lot like the above description of my first day. Both special educators and intellectually disabled adults participated in multiple activities. Along with tasks such as sewing, cutting, folding, and staking dusters, which pertained to the production activities carried out at Sankalp workshop ( I will describe these activities in detail shortly), there were other kinds of practices taking place as well. For instance, special educators spent a lot of time instructing intellectually disabled people to do things, such as folding the carpets or sweeping the floor. Intellectually disabled people spent their time doing things other than sewing, cutting, and folding dusters as well, such as drawing, tracing, or writing in their notebooks. As Sandhya maushi said to me on my first day of fieldwork, “the purpose of this place is to give them activities to keep them occupied”. The term she used for occupied was the Marathi phrase, *Guntavun Thevna*, which originates from the Marathi word *gunta*.

Gunta literally means a tangle and guntavun thevna means keeping tangled. For instance, in Marathi, people often talk about there being a gunta in their hair or their life being a gunta to denote a tangled situation. Indeed, I noticed the ways in which special educators at Sankalp workshop tangled intellectually disabled adults (especially their hands) in activities, such as, folding, cutting, writing, tracing, sweeping, to keep them occupied. They also used the term

*haata-chi kaam* (work done with hands) to refer to the kinds of work intellectually disabled adults excelled at. Not only that, but special educators also kept their own hands tangled in activities ranging from sewing and folding to making *rangolis* (auspicious drawings in Marathi) before festivities and writing multiple daily reports. Thus, being occupied or tangled with work was an essential stated objective and feature of Sankalp workshop.

However, while staying occupied with work or *kaam*, the Marathi word for work, was the stated objective at Sankalp, it did not fully encapsulate all the activities that occurred there. People's hands (and bodies) did not and could not stay occupied or tangled in work all the time. There were many moments in which they were untangled. Intellectually disabled adults would spend many hours sitting and even napping- resolutely not keeping their hands tangled or busy. Further, people would do other activities, such as dance or spontaneously break into giggles and run around, such as Darshan did on my first day in Sandhya maushi's section. None of these activities fit the mold of work. If work was the valued mode of keeping intellectually disabled people occupied within Sankalp, how did the institution approach those practices (and the people who enacted them) that did not fit the mold of work? What happened to those people who came to Sankalp workshop to spend most of their day sitting and napping and how were they valued by the institution? Moreover, what about those who refused to or simply did not keep themselves busy- how were they approached by the workshop?

I address these questions by examining everyday life at Sankalp workshop through the lens of occupation. I demonstrate that even though work or *kaam* was institutionally valued at Sankalp, just focusing on work and how it organized life there proves insufficient to understand the role Sankalp played in the lives of intellectually disabled adults. Instead, occupation, imagined broadly as including both institutionally valued productive work and the less valued



but equally present so-called non-productive practices (such as sitting and napping), is a more capacious analytic to understand the everyday routine, social relationships, social roles, and forms of personhood that emerged at Sankalp. While administrators and special educators intervened in the lives of intellectually disabled adults by keeping them occupied in productive and busy work, intellectually disabled adults found other avenues, such as sitting, napping, running around, and spontaneously talking, to occupy time and space at Sankalp. Before addressing these multiple forms of occupation in detail, I first contextualize Sankalp within the larger Indian economic labor context and then discuss how I use the analytic of occupation.

### **Occupation in Various Forms: Kaam and Timepass**

According to the World Bank, with a population over 1.3 billion, India has one of the largest work forces in the world, at nearly 530 million people. The Indian Ministry of Labour and Employment (2022) states that as of 2020-21, agriculture remains the main sector of employment, absorbing around 46.2% of total workers, followed by the service and industrial sectors, which cater to 32.3% and 25.2% of the labor force respectively. Over 80% of the Indian work force is engaged in the informal sector, which is characterized by subsistence wages and employment and social insecurity (Hammer, Keles, and Olsen 2022).

Further, despite modernization and urbanization, the traditional caste system still structures and organizes occupations in India. For instance, many landless agricultural laborers in India are from the marginalized caste backgrounds (Thorat 2007) and there is a strong correlation between marginalized caste status and poverty in India (Mehta and Shah 2003). According to the 2011 census, 36% of the disabled population in India is categorized as workers. Under the Indian census, work is defined as participation in any economically productive activity. Workers are classified as: main workers, marginal workers, and non-workers. While main workers are

classified as people who work for a major part of the year (which is 183 days or 6 months) preceding the census enumeration, marginal workers are categorized as those who work for less than 183 days or 6 months<sup>13</sup>. Of the 36% of disabled people who were categorized as workers, the largest share of them were agricultural laborers, making two-thirds or, the majority of disabled people, officially unemployed<sup>14</sup>. Although the disability related laws in India, namely, the Persons with Disabilities Act (1995) and the more recent Rights of Persons with Disabilities Act (2016) mandate 3% and 4% reservations respectively in government jobs, these reservations are not implemented in a transparent or efficient manner, making it difficult for disabled people to apply for and retain their jobs<sup>15</sup>. According to a World Bank report published in 2009, disabled people only occupy 0.44% of public sector jobs<sup>16</sup>. While there are no clear estimates, in all likelihood, the numbers are even lower for intellectual disabilities given that most of them do not even receive a mainstream education and are therefore ineligible for most of these posts, even though a few so-called “high functioning” adults with autism, ADHD, and dyslexia are getting absorbed into the corporate sector through tie-ups with non-profits and special schools<sup>17</sup>. In sum, the Indian economy is highly informalized, steeped in social inequalities, and characterized by economic vulnerabilities, especially for people from marginalized caste and class backgrounds. Within this economic context, a majority of intellectually disabled adults

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<sup>13</sup> Definitions of work, main worker, and marginal worker from the Indian District Database Home Page: <http://vanneman.umd.edu/districts/codebook/deflf.html>

<sup>14</sup> Statistics from the website of the Office of Chief Commissioner for Persons with Disabilities: <http://www.ccdisabilities.nic.in/resources/disability-india>

<sup>15</sup> Amrita Chanda, “Is horizontal reservation ensuring jobs efficiently for the disabled?”, *Varta: Gender, Sexuality, Intimacy, Publishing*, January 14, 2022, <https://tinyurl.com/458x3ftp>

<sup>16</sup> World Bank, “People with Disabilities in India: From Commitments to Outcomes”, accessed May 26, 2024. <https://tinyurl.com/42v4d8xs>

<sup>17</sup> Sreeradha Basu and Brinda Sarkar, “India Inc embracing neurodiversity”, *The Economic Times*, April 14, 2024, <https://tinyurl.com/yw4wfekb>

have no job prospects and therefore have nowhere to go expect for institutions such as vocational centers, workshops, and residential facilities, especially in urban India.

In these institutions, intellectually disabled people participated in a lot of activities that can be categorized as “work”. Special educators instructed and supervised them to paint diyas, package food products, bind books, and sew dusters. These products were later sold by these institutions. However, intellectually disabled people were usually not compensated as workers for their labor, except for a small stipend in some institutions<sup>18</sup>. Further, aside from working on commercial/production tasks, intellectually disabled people also did other seemingly productive activities such as sweeping the rooms in the institution and fetching water for educators, and seemingly unproductive activities such as sitting and napping. Thus, intellectually disabled adults who existed in institutional spaces did not quite fit into or could not achieve the standards of the normative category of an Indian worker. Instead of work, I use the lens of occupation to move beyond the realm of economically productive work to understand the diverse ways in which intellectually disabled people spent their time, working and not working, in these institutions.

According to the Oxford English Dictionary (OED), occupation can variously refer to, among other things, the action of residing in a place, mercantile employment, or trade, and the act of filling or taking up space or time<sup>19</sup>. Scholarship that critically examines the field of occupation therapy and occupation sciences challenges the idea of occupation as productive

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<sup>18</sup> Café Khushi in Mumbai was the only exception where intellectually disabled adults cooked, served, and managed the register, and were paid wages for their services. The founder of café Khushi, Usha Kale (who I interviewed), had earned a PhD in special education from the United States and had an adult daughter with intellectual disabilities. She approached the café from a disability rights model and framed the intellectually disabled adults who worked there as “self-advocates” who were empowered to decide the kind of work they wanted to do and were trained to carry out their responsibilities in an independent manner. While there were non-disabled staff present at the café to provide support, Usha stated that the intellectually disabled adults were the ones who ran the café.

<sup>19</sup>*Oxford English Dictionary*, s.v. “Occupation (n.)”, accessed July 13, 2024, [https://www.oed.com/dictionary/occupation\\_n?tab=meaning\\_and\\_use#33716940](https://www.oed.com/dictionary/occupation_n?tab=meaning_and_use#33716940)

work and frames it as a complex form of engagement that can occur in any sphere of human life and can structure daily routine, affect identity formation, and provide a sense of meaning, achievement, and belonging. For instance, Clark et. al (1991) define occupation expansively to include, “the ordinary and familiar things that people do every day”. Further, occupation can be an avenue to feel pleasure, develop relationships, and achieve well-being (Pollard and Sakellariou 2012; Wilcock 2006). Critical occupational studies scholars (Pollard and Sakellariou 2012; Wilcock 2006) also understand occupation as a social and political phenomenon that does not operate only on the level of the individual and may become a means to exercise power by validating experiences of certain social groups and invalidating others, such as in the case of military or colonial occupations. In resonance with these authors and with the OED definition that views occupation as an act of filling or taking up space and time , I understand occupation as encapsulating all activities, practices, and doings that one can do to take up time and space. Further, I also approach occupation as a social phenomenon that can structure everyday life, provide meaning and belonging, be the basis of forming personhood(s) and relationships, and be a way to feel pleasure and well-being. Finally, I frame occupation as a political phenomenon, with some people’s occupations and some forms of occupation being normatively and institutionally valued and some others invisibilized or devalued.

In her ethnographic research with deaf young adults in Bangalore who circulate through vocational centers, Michele Friedner (2015) demonstrates how these centers become spaces of waiting, wherein deaf young adults occupied their time in the absence of steady employment. She illustrates how while waiting in these vocational centers was not necessarily economically productive for deaf young adults, spending time together in these spaces encouraged them to socialize, learn Indian Sign Language from each other, and discuss their futures. Here, Friedner

approaches occupation as an expansive concept to address the diverse, and often economically unproductive ways in which deaf young adults spent their time in institutions. While I do not intend to draw a direct comparison between intellectually disabled adults and deaf young adults in India, Friedner's insights into the different registers of "occupation" and the various ways in which disabled people come to occupy time and space within imperfect institutions in India helps frame my ethnographic findings from Sankalp. By sitting, napping, and gesturing and behaving in ways that did not fit the mold of work, intellectually disabled people did occupy time and space within Sankalp workshop in economically unproductive, unintended, spontaneous, and organic ways.

### **Sankalp: Both a Workspace and a Space for Timepass**

To frame Sankalp workshop as a workplace and to understand its institutional emphasis on work, I draw on Jack Levinson's ethnography *Making Life Work* (2010), which presented a portrait of everyday life at a New York group home for intellectually disabled adults named Driggs House and situated it as a workplace. According to Levinson, Driggs House was a workplace, not only to its employees, the counselors, but also to those who lived there. He argues, "Routine group home work, which includes the work of everyday life, involves the continuous and skillful activity of all those who work and live there" (Levinson 2010, 59). By ethnographically documenting everyday life at Driggs House, Levinson illustrates how it was not only the counselors, but also the residents who worked towards the upkeep of the group home, and importantly, they also worked on themselves to keep the group-home functioning smoothly. Further, the author demonstrated how for the counselors who managed the group home, "all of life is potentially clinical domain" (Levinson 2010, 102). Levinson documented the ways in which counselors at Driggs House not only did their clinical or formal duties, such as administering medication, scheduling appointments, and organizing recreational trips for the

residents, but also surveilled the “ordinary course of life at Driggs House and the opportunities for work it presents” (2010, 102). Sankalp workshop was not clinical in the same way as Driggs House. The intellectually disabled people who attended Sankalp often did not have a precise diagnosis (although some of them had a medical diagnosis). Further, people’s diagnosis did not shape everyday life in any significant manner. Special educators did not have to administer medication to intellectually disabled people as part of their everyday routine either. However, in resonance with Driggs House, Sankalp workshop too was a workplace, not just for the special educators who earned a livelihood by fulfilling their formal duties, but also for intellectually disabled adults, who worked in diverse ways to maintain the status of Sankalp workshop as a workspace. Indeed, Sankalp needed intellectually disabled adults to even be considered a workspace to begin with.

However, while work was an institutional focus at Sankalp, passing time explicitly not working, or by doing “timepass” (Jeffrey 2010), a uniquely South Asian concept, while not institutionally valued or enforced, also emerged as a mode of occupation at Sankalp workshop. Craig Jeffrey used the concept of timepass to analyze the lives of young, unmarried, and unemployed men in the Indian city of Meerut who did not have much structure to their time and thus spent their days standing around at urban nodes such as tea-stalls, talking, joking, and commenting on passing people for long periods of time- all of which they understood as “timepass”. For Jefferey, timepass was not to be equated with timewaste. Instead, he posited timepass as a complex social phenomenon through which young men negotiated their “social suffering” (Jefferey 2010, 477) of being unmarried and unemployed. While I do not claim that intellectually disabled people at Sankalp negotiated or experienced social suffering, I adapt the concept of timepass to the institutional context of Sankalp to demonstrate the ways in which

passing time in a leisurely manner, doing nothing for long periods of time, or socializing in unexpected and spontaneous ways emerged as ways of existing and occupying time and space for both intellectually disabled adults and special educators at Sankalp. While doing timepass was not economically unproductive, it was productive of passing time.

Although not institutionally valued by the higher administration, I demonstrate that moments of timepass were vital for both special educators and intellectually disabled adults to experience rest, respite, and social connection. In the rest of the chapter, by drawing on my ethnographic findings at Sankalp, I explore the different registers of occupation as both the institutionally normative *kaam* (work) and the nonnormative and sometimes spontaneous timepass. However, note that I do not want to set up a binary between *kaam* and timepass because people would often do both at the same time. I examine how both forms of occupation shaped the personhoods of special educators and intellectually disabled people. In brief, I demonstrate how although special educators attempted to make up the personhood of intellectually disabled people as workers who could stay occupied or tangled up with busy work, many intellectually disabled people emerged as persons who occupied themselves through timepass, instead of work, by sitting, napping, and forging social connections, instead of doing the busy work assigned to them.

Further, I explore how keeping intellectually disabled adults occupied at Sankalp also served their families, who, relieved of their caregiving duties, could pursue their own jobs or occupations. Before proceeding I want to list and clarify the ways in which I use different terms and concepts in the chapter. The marathi terms, such as, *guntvun thevne* (keeping them busy), *matimanda mula* (mentally retarded children), *haata-chi-kaam* (work done by hands), *changli mula* (good children), *kaam-karnari mula* (children who work), *basnari mula* (children who sit),

and *madat-karnari mula*(children who help) were used by special educators and administrators at Sankalp. I have retained those terms whenever I am quoting them or directly referring to practices at the workshop. While *kaam* is an emic term which emerged in multiple conversations at the fieldsite, *timepass* is an etic term I use to analyze practices of sitting, napping, and so on, which did not fit the mold of productive work. Next, I address why I chose Sankalp and not any of my other field-sites to examine the domain of occupation.

### **Why Sankalp? Challenging My Own Biases About Sitting as Occupation**

Why I chose to focus on Sankalp workshop for this chapter has much to do with my own biases, values, and perceptions of the institution, which changed over time, during fieldwork and later during the writing and editing process. When I started doing my fieldwork at Sankalp, the institution felt archaic to me. The workshop building, a 2-storey structure, was built in the 1970s and it looked the part. While most of my other field-sites were based out of homes, apartments, or bungalows, Sankalp workshop looked more like an old government office with dull purple walls and dark interiors. A relic frozen in time. Objects like power looms and sewing machines gave it a feeling of an assembly line factory- a place where people came to do manual labor. To me, Sankalp felt out of touch with more contemporary forms of vocational activities geared towards intellectually disabled adults in India; activities such as painting diyas making paper bags, lanterns, and jewelry. These activities are also more typically associated with neoliberal, corporate social responsibility driven work in the non-profit sector (something I was more familiar with), while assembly lines connoted an older, industrial world- something I had never encountered before. While I understood that activities like painting diyas were not necessarily “better” in terms of skilling or capacitating intellectually disabled people, they at least seemed more pleasurable and less mechanical to me. Not only did Sankalp workshop look like a factory,



but it also sounded like one. The sounds of loud power-looms, sewing machines, and papers being shredded on a large ancient-looking machine (that often shut down when it overheated) filled the workshop building from 10 am to 4 pm on weekdays.



Image 1: A sewing machine on a brown tabletop with purple walls and white sockets in the background.



Image 2: A brown table with stacks of paper, scissors, and some thread arranged on top.



Image 3: Stacks of folded industrial dusters atop a brown table with purple walls and an old, stitched cloth on display on the wall in the background.



Image 4: Power loom room at Sankalp workshop with white ceilings and a bright tube light for illumination.

Sankalp workshop had an official accountant, who sat on the ground floor next to the book-binding section and managed the financial records in official looking record books and an old-school desktop. Male and female special educators rarely socialized with each other and even the women educators were discouraged from socializing much during official work hours. My role at Sankalp trust was restricted and formalized. I was never called upon to assist the educators with their tasks, something I did at my other field-sites. In fact, whenever I volunteered to help intellectually disabled people with a task, I was categorically asked to step back and told by educators that it was important for them to do things on their own (although as I pointed out in the previous chapter, intellectually disabled people rarely did things without instructions and prompts from special educators).

Given that I was asked not to get too involved, I too, along with many of the intellectually disabled adults would spend hours sitting, either on the floor, a chair, or a bench. Sometimes I would scribble quick notes and would ask follow-up questions to the educators (which I felt less comfortable doing here than at my other field-sites, given how rule-bound Sankalp workshop felt to me). Very infrequently I struck up conversations with intellectually disabled people. Sitting for such long hours inspired only two feelings within me: boredom and a body-ache. I was furious at how outdated the institutional space and activities felt: Why was making industrial dusters still the main production activity at Sankalp? Could they not update their production to be more stimulating and aesthetically appealing? No wonder people just sat and sometimes even fell asleep! I thought they might be as bored as I was which meant that I was also engaged in acts of making up persons by reading minds. With such negatively charged feelings in mind, I decided to write a chapter about Sankalp which would criticize the value the institution placed on outdated production activities and the consequences of these outdated

practices on intellectually disabled people and their special educators. I wrote a previous draft of this chapter that argued that because at Sankalp, work, specifically keeping intellectually disabled people occupied with busy work (guntavun thevne), was the central priority, those who did not or could not be trained into becoming productive people were valued less. I was convinced that for those who just sat for hours, and there were many such people, Sankalp was a “zone of social abandonment” (Biehl 2013, 35), wherein they received no engagement, praise, or attention from administrators or educators.

However, when I presented a draft of this chapter at the Disability Studies Workshop at the University of Chicago, my colleagues were quick to ask many follow-up questions about Sankalp which made me confront my own biases about the institution such as: why is it important for intellectually disabled adults to be mentally stimulated- or is that what you want? What is wrong with sitting? Does sitting not count as occupation? Is napping necessarily a sign of boredom or could it mean something else? If at the end of the day, intellectually disabled people had families to go back to, how can you say that they were abandoned at Sankalp? And what about the fact that Sankalp capacitated families by allowing them to have time to work?

While I was taken aback by these questions, these provided me with clarity regarding the fact that I was confusing my own values (about what should be happening within a workshop, which was along the lines of skilling and capacitation for all, irrespective of their abilities) with what was occurring there, which was not as simple or straightforward as abandonment. Joao Biehl in his book *Vita* (2013) brings up the concept of abandonment to illustrate how state institutionalization in Brazil warehouses socially vulnerable citizens such as mentally ill people, instead of caring for them. Biehl analyzes how the state, pharmaceutical market, medical institution, and family and kin, come together to sequester certain individuals into spaces like

Vita, a state institution for the mentally ill, which he refers to as a zone of abandonment. In Vita, individuals, without any social or relational recognition effectively face social death, despite their biological existence still being maintained in some form.

However, this was emphatically not the case at Sankalp workshop. The feedback I received at the workshop made me re-evaluate my understanding of Sankalp workshop and its value in the lives of intellectually disabled people and their families. I combed through my fieldnotes to read through the intake process at Sankalp- about how the institution provided an in-house psychologist and a visiting psychiatrist for purposes of evaluation and medication. I thought about all the festivities and celebrations that took place at least once a week, at the end of which everyone would receive biscuits and juice packets. I reflected on the lunch-hours, during which, even though the special educators could not share lunch and gossip with each other, they checked what their charges were eating, and video called their families. During some of these calls, they would turn the cameras around and ask their children to wave at the intellectually disabled adults in their sections. They would also regularly write diary entries for each intellectually disabled adult informing their families about their day at the workshop and whether they needed to pay attention to a specific behavior or send something special next day to the workshop. Importantly, I realized that Sankalp also served as a site where parents of intellectually disabled adults gathered information about Indian government's legal guardianship and disability pension policies. Thinking through these moments made me realize that Sankalp workshop, while hierarchically organized, was emphatically not a zone of abandonment. The institution, through its connection with families, psychologists, psychiatrists, corporates, and state actors, made attempts (however imperfect) at caring and providing occupation for intellectually disabled people, by giving them a place to be and things to do.

I argue that complicating the role of institutional spaces such as Sankalp workshop in the lives of intellectually disabled people is significant because most literature within disability studies that focuses on institutional spaces that cater to disabled people, either in the West or in India, critique such institutions for being spaces of social control, surveillance, and regulation for intellectually disabled people. This scholarship examines how, in these institutions, instead of receiving living wages or successfully transitioning to employment in the open-market, intellectually disabled people often perform repetitive and mundane labor for minimal to no wages and that whatever income there is goes towards sustaining and furthering the institution rather than their own personal development (Gill 2005; Snyder and Mitchell 2006; Gill 2015).

This literature is significant because it points to the ways in which institutions that claim to capacitate, or skill intellectually disabled people often exploit their labor and do not pour any resources into their development. This also stands true for most institutions in India where I did my fieldwork. As I analyze Sankalp and the other institutions, I draw upon this literature to point to the ways in which intellectually disabled people's labor was invisibilized and often unpaid in these institutions. However, it is also important to note that these institutions in India ran on very limited resources. Despite their limitations, I focus on the ways in which these institutions made possible other, however narrow or restricted, opportunities for intellectually disabled people. I demonstrate how while institutions such as Sankalp workshop did not shape intellectually disabled adults into skilled, earning, productive members of mainstream society, these emerged as spaces where intellectually disabled adults could occupy time and space. They did the same by both having their hands and bodies tangled with *kaam* (busywork) as well as by doing *timepass*, which afforded them rest and social connections. Further, it also afforded their families rest as well as an ability to go out and earn money, instead of staying home to care for their charges. I

next move to providing details about Sankalp's history, structure, culture, demographic composition, and organizational objectives to better situate its current institutional culture and dynamics.

### **Situating Sankalp : A Brief Origin Story**

The founder of Sankalp, Mrs. Iravati Damle, a widow and a single mother was born in 1916 in Pune. She had earned diplomas in social work and started the institution as a small school for matimand mula (which literally translates to slow minded children from Marathi and is a counterpart of the term mental retardation). In her autobiography<sup>20</sup>, she wrote about how she visited 21 schools for matimand mula in the United States in 1964 and was inspired by how children in these spaces learned not only through reading books but by practically using instruments and tools. She wrote, "In schools, children work with the teachers. They were made to get into the habit of doing work such as washing and cleaning their classrooms, things that all Americans are used to doing anyway. I started doing a lot of these things in our school too."

Upon returning to Pune, she collaborated with a woman psychiatrist, Dilnaz Irani, who worked in a remand home. When Mrs. Damle met these children in the remand homes, she felt that many of them did not have criminal tendencies, but instead, in her words in Marathi, had "a very small IQ" who often did not even understand that they had stolen something. With Dr. Irani's support and expertise, Mrs. Damle started Sankalp in 1964 in her Bungalow with only two students. From its inception, she was faced with the question of how to keep her students occupied or guntvun thevne (tangled) in her words. She wrote that she could have them spend at most an hour on activities like singing and practicing writing on a slate. This made her think that

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<sup>20</sup> Even though I quote from Mrs. Damle's autobiography, I do not cite it because it would compromise the anonymity of Sankalp.

she had to give them some work (kaam). They started small with making paper bags. Next, she started buying tapioca and ground nuts in bulk from wholesale markets, which the students learned to weigh and pack into small packets, which they would place into the paper bags they made and eventually sell to local shopkeepers. Along with keeping them busy with work, she also shared that another important purpose of Sankalp was for parents to get respite or freedom (*muktata* in Marathi) from their caregiving duties. Thus, occupation for the children and respite for their parents were foundational objectives of Sankalp. Under her guidance, Sankalp became renowned and gained goodwill as an institution that worked for the underserved community of *matimand mula* in the state of Maharashtra. Over time, she wrote that students at Sankalp were making diyas, candles, towels, soaps, greeting cards, and Ganesh idols. In Mrs. Damle's words in Marathi, "their hands are always tangled in creation." Thus, keeping hands occupied was always an important orienting principle at Sankalp.

Aside from keeping her students entangled or occupied, love was also an important value for Mrs. Damle. She was of the belief that there was no cure for *matimandatva* (mental retardation in Marathi) and stated that the only remedy for this condition was to shower such people with love. The educators at Sankalp, till date, repeat these words and are referred to as *maushis* (the word for maternal aunt in Marathi) instead of madam. Thus, familial or kinship terms, instead of professionalized terms circulated at Sankalp, leading to Sankalp being both a workspace as well as a site for providing kin-like love or care. Another important feature of Sankalp, that continues to date, is the celebration of Hindu festivals with much fervor and enthusiasm. Mrs. Damle was a devout Hindu Brahmin, and she started the tradition of frequently celebrating festivals at Sankalp wherein women educators draw rangolis (auspicious patterns with colorful powder on the floor) and prepare speeches describing the importance of the day.



The celebrations end with snacks and *prasad* (god's offerings) being distributed to everyone. Thus, from its inception, the vision of Sankalp included keeping intellectually disabled people occupied with work (especially busy work that kept their hands entangled) as well as festivities while also treating them with care. Further, providing families with relief from their caregiving duties was also always a guiding principle at Sankalp.

### **Current Realities at Sankalp**

Over time, Sankalp became more formalized as a registered public trust. In 1978, the government of Maharashtra sanctioned two and a half acres of land to Sankalp in Shivajinagar, a central area in Pune district, where Mrs. Damle, with help from her social and familial networks, built a special school and a workshop. She also ran a training center there which provided diplomas in special education until 2005. Sankalp also gained the recognition of the Rehabilitation Council of India (RCI), the government body that regulates the fields of special education and rehabilitation in India. At present, Sankalp has three campuses- two urban campuses in Shivajinagar and Pimpri, two bustling areas in the city of Pune, and a rural campus in Talegaon, a semi-rural area on the outskirts of Pune. I conducted fieldwork at the Shivajinagar campus from March to August 2022. This is the only campus that has both a special school and a workshop (the other two campuses only have workshops). The Shivajinagar campus is also the only one that receives a salary grant of Rs. 4 crore per year ( USD 480,000) from the Maharashtra government. However, despite the government grant, which covers the salaries of employees on the government payroll and basic amenities such as electricity, water, and fuel for the buses, Sankalp trust requires Rs. 5 crore (USD 603,500) per year for its operation and thus continues entertaining individual donors, social clubs, and corporate social responsibility

stakeholders to receive funding for infrastructural costs, maintaining the other two campuses, and paying salaries to those employees not on the government payroll.

On the Shivajinagar campus, the special school caters to children between the ages of 7 to 18 years, after which they transition to the workshop, which caters to adults from the ages of 18 to 65 years. The special school and workshop co-exist alongside one another (they are physically right next to each other on the campus), and people often transition from the school to the workshop. The school operates like a mainstream school, with structured lessons and a syllabus comprising of functional academics and vocational skill building activities, and educators follow an IEP (Individualized Educational Plan) for the students. The school also has many resources, such as a refrigerator, smart TVs for each classroom (a new addition I noted in November 2023), and vocation specific teachers aside from the special educator assigned to each classroom. However, what sets the special school apart from mainstream schools was that instead of being divided into grades, the school is divided into three sections- primary, secondary, and pre-vocational. The pre-vocational classes serve students between the ages of 14 to 18 years and in principle prepare them for the workshop and possibly even work in external workplaces by focusing on vocations such as sewing, cooking, and carpentry. At 18 years of age, many of these students transition to the workshop, where in theory, they receive further training and skilling in production activities to eventually participate either in economically productive activities in the open market or to continue doing the same production activities at the workshop. In an interview with Mr. Sathe, a trustee of Sankalp trust and the nephew of the founder, Mrs. Damle, he shared with me that the main objective of the workshop was to train intellectually disabled adults into various vocational skills between the ages of 18 to 22 years and then finding paid employment for them in the open market. However, he stated this had not worked out and aside from a few

exceptional cases, most intellectually disabled adults either remained in the workshop beyond the age of 22 years or dropped out after a certain point to stay at home<sup>21</sup>

At the workshop, long gone are the days of making paper bags, soaps, and candles. For the last 30 years, Sankalp Trust has had a contract with Tata Motors to weave and sew industrial dusters which are used to soak up grease, oil, and dirt at their factories. Another production activity is bookbinding, for which Sankalp workshop has had a contract with a major private hospital in Pune for around 20 years. The hospital orders writing pads and notebooks from Sankalp which are pasted and bound by educators and intellectually disabled people at the workshop. The last production activity is that of paper-shredding for which the workshop has a contract with another private hospital in Pune: the hospital sends Sankalp its confidential bills and documents which are shredded here. Recently, the workshop has started recycling shredded paper or sending it to certain merchants and mills to be used as packing material. Most of these contracts, according to Mr. Sathe, have been acquired, not through contemporary CSR activities, but through older family networks and goodwill. The workshop does not make much money from these activities (for instance, they receive a meager Rs. 8 (USD 0.096) per industrial duster from Tata Motors). Thus, although Sankalp operates as a formal workplace which houses multiple commercial activities, the money accrued through the production activities is minimal and barely covers the operational costs of the three Sankalp campuses. In this context, the trustees, treasure, and the superintendent of the workshop do the work of making contacts with

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<sup>21</sup> Although during the interview, Mr. Sathe did not provide any reasons for intellectually disabled people from Sankalp not finding paid employment opportunities, I observed during my fieldwork that the programming and activities at most workshops and vocational centers in India were not geared towards preparing intellectually disabled people for competing in the open job market. For instance, to the best of my knowledge, there were no paid jobs available for sewing industrial dusters, using paper shredding machines, and painting diyas, which were the kinds of activities that took place in these institutions. Further, in settings like workshops and vocational centers, intellectually disabled people received constant directives from special educators, something that is not common in regular paid jobs.

multinational corporations to receive funding for various costs: building new units in the school and workshop, maintenance of machinery and school buses, and salaries of non-government employees. Despite its (meager) government funding, Sankalp Trust still makes appeals to private agencies and individuals to continue its operations.

In my initial conversations with educators and administrators at both the special school and the workshop at Sankalp, one thing became clear: the two spaces were seen as serving different purposes. The school was framed as a space to learn, both functional academics and vocational skills, while the workshop was a space where while training continued, the objective was to make intellectually disabled adults work or do kaam. This even reflected in the background of the educators at the two sites: while all special educators at the special school had received bachelor's level degrees in special education, not all the educators at the workshop had such degrees. However, all the educators at the workshop had received degrees in vocations like tailoring and bookbinding from the Indian Industrial Training Institute (ITI). Thus, for the special educators at the workshop, having expertise in vocations was considered equally, if not more important, than being formally trained in educating intellectually disabled people. This is significant because it demonstrates how the administrators at Sankalp framed and valued the workshop as a place of work rather than a place for skilling or educating intellectually disabled people, which in theory, formally trained special educators would be considered more adept at.

During my fieldwork tenure, Sankalp workshop had seven educators (two men and five women). Each classroom also had a designated caretaker (*madat-nis* in Marathi, which translates to helper or assistant) who supported the educator with his or her tasks and often did the more challenging manual care-work, such as changing pads for women with significant intellectual disabilities, accompanying intellectually disabled people on buses to assure they

reach home safely, and cleaning toilets. There were around one hundred intellectually disabled adult attendees at the workshop (the government rule required there to be 50 attendees for Sankalp to continue its operation). Intellectually disabled people at Sankalp came from diverse backgrounds but given that the institution was government-aided and there were no fees required, most of the members were from lower middle class to lower class backgrounds (in contrast to my other field-sites, which usually required a fee and thus catered to more middle to upper-middle class families). They also belonged to diverse religious and caste backgrounds at Sankalp workshop (even the special educators here belonged to non-dominant castes) unlike my other non-governmental field-sites. One of the reasons for this was the fact that Sankalp workshop, being a government institution, had a few job posts reserved exclusively for people from marginalized caste backgrounds. In contrast, private institutions, such as Udaan, did not have any such government stipulations and therefore were not obligated to hire special educators from marginalized backgrounds. Thus, despite having dominant caste trustees and an institutional culture that glorified Hindu traditions and rituals, the special educators, and intellectually disabled people at Sankalp belonged to diverse class, caste, and religious backgrounds.

The two male teachers managed ground floor activities, which included the power-loom weaving and bookbinding sections. The upper floor had five sections: three sewing sections (one for men and two for women), one arts and crafts section for men, and a care-group, which was formed by the trustees at Sankalp workshop to accommodate intellectually disabled people over the ages of 45 years who, in accordance with the Indian government policy, aged out of the workshop at this age. Thus, the care group was the only section at Sankalp workshop not funded by the government. Instead, Sankalp trust financed and managed this section by appealing to

donors, clubs, and CSR initiatives. They made their appeals by using the social networks of their trustees and inviting donors for visits and social events (with music and dance performances done by intellectually disabled people) at the institution to convince them to donate. While I spent some time in each section of the workshop, I spent most of my fieldwork tenure on the first floor in sections overseen by women educators. I now move to the ethnographic section divided here in two parts, kaam as occupation and timepass as occupation, to examine the different ways in the workshop shaped the personhood and everyday life of both intellectually disabled adults and special educators.

### **Kaam as Occupation**

#### *The Work of Prompting and Following Instructions*

“We have adults here in the workshop, 18+. So, the first thing is their personal things, doing their own things independently, on their own. We want the children to be active, so we make efforts in that direction by making them exercise”. This is an excerpt of Sandhya maushi talking during a focus group discussion I organized with the five women special educators. I had asked them to elaborate on the purpose of the workshop. None of the educators focused on production activities while listing the purpose of the workshop. Instead, they listed various markers of adulthood, such as doing things on one’s own, social appropriateness, hygiene, menstrual management, and physical wellbeing, as their goals. During my fieldwork, I noticed educators working on some of these goals. For instance, every morning began with physical exercises and everyday post lunch, everyone, including the educators, would walk for ten minutes before resuming class. Further, educators would constantly ask intellectually disabled people to work on their own hygiene, cleanliness, and social manners.

For instance, educators would ask intellectually disabled adults to say “thank you” if someone gave them a gift or food. They would ask them to straighten their clothes if they were disheveled or riding up. This was especially true for women, who would often be asked to cover their chests properly with a *dupatta* (a flowy garment). Pushpa maushi, the youngest special educator, who oversaw the arts and crafts section, which comprised of young men, would check their nails daily and reprimand those whose nails were too long or dirty. She would also ask them to comb their hair neatly before coming to the workshop. If people hunched or slouched too much, they were immediately asked to correct their posture by the educators. To my amusement, given that the workshop had re-opened for its attendees after a two-year long shutdown due to COVID-19, educators often instructed intellectually disabled people to wear their facemasks, but never wore masks themselves. Such directives were not sporadic or rare; instead, these formed a significant chunk of the communication between educators and intellectually disabled adults and took up a lot of time.

Thus, the work of prompting for special educators and for intellectually disabled adults to follow those prompts was an important part of everyday routine at Sankalp. While as stated by Sandhya maushi in the focus group and other educators during informal conversations, the point of the workshop was to make intellectually disabled people “independent” and to teach them how to do their own things, this was not quite what transpired at the workshop. Levinson, while talking about the way counselors at Driggs House engaged with intellectually disabled residents stated, “residents are also kept always at work: they are oriented again and again to the way they conduct themselves and to the project of becoming more independent—the endless work that defines them as residents” ( 2010, 102). In resonance with Levinson’s interlocutors, special educators at Sankalp intervened in intellectually disabled adults’ lives by directing them towards

their own appearance, manners, and behaviors, and kept them occupied with the task of “self-work”. Appearances, manners, and grooming were important goals for special educators as these institutions were invested in presenting intellectually disabled people as respectable looking members of the society to their donors, parents of prospective attendees, and the general public. However, intellectually disabled people never became independent by coming to the point where they no longer needed prompting. Instead, prompting (and following) directives or instructions around “self-work” or taking care of oneself as told became an important part of everyday life. Not only did educators use such directives to communicate with intellectually disabled adults, but intellectually disabled adults also used directives to supervise each other’s behaviors. For instance, members of the workshop would often scold each other about not wearing their facemasks correctly, ask each other to tuck their shirt in, or do their hair properly. Thus, by learning the “social script” (Carr 2010) of prompting people to look after themselves, intellectually disabled people engaged in a practice that was both self-work and other-work. Thus, self-work, either directed by special educators or by intellectually disabled people themselves was important “work of everyday life” (Levinson 2010, 59 ) at Sankalp workshop. Here, self-work was about managing one’s own appearances and grooming and looking and behaving in an appropriate manner, when told to do the same by authority figures or peers.

### *The Work of Shaping Helpful People*

“Who is going to fetch a glass of water for me?” said Kulkarni maushi addressing the women’s sewing section. Anjali, a talkative and enthusiastic woman in her twenties, quickly got off the floor and fetched Kulkarni maushi’s bottle. She also switched off the fan because people were complaining about it being too cold. Meanwhile Kulkarni maushi spotted Shikha, another intellectually disabled member of the section, sitting on the floor, not folding dusters or coloring,



the options available to those who did not use the sewing machine. She asked her, “Shikha, what is up with you, girl? Anjali, will you fix Shikha’s hair?” Anjali promptly followed Kulkarni maushi’s prompt and proceeded to comb and neatly plait Shikha’s hair. Meanwhile, Kulkarni maushi and the assigned caregiver (madat-nis) for the section, an older woman called Kusum maushi, kept sewing colorful mobile pouches, which were to be presented to the women of the Lion’s Club, who were invited to Sankalp for a felicitation ceremony, in honor of them donating a smart TV to the workshop. The scene described above was representative of everyday life at Sankalp workshop, wherein multiple modalities of work would occur at the same time. Special educators would often be working on their production deadlines while instructing intellectually disabled people to do work that may or may not be related to production work. Sometimes, as described in the scene above, they would ask members to do work (that kept their hands and bodies busy), such as fetching their water and washing their spoon. At other times, they were also asked to do things for each other, such as Anjali being asked to do Shikha’s hair in the abovementioned vignette. Educators were invested in teaching intellectually disabled adults how help others, be it the educators or other intellectually disabled people. Each section had an informally assigned “helper” member who would promptly follow the educator’s instructions and do tasks for her. For instance, Vijay, a chubby enthusiastic 30-year-old man in Pushpa maushi’s arts and crafts section, was her helper. On the first day I visited her section, I noticed that without her even asking, Vijay cleaned up the arts supplies once done with the activity. Upon seeing this, Pushpa maushi looked at me and said, “he really helps me so much”.

Not everyone was equally receptive to being asked by their educators to help- with some people, educators would have to prompt more frequently. However, this did not deter the educators, who would often pick unlikely volunteers to help with tasks. For instance, Kumud

maushi once asked Disha, a shy and non-verbal young woman in her women's sewing section, to wash her spoon after she was done with her meal. When Disha left for the bathroom to do the task she was assigned, Kumud maushi turned to me and said, " Her mother keeps insisting that Disha cannot do anything, but look at her here in the workshop, she can wash my spoon". Unlike Anjali and Vijay, Disha did not volunteer to help. During my time at Sankalp workshop, I never once saw her develop a so-called "helper" disposition. Unless called upon to do something specific, Disha would just sit on her spot on the carpet, usually not engaged in any apparent activity. However, in getting Disha to successfully wash her spoon, Kumud maushi recognized Disha as someone who (if supported or nudged correctly) was someone capable of doing work (with her hands) and recognized herself as an expert, who unlike her mother, was able to successfully make her do the task at hand. Further, according to Kumud Maushi, washing a spoon was an action worthy enough to be classified as work.

Special educators would also ask intellectually disabled adults to do chores that helped with the everyday upkeep and maintenance of the workshop. As mentioned in the opening vignette, educators would always ask members to sweep the floor at the beginning and end of the day and lay the carpets. Sometimes they would ask them to deliver a message to the educator in the next section or deliver a stack of dusters downstairs. Doing such chores was an important way in which many intellectually disabled adults stayed busy and passed their time. Further, special educators too stayed busy by directing intellectually disabled adults towards such chores. Though seemingly insignificant, these small asks constituted everyday exchanges that shaped everyday practices at Sankalp. These instructions or directives could also be viewed as opportunities or avenues, although limited and hierarchically imposed, for intellectually disabled adults to become contributing or active members of the workshop- as people who contributed by

working with their hands. In a later section, I will examine what happened when educators were faced with someone who refused their directives to work. But for now, I wanted to demonstrate how special educators intervened to make up a very specific helpful, obedient, and socially appropriate personhood for intellectually disabled adults at Sankalp: as people who when asked or prompted could look after themselves, help their peers and people in positions of authority, and perform chores. By being helpful and obedient, intellectually disabled people could contribute to Sankalp and their contribution was valuable in maintaining the order and workflow at the institution.

### *Valuing people through productive work*

While educators would try their best to intervene through the framework of work, people who did not excel at completing tasks, for a variety of reasons, often received less attention and praise compared to those who completed their tasks successfully. As mentioned earlier, there were a few people who were made up as “helpers” who played the role of the educator’s assistant, often anticipating their needs and easing their workload. Such members received a lot of praise from the educators. Another category of people who often received a lot of attention were people who could perform the production tasks adeptly. For instance, Ramesh and Bilal were the two men in Sandhya maushi’s section who could sew well, and she would always speak highly of them to me and the others, sometimes in an effort to spur competition by comparing their work output to that of others. While the “helpers” and “productive” types did not always overlap, they often did. For instance, Ramesh was both an eager helper and a proficient worker. He also used normative speech to communicate and would often chat with his peers, Sandhya maushi, and me. However, this was not always the case. Unlike Ramesh, Bilal was the best sewer in Sandhya maushi’s opinion, but he never used speech to communicate. He preferred not to socialize and usually

worked by himself on the machine and did not perform any other chores. Thus, while there was some variety among those who at Sankalp came to be made up as the changli mula or kaam-karnari mula (good children or children who work), they either embodied some or all these abilities: they could do production work, be helpful, or could use normative speech to communicate.

On the other hand, there were many intellectually disabled adults who could not do production work or even follow verbal instructions without difficulty. While educators often tried delegating them tasks or chores, they would give up after making a few attempts and turn their attention to their other tasks, such as sewing, filling out diary entries, or writing daily reports, which were always present and pressing. Many of these individuals also appeared to be more significantly disabled than the ones who were able to perform work. Riya, for instance, was an older member of Kumud maushi's women's sewing section. She did not communicate much verbally or non-verbally with her peers or Kumud maushi. Kumud maushi once asked Riya to fold a stake of dusters. Riya folded just one duster before giving up on the rest and resting her chin in her hands and drifting off to sleep. When Kumud maushi saw her, she woke her up by calling her name out and shaking her a little. To keep her awake, she asked her to practice writing *Aai*, the word for mother in Marathi, in her notebook. She also asked her to get up and move a little and said that she would get fat otherwise. While Riya opened the notebook, she never wrote anything in it. Neither did she get up and walk. However, Kumud maushi did not follow up with her, as she had her own sewing tasks to return to. This was one of the rarer instances of Kumud even following up with Riya- usually Riya would just sit in her spot not being addressed as much as some of her peers who would more actively follow instructions and perform chores at the workshop. Intellectually disabled adults like Riya (and there were many

like her) came to be known as the *basnaari mula* or *madat-karnari mula* (sitting children or children who help). Not to be confused with “helpful children” who fell into the category of *changli* or *kaam-karnari mula* (good children), children-who-help were constructed as those who could only do ancillary or support work (such as folding, cutting, shredding paper, washing spoons) and not the heavy lifting of sewing or sending verbal messages to educators in other sections.

Administrators and educators often used the terms good children and sitting children while talking about intellectually disabled adults to each other or me. It was a matter of pride for Sandhya maushi to have a class of mostly good children and she would often mention the same to me. This categorization affected classroom practices beyond just those who received praise and who did not. Those who were known as good children would often be occupied with higher stakes work and would appear to be busy through most of the day. On the other hand, while educators made attempts to occupy the sitting children as well, these efforts were never made through long-term sustained interventions, such as in the case of Riya. Educators would start with asking them to fold dusters, and if they did not, they would ask them to write, draw, or “study” (*abhyas* in Marathi), which puzzled me because all the workshop educators were always vehement about workshop not being the space of education, but that of work. What they meant by “study” was writing or tracing letters and words in the notebook as a way of keeping hands busy in some other way. However, writing or drawing never sustained the interest of these adults who would abandon these tasks and instead just sit for hours.

The categorization of good and sitting children also affected larger institutional practices. Given that Sankalp Foundation was invested in Hindu traditions and often celebrated Hindu festivals (every other week), time and effort went into preparing for these events or functions. In

fact, celebrating festivals was an essential part of the institutional culture. While the educators were expected to host the function and give the audience (which consisted of other educators, administrators, trustees, and on some occasions, current or prospective donors) information about the festival, intellectually disabled people were asked to take to the stage to give a short speech or to hand gifts or souvenirs to the guests of honor; the rest were the default audience who were seated outdoors on wooden benches and received a snack-pack at the end of the event. Thus, only those who could use normative speech or comprehend and execute the task of handing gifts were selected to be on stage. Aside from festivals, Sankalp workshop also often courted potential donors by doing cultural events. For instance, in March 2022, when I had just started doing fieldwork at Sankalp, Rajesh sir, the special educator formally in charge of the bookbinding unit and de-facto in charge of setting up technology for events at Sankalp workshop came running to special educator Sandhya's section and asked her if he could borrow some changli mula or good children for the event occurring in the adjacent room. The event was a function felicitating the ladies of Lion's club (a social club in India), an event I mentioned earlier in reference to special educators sewing colorful bags for the guests of honor. Sandhya maushi chose Akash and Ramesh, two young intellectually disabled men who could communicate verbally and were adept at sewing and sent them with Rajesh sir for the event.

Thus, the changli mula often occupied the lime-light when it came to receiving attention from administrators and educators. These categorizes, based on people's ability to follow instructions, and do normative work organized the social world of Sankalp. People made up as good children occupied the role of the helpers or workers and completed normative work as instructed, while people who sat were often ignored or left to their own devices. Using these categories also helped special educators make sense of their own work. For instance, as

mentioned earlier, Kumud maushi considered herself as expert for being able to make Disha wash a spoon. Given that Disha was viewed as someone who sat, this was seen as a big step for her. Further, while those categorized as sitters were institutionally valued lesser because they could not work as quickly and efficiently as those classified as good children, I saw them as also doing work. When children who sat folded dusters slowly and intermittently or washed their special educators' spoons or filled their water bottles in a so-called imperfect manner, they were still doing work. Their work as well as the work put in by special educators in instructing and supervising them was valuable for maintaining the workflow and order at Sankalp.

### *The Work of Managing Problem Children*

Unlike children who sat, problem children did not necessarily sit quietly for long periods of time. Instead, they disrupted the workflow routine at the workshop. Despite being less productive or efficient, sitting children were not seen as disruptive or harmful by the special educators. Rather they were conceived as having a peripheral or lesser role. They were not scolded or reprimanded for their low productivity, but rather ignored by the educators, who would usually leave them alone to sit or nap, as they continued doing their work. In contrast, problem children often took up a lot of space and time and were seen as taking time away from the work that both educators and other attendees were supposed to be doing with their time. In this section, I demonstrate how those made up as problematic by Sankalp were indeed valuable members of the institution given that engaging with and talking about supposedly problematic behaviors comprised an important part of everyday work for special educators and solidified their own sense of identity as people who did difficult but ultimately satisfying and important moral work. Further, discussing problem children was a practice that broke the binary between kaam and timepass as it was both at the same time.

An example of this emerged during my fieldwork when Anu, a young woman in her early twenties, was admitted to Kulkarni maushi's class in April 2022. Anu was not from Sankalp special school and had previously been a student at the Rainbow Foundation special school and vocational center, a privately managed institution a few miles away from Sankalp, where I had conducted my preliminary fieldwork in 2019. I had fleetingly known Anu back in Rainbow Foundation, but never interacted closely with her. She did not seem to remember me when we met again here. At Sankalp, Anu refused to call the special educators maushi and wanted to call them madam, like she did in her previous institutional home. She also refused to sit on the ground with others, would never ask for permission before entering or leaving her section, and spent most of her time walking around the classroom passing orders to the women in her section, saying things like, "very good", or "do that properly!". On her first day at school, Kulkarni maushi turned to me smilingly and said, "She is the leader type".

However, very quickly, over the span of her first week at Sankalp, Anu stopped being known as a leader and came to be known as a problem. My fieldwork routine usually involved spending one day a week at each section on the first floor of the workshop (covering all 5 sections over the 5 days of the working week) and I would meet Anu at each section, trying to chat up the educator, instead of staying in her section as was expected of her. As soon as she left, the educators would turn to me, and say something along the lines of, "this girl is a problem". Because Anu refused to sit on the floor, Kulkarni maushi agreed to let her sit on a stool next to her for the first few days. However, Mr. Borse, the superintendent of the workshop, who rarely got involved in the everyday working of the workshop, especially came to the section, and let Kulkarni maushi know that while it is okay that Anu wanted to sit on the stool during her first week, this behavior would eventually have to be corrected, maybe starting next week. Not much



changed over the next week, and Anu continued sitting on the stool, refusing to follow the rules and routine of Sankalp. While educators would intervene using different strategies, ranging from scolding her to cajoling her by trying to be her pal, they did not come up with any systematic plans to work on her problems. However, what did change over the next few weeks was the frequency and intensity of talking about Anu as a “problem child”.

Educators talked about Anu’s life experiences and history with each other and me and came up with a narrative that provided an origin story for her problems. They told me that Anu came from a rich family but since her mother died, her father remarried and often travelled abroad, leaving her alone with her stepmother who neglected her, which led to all her problem behaviors. Her origin story quickly gained traction at the workshop, and soon enough Anu’s status as the problem child, whose only hope was psychiatric medication and institutionalization was established, which was only exacerbated by events such as the screaming bouts she experienced on a regular basis. I noticed educators discuss Anu more and more often during their breaks. Even I was called upon by Mr. Borse to his office where he talked at length about Anu’s supposedly problematic behaviors and her origin story, which I had already heard several times by then, and asked me if I could offer any solution, despite already having made up his mind that the only solution for Anu was psychiatric institutionalization and medication- something her family refused to do. Thus, an institutional narrative about Anu’s problems emerged, wherein her problems were rampant but despite their best efforts, the institutional actors at Sankalp could not solve her problems, as this was ultimately the responsibility of her family.

In his ethnography, Jack Levinson addresses the workplace practice of “shoptalk” ( 2010, 108), wherein counselors shared insights about their work with each other, as important work in itself. He describes how counselors at Driggs House constantly puzzled over and analyzed the

smallest of changes in the residents. He further states that it was the supposedly most problematic residents who were often the most discussed during shoptalk. However instead of solving the problem conduct, Levinson argues that shoptalk provided an outlet for counselors to discuss the challenges and limitations of their own work and complain about authority figures who limited what they could or could not do to solve the problem conduct. Similar to Levinson's interlocutors, by engaging in shoptalk about Anu as a problem child, institutional actors at Sankalp framed Anu's parents as the ultimate authority figures who, by not agreeing to send Anu to a psychiatric institution, refused to acknowledge Anu's problems and did not cooperate with them to solve her problematic behaviors. In doing so, they managed to both frame themselves as moral actors who cared about Anu's problems while also being helpless or powerless in the face of uncooperative parents, who lacked the expertise as well as the empathy needed to deal with the situation. Thus, "problem children" like Anu were not just nuisances or roadblocks for the workshop even though they did provide a rupture in everyday routine. Instead, they produced value because their "problematic conduct" became a topic of discussion and discourse during "shoptalk" that allowed special educators to make themselves up as people who were caring experts but ultimately not responsible for implementing the solutions to solve the problem.

I do not want to minimize either the engagements and interventions made by special educators or dismiss Anu's possible experiences of pain and frustration caused by the strict and conservative rules around dress and conduct at Sankalp. Instead, I argue that even the so-called "problem-children" were not undesirable actors who did not contribute to the workshop. Moreover, I also demonstrate it is neither realistic nor feasible for special educators to implement a "solution" when they are relatively powerless compared to actors such as parents and administrators (it is a whole other matter that the suggested solution of psychiatric

institutionalization could be seen as a way of washing one's hands of Anu's problems by delegating her to professionals possessing medicalized expertise). Thus, within the constraints of the workshop, constantly analyzing and narrativizing about the problem child became a way for special educators to convince themselves that they were working and doing their best. And that too was work (intertwined with timepass) even though it did not look like work. Having covered diverse forms of work and the ways in which intellectually disabled people came to be valued and categorized differently based on how willingly they did or did not (or could not) work, I will next address the more prevalent form of occupation at Sankalp workshop: timepass.

### **Timepass as Occupation**

#### *The Value of Sitting: Seeing Timepass as an Occupation*

Upon seeing the apparently preferential treatment received by the good or working children, I was convinced those who were normative (in terms of their productivity, behaviors, and speech) were the ones who were constructed as good and subsequently chosen to literally be center-stage at events, while the more non-normative people, who could not and did not participate in the work regime of Sankalp as willingly or enthusiastically, had to watch from the peripheries. However, upon re-examining my own biases towards the acts of sitting and napping, I realized that these activities too, while not productive in straightforward ways such as sewing, were indeed very valuable. Given that the workshop required an enrollment of fifty people to receive its yearly government grant, the sitters served a very important function: their presence assured the continued existence of the workshop and the jobs of the various people affiliated with the workshop. However, even beyond the value that sitting children produced for Sankalp by maintaining its status as a government-aided institution (which in no way can be minimized), I demonstrate that practices of sitting and napping should not be simplistically reduced to being

indicative of boredom or lack of stimulation. Instead, I contend that by using the framework of “timepass”, these activities can be viewed as forms of occupation. By sitting and napping, intellectually disabled adults occupied space and passed their time between the hours of 10 am to 4 pm.

While people did not appear to be busy when they sat or napped (unlike when they sewed, folded, washed spoons, or cleaned carpets), much like Jeffrey’s (2010) unemployed young male interlocutors, who engaged in timepass and not timewaste by hanging out at tea-stalls chatting and people watching, those made up as “the sitting children” could also be seen as engaging in timepass by taking up (or occupying) space by sitting and napping for long hours. When viewed as timepass, sitting and napping can be viewed as modes of accessing rest and respite within an institution, in which intellectually disabled adults are often instructed to do busy work with their hands. Moreover, knowing the toll that sitting for long hours on the carpets laid on the floor without back support took on my own body, I would argue that sitting at Sankalp workshop was an activity (and not just a passive state) that involved using the body, albeit in seemingly unproductive ways. Akemi Nishida’s (2020) through her concept of “bed activism” (Nishida 2020, 8) frames the bed as not just as a space to sleep but as a generative and complicated space for sick and disabled people to rest, dream, perform their activism, as well as experience pain for simply existing in their disabled and chronically ill bodyminds. Drawing on Nishida’s concept of bed activism, I too contend that sitting, while restful, was also an embodied and perhaps even laborious practice for intellectually disabled people, even though it did not fit into the norms of productive work.

### *Spontaneous Interactions as Timepass*

However, it was not just sitting and napping that could be framed as timepass. At Sankalp, there were many such instances of timepass that made passing time easier. For instance, as I mentioned earlier, those who could use verbal language would often talk to each other about topics, such as food made at their home, popular songs, and so on. Those who gestured would often gesture to each other or even to me. For instance, as mentioned in the previous chapter, Shalini, a young woman from Kulkarni maushi's section would often repeat the same phrase to everyone, which was, "Will you go to Bal Kalyan? I will be singing there!". Sankalp workshop often made fieldtrips to Bal Kalyan, which was an arts center a few miles away from Sankalp. However, Shalini's use of the phrase did not necessarily correspond with an impending trip. These repetitive comments, utterances, and questions could also be seen as attempts, however unclear and non-linear, at passing time or doing "timepass" by chatting in unconventional ways, perhaps, until something more exciting, such as a fieldtrip to Bal Kalyan came along. Moreover, Shalini's expressions could also be seen as attempts at making a social connection with me, an outsider, whose presence was never fully communicated to them (I was only introduced as Shruti didi, someone who was there to learn about their lives).

Timepass was a form of occupation not only for intellectually disabled adults but also for the special educators. Aside from chit-chatting with each other whenever they managed to, talking to me about my life (or rather telling me about theirs), and regularly talking to their children and husbands over Whatsapp video calls during lunch time, during which time they sometimes ignored their charges and/or included them in their calls, special educators also engaged in timepass with intellectually disabled adults. The most memorable instance of this for me was the pleasure and amusement felt by Sandhya maushi whenever Darshan, a non-verbal

autistic man, introduced in the first vignette, would pick up her phone, just to access a specific ringtone on it, and listen to it while running up and down the room. While Darshan's behavior was neither productive nor obedient, Sandhya maushi appreciated his "antics" and burst into laughter whenever he did the same. Darshan also regularly popped his cheek in an unusual manner, another behavior that made Sandhya maushi laugh in the middle of her day. Sometimes she even requested him to pop his cheek to show me how amusing Darshan could be. I understand Sandhya maushi's engagement and encouragement of Darshan's unusual behaviors as a form of timepass. Thus, it was not only the intellectually disabled adults, but also special educators who occupied their time at the workshop with timepass, which could look like sitting, napping, chatting, or laughing at unusual behaviors.

While the sitting children received comparatively less attention in the form of praise, they also emerged as people who did timepass- who occupied their time and the institutional space with sitting, napping, and chatting in unconventional ways. Although intellectually disabled adults who were more obedient and followed the directives of their special educators, stayed occupied with busy work, and emerged as the changli or kaam karnari mula (good children and children who work), those who did timepass were less tied to the directives and instructions of the special educators. Timepass, unlike work, emerged as a more spontaneous form of occupation at Sankalp Trust in that it was not planned and there were no goals or quotas for these actions.

#### *The Case of the Care Group: An Entire Section Engaged in Timepass*

Under the Indian government's regulations, Sankalp workshop could only accommodate people between the ages of 18 to 45 years, after which they aged out of the workshop. Mr. Borse told me that this proved to be a problem for many ageing parents who did not have the financial

resources to house them in private residential homes or respite care facilities. They also had health problems of their own which made it difficult for them to care for them on a full-time basis. Further, he also shared that some intellectually disabled adults had lost their parents and were living with their siblings, who had their own familial and work responsibilities, and could not afford to care for them full-time either. Given this scenario, the trustees at Sankalp Foundation decided to start a care group for intellectually disabled adults over the age of 45 years. Since the care group did not receive funding from the government, Sankalp Trust had to rely on donations and corporate sponsorships to pay the salary of the special educator assigned to the care group. Moreover, unlike other intellectually disabled adults at the workshop who were funded by the government and thus did not have to pay a fee, those who were a part of the care group had to pay a nominal fee of Rs. 500 ( USD 6), which too was often waived given the difficult socio-economic condition of most families. Thus, the care group emerged as an exceptional site within the workshop which was overtly dedicated to caring for its attendees rather than making them productive.

When I first visited the care group, it was difficult for me to understand it as a space of care. Within the care group, sitting was the norm. The section had just one sewing machine, unlike the other sewing sections which had at least three. The machine was used by Anisha maushi, the special educator, who sewed dusters on it on a daily basis, multiple stakes of which were delivered downstairs to the accounts department at the end of day. Many of the older members would doze off or just sit staring into space for long periods of time all day long. Certain institutional practices also made me believe the care group was the least valued and most taken-for-granted section of the workshop. For instance, given that the care group did not have any pressing production work taking place on its premises, it was the de facto event space. Thus,

people in the care group were often displaced in case a high-profile function took place, such as the cultural event felicitating the women of Lion's club. During my fieldwork, I noticed that while other sections had a set routine, every day looked a little different at the care group.

Aside from being the de-facto event space, it was also the de-facto rehearsal space for intellectually disabled people from the special school and workshop to practice their musical and dance numbers. Further, trustee meetings and teacher trainings workshops also took place in the care group room. Whenever such events took place, Anisha maushi , the special educator in charge , and the intellectually disabled attendees of the care-group would either scooch to the corner of their room or sit in one of the other sections. Thus, the time and space allotted to the care group was always up for grabs- people here were not granted the same stability as members of the other sections. Even Anisha maushi , the special educator in charge of the care group, received a salary much lower than her peers who were on the government payroll (the starting salary for the care group teacher was Rs.12,000 (USD 144) per month compared to Rs.30-35,000 (USD 360) per month for educators on the government payroll). This was even though she had earned a bachelor's degree in special education unlike many of the other special educators in the workshop who earned more than her. Thus, I was generally left with the feeling that the care group was the most neglected section of the workshop.

However, while these things were true, and in no way insignificant, this was a decontextualized analysis of the care group and its value, which did not consider its alternative: which was intellectually disabled people spending their time at home (alone), with either ageing parents or family members who did not have the time or resources to engage them meaningfully. For instance, Babu, a 60-year-old member of the care group had recently lost his mother and



lived with his sister, who worked as a domestic worker. The care group served as a space for Babu to occupy his time around his peers and educator when his sister did her day jobs.

Moreover, the care group was the only section of the workshop which did not need to exist. Its formation was an institutional response to the changing needs of its ageing intellectually disabled attendees and their families. In making space for the care group, the institutional heads at Sankalp trust demonstrated their ability to value intellectually disabled people (and their families) on their terms- not because they were (or potentially could be) productive and obedient, but because families needed respite from fulltime caregiving duties and intellectually disabled adults needed an alternative to being at home all day. Thus, Sankalp's decision to create the care group could itself be viewed as an act of care. As stated by Mr. Borse, "They have low IQ, their speed of operating as compared to the other children is slow. But they feel good to come here, sit for a while, eat their tiffin, and go home." When framed as an intentional space created to accommodate ageing intellectually disabled adults from marginalized socio-economic backgrounds, the care group appears to be more complex than being just the most neglected or marginalized section within the workshop.

When viewed through the lens of timepass, the care group attendees could be seen being most consistently engaged in diverse forms of timepass. For instance, I regularly saw many older people napping uninterrupted at the care group. I do not know whether it was their ages or their status as people who were cared for and not expected to be productive, but intellectually disabled people at the care group were less restricted by constant instructions and directives by their special educator to do work. They were not expected to sew and fold stakes of dusters or do arts and crafts activities, although Anisha maushi would make them do self-work by asking them to take care of their own appearances, hygiene, and social manners and by the end of my fieldwork

period, the care group got a paper-shredding machine for the attendees to use. However, despite the presence of intermittent work-related activities, more often than not, people in the care group would sit and nap without much consequence, which could be viewed as restful ways of passing time.

Further, when viewed as timepass, disruption in everyday routine can be seen as exciting, compared to doing the same busy work every day. Being able to witness dance and music rehearsals and donor events can be re-framed as pleasurable and fulfilling ways of doing timepass at the workshop. Further, being displaced also meant having an opportunity to go to another section, seeing the people and activities that occur there, and maybe even interacting with some of the people there. For instance, during a donor event, the entire care group had to move to Sandhya maushi's sewing section. I was observing Sandhya maushi's section on that day and I remember feeling the chaos that was created by the influx of the care group. But the chaos also created a disruption in the routine, which created opportunities for people in both section to co-mingle, even if no one appeared to mingle in an active manner. For instance, Parna, a tall and talkative woman attendee from the care group in her 40s, appeared to be excited by this displacement and started talking to me and Sandhya maushi about her family with enthusiasm. Further, Sandhya maushi and Anisha maushi also halted their regular activities and chatted for a little while. Thus, while the care-group may have been taken-for-granted by the institution as the de-facto space to do other activities, it still created opportunities of rest, respite, and social connection for intellectually disabled adults and their educators.

Attendees in the care-group also spent a lot of time chatting with Anisha maushi and me. Anisha maushi knew many details about their families and would enquire about their wellbeing. She would also humor them by letting them talk about their family life. For instance, she would

listen to Parna talk about her father, brother, and nephew daily. While she would nod and listen to her most times, sometimes she would also let me be Parna's interlocutor, especially if she was busy with some immediate sewing deadline. Similarly, Anisha maushi would placate Babu who was always nervous about someone stealing his shoes. After assuring him that his shoes were safe outside, she would often turn to me and say, "these children are so innocent". She would ask about recent events in their households- such as a sibling's marriage or the birth of a niece or a nephew or a recent trip or vacation. While some of them replied to her inquiries with great enthusiasm, others did not (and perhaps could not articulate themselves in verbal language). In such cases, she would often fill in the blanks by announcing the big news to me and others in the section. By chit-chatting about their families, Anisha maushi made up intellectually disabled adults as social, familial, and relational beings, who had a life outside the workshop. Thus, by affording rest, respite, exposure to changing social landscapes, and conversations about their family lives, the care-group emerged as a space wherein the social personhood of intellectually disabled adults was recognized.

Having examined Sankalp workshop, an institutional site in which busy-work and timepass co-existed as modes of occupation for intellectually disabled adults, I next move to Udaan, a newly registered, home-based organization. At Udaan, keeping intellectually disabled adults occupied with fun, instead of work, emerged as the institutional priority. While at Sankalp, intellectually disabled adults engaged in timepass by sitting or napping (often in organic ways, on their own) at Udaan, they were explicitly and actively provided with social and recreational opportunities to have pleasurable or enjoyable experiences, such as, eating out at restaurants, watching movies, and going for hikes. Such social experiences were seen by the founders of Udaan as essential for living a good life. Through examining the two field sites relationally, I am

interested in examining the different kinds of opportunities, everyday routine, and personhood(s) the two sites offered to both special educators and intellectually disabled adults.

## Chapter 3: Occupying people through fun

### Introduction

It was almost Diwali and there was a buzz in the air at Udaan. Sarika ma'am, the co-founder of the organization was in the kitchen, wearing an apron, supervising two temporary women staff members as they prepared large consignments of karanjis, a traditional Maharashtrian fried sweet delicacy made during Diwali, to be delivered to family members, friends, and corporate clients, who placed orders. Sahil sir, the other co-founder of Udaan, and Sarika ma'am's husband, was cleaning and decorating the house along with Swarup, a 31-year-old adult attendee with intellectual disabilities. I accompanied Sonali ma'am, the special educator in charge of crafts, and a few attendees in the crafts-room where we assembled and packed colorful Diwali kits with candle wicks, rangoli colors (a powder used for floor decorations during Hindu festivals), and various food items that are offered to gods, such as jaggery, and batashe (a semi-spherical and crispy sugar cake). As we sat on the floor doing our work, Sahil sir came into the room to look for his hand gloves. He looked around but the room was crowded with us, and the raw materials sprawled on the floor. Sahil sir moved past each one of the attendees, and tickled all of them, while he searched for his gloves. He tickled and pushed Prathamesh from behind and said in Hindi, "Now laugh at others!" Prathamesh laughed and gave Sahil sir a little kiss on his hand. As he was leaving the room, Sahil sir tickled Geeta, another attendee, one last time and everyone burst out laughing.

This scene at Udaan Foundation is emblematic of the many moments of joy I witnessed and participated in during my fieldwork. While it is important to talk about the hierarchical relationship between special educators and intellectually disabled people and the problematic

ways in which educators control and regulate their lives, it is also significant to point to moments of fun and pleasure that are co-created and experienced by both special educators and intellectually disabled adults. I came across such scenes of joy in all my field-sites. Special educators shared with me that enjoyment and fun were important aspects of their jobs. On one of my initial days at Sankalp workshop, Anisha maushi, the special educator in charge of the care group said to me, “We are all jolly here. We have to be jolly in this job. And patient.” Even in the care group, a space often taken for granted by the institution, wherein older adults spent their days often not doing much aside from sitting and napping, being “jolly was a priority for the special educator. Indeed, most special educators I interacted with had a jolly disposition. They would often speak to intellectually disabled adults in a performatively cheerful manner while smiling, using exaggerated, slapstick, and comical gestures and facial expressions, in ways that resembled adults communicating with young children. I also observed special educators sharing moments of levity with each other during lunchbreaks and teatime. However, for the most part, most special educators performed a no-nonsense seriousness and often instructed and even scolded their attendees when they had to get work done.

Aside from occasionally being jolly, special educators also worked on creating a pleasant work environment. For instance, at Sankalp workshop, Sandhya maushi, who oversaw the men’s section that sewed industrial dusters, would always have the radio playing in the background. Further, most institutions also had fun or recreational activities scheduled in their daily or weekly programming. At Srushti, an established vocational training center in Pune, where I spent a month doing fieldwork (I mention this organization once in the introductory chapter) , teachers and attendees focused on staying occupied with work all day, except for an hour post lunch, which was reserved for a music session. The music teacher was an intellectually disabled

employee who would lead with the tabla (an Indian percussion instrument) and have two attendees follow him on their own tablas, while others would join along with percussion instruments that were easier to play. At Sahavas, a residential center at Wada, a village an hour and half from Mumbai, intellectually disabled people, special educators, and caregivers formed a circle with their chairs every evening to sing Bollywood songs. The teachers also turned on the flat-screen TV in the main hall on the weekends and played videos of Bollywood and Marathi songs on YouTube and danced along with the residents. At Sankalp workshop, special educators and attendees regularly visited Bal Kalyan, an arts center, where the attendees could participate in informal dance, music, and game sessions. Thus, fun or enjoyment in most institutions was either witnessed in the occasional “jolly” performances of special educators or through activities that were carved out systematically in an otherwise productivity or work oriented schedule of sewing and folding dusters, beading necklaces, and doing physical exercises. Typically, these institutions prioritized values of productivity, work, and discipline. However, unlike most field-sites, wherein fun was present, but not the priority, at Udaan, fun, pleasure, and enjoyment were essential guiding principles. Unlike Sankalp workshop where, as addressed in the previous chapter, special educators made systematic attempts to occupy intellectually disabled adults through kaam or productive work, at Udaan, special educators adopted a playful stance and occupied intellectually disabled adults through activities of fun and enjoyment. At Udaan, fun and pleasure were not understood as supplemental or secondary experiences to be had after the day’s “serious” work is done. Rather, Sahil sir and Sarika ma’am, the co-founders of Udaan, framed fun and pleasure as fundamental aspects of a good life and ranked them as being even more important than work for a person’s well-being and happiness. From its inception in 2019, Udaan had always prioritized ideas of fun and pleasure. Their newly minted brochure read as

follows, “They can learn, they can earn. They can create and craft. They can perform. They can enjoy life just the way we do”. The brochure mentioned productive vocational activities that brought the organization revenue, which include cooking, arts, and crafts, but it also talked about less productive activities, such as music, and camping, in the same breath and stated, “our children show delightful prowess in playing a variety of musical instruments” and “their joy and zest knows no bounds when taken outdoors”. Sarika ma’am and Sahil sir believed that special mula (their term of preference) deserved to have fun. At Udaan, special educators occupied intellectually disabled adults by taking them out for dinners at restaurants, fieldtrips to malls, and outstation trips. The founders of Udaan believed that these were social experiences that were vital for special mula to lead a good life. During an informal interview, Sarika ma’am said that she never went down the route of obtaining special education degrees and only ever focused on connecting with her attendees as a friend. She said in Marathi, “See, when these kids come to me they are 18-20 years old, so they are like college [in English] goers, so when we used to attend college, we were not serious [in English] all the time, someone can put up that face but that is not real. So, why can’t they have some fun? Why should they have that kind of serious life, as it is their life is serious”.

Here, Sarika ma’am framed fun as the opposite of being serious and stated that being a young adult is the time to have fun. She believed that since other young adults who go to college have fun at this stage in their life, so should her attendees. She also stressed that the life of her attendees is serious anyway, so why add to that seriousness. In this chapter, I document how fun was weaved into the fabric of Udaan as an organization. I demonstrate that by adopting a playful stance and intervening in intellectually disabled adults’ lives through activities that appeared to be fun and enjoyable, Sarika sir and Sahil ma’am broke the monotony so deeply associated with



institutions that cater to intellectually disabled people and made up a “fun” personhood for themselves and intellectually disabled people. This fun personhood made it possible for intellectually disabled people to engage with each other and their educators through jokes, travel to different places that were not just the institution and their homes, perform in front of non-disabled audiences in public spaces, and consume restaurant food and entertainment that was not easily accessible to them otherwise. At Udaan, Sarika ma’am and Sahil sir were attempting to shape a personhood that was explicitly in opposition to the productive and disciplined personhood made up in the more established institutions, such as, Rainbow Foundation and Sankalp workshop. This fun personhood was modelled after an ideal of upper-middle/middle-class college-going youth in India who enjoyed their lives by socializing, dating, and participating in pleasures, such as, traveling and eating out. The co-founders of Udaan did not dwell too much on the educational or learning aspects of the college experience. Both Sarika ma’am and Sahil sir aspired to create this form of care-free and consumption oriented upper-middle/middle class young adulthood for intellectually disabled adults. I never found out why they were so focused on creating a “college-like” experience. They may have based this understanding of personhood on their own college experience, although I never learned about Sahil sir’s college experience and Sarika ma’am attended a women’s university in Pune, making her own experiences different from the mixed gender environment she attempted to create at Udaan.

While this fun personhood and young adulthood opened various opportunities of enjoyment for intellectually disabled people which were unique and perhaps not available in any other institution that I had visited in India, this personhood was limited. For one, the fun and playful interventions made by Sahil sir and Sarika ma’am did not usually extend beyond the

programming of Udaan and often did not affect the lives of intellectually disabled people beyond Udaan. For instance, although the attendees at Udaan visited malls in the company of their special educators, educators did not and likely could not capacitate them to travel to malls on their own<sup>22</sup>. Further, Udaan, unlike Sankalp, did not have long-term funding or a consistent everyday routine, and was thus not always open and operational five days a week (something I address in depth later in the chapter). This made it an unreliable and unpredictable space for both intellectually disabled people and their families. While intellectually disabled people could not depend on Udaan to be the institutional space which they could come to everyday, families could not depend on Udaan to provide them with consistent rest, respite, or time to pursue their own occupations. Finally, because the fun personhood shaped at Udaan depended heavily on ideas of upper-middle/middle-class consumption (going to restaurants, movies, and outstation trips), Udaan was not accessible to intellectually disabled people from lower class backgrounds whose families could not afford to provide the fees and the additional expenses for these activities. The fees at Udaan varied between Rs. 3000 (USD 36) to Rs. 5000 (USD 60) per month depending on the economic condition of the families (only two attendees had families who could afford to pay the Rs. 5000 per month fee). Further, Sahil sir and Sarika ma'am made an exception for Swarup who did not pay any fee despite being a full-time attendee who also lived with them for a few days a week. This was because Swarup's mother was recently widowed and was facing financial struggles. Despite the sliding scale nature of the fees and the exceptions made by the co-founders (which are not to be minimized), the fee amount was still substantial for most families in Pune.

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<sup>22</sup> I say "did not as well as likely could not capacitate" because special educators across institutions talked to me about how the parents of their attendees were the biggest challenge that they faced when they tried to do their work of making special children independent. They shared that the parents either opposed special educators (by being too protective to let them go alone) or did not cooperate enough (by never getting on board with the goals that special educators set for their children).

Considering this, most attendees at Udaan belonged to upper-middle or middle class, upper caste Hindu backgrounds, except for two upper-middle class Muslim attendees. Further, because Udaan, unlike Sankalp, was a private institution, it was not obligated to hire staff from marginalized caste or tribe backgrounds under the Indian government's reservation schemes. Thus, even the special educators who worked at Udaan or volunteered their time there belonged to upper-caste backgrounds, much like Sarika ma'am and Sahil sir. Despite being radical and unique in some ways by rejecting values of work, discipline, and productivity, Udaan was also exclusionary and inaccessible in other ways.

Further, the issue of teasing or "making fun" came up repeatedly at Udaan. The special educators, especially Sahil sir, often made fun of the attendees, but the attendees also made fun of each other. I too was implicated in these practices, especially by Sahil sir, who would often tease me for adhering to COVID norms, such as wearing a mask during my visits to the organization. This made me uncomfortable and led to moments of tension and even confrontation. Moments of joy and teasing often co-existed, overlapped, but sometimes diverged- especially if they led to feelings of upset and hurt. By talking about practices of "making fun" and their ability to charge the atmosphere with negative or uncomfortable feelings, I want to make note of how complicated scenes of fun and laughter are, depending on who is in charge, and who get to say what, and at whose expense. I also want to make the point that no institutional space, no matter how different or unique it may appear, is perfect or without moments of conflict and tensions. However, despite these limitations and tensions (which I will attend to throughout the chapter), I focus on the affordances of prioritizing joy and fun.

I document and analyze the significance of the scenes of enjoyment and fun that I came across at Udaan by drawing on Anjaria and Anjaria's (2020) special issue on Mazaa (2020, 233), the Hindi and Urdu word for fun or pleasure. In the words of the authors,

Thinking with mazaa helps us write in new ways about how enjoyment is expressed, felt, imagined, spoken about and experimented with. Mazaa also allows us to highlight new worlds, social configurations and political possibilities that are emergent, whose outcomes we cannot yet know. At times, mazaa can challenge the status quo, but at other times, its implications remain latent, unknown or indeterminate. (Anjaria and Anjaria 2020, 234).

Referring specifically to South Asian anthropological scholarship, the authors argue (ibid 234) that scholars either take up projects that appear to have “gravity, depth, and immediate political purpose” or “mazaa is written in such a way that makes it a window onto something more serious” (Anjaria and Anjaria 2020, 234). The authors suggest that mazaa be considered on its own terms. They argue (ibid 234) that mazaa is “unwieldy, uncertain, and open ended”; things that are considered roadblocks for academic projects that emphasize “abstraction, big narratives, and extractable meaning”. However, the authors contend that it is precisely the open-ended and uncertain nature of mazaa that makes it generative of new possibilities. Finally, the authors also suggest mazaa not just as an object of study but also a methodology. They challenge the stance of the “scholar as appraiser” (Anjaria and Anjaria 2020, 237) by demonstrating how being open to passions and pleasures while doing fieldwork as well as describing ethnographic scenes with abundance can lead to unexpected and surprising findings.

In resonance with Anjaria and Anjaria's insistence on holding on to mazaa for its own sake, I write this chapter on the fun, joy, and majja (Marathi word for mazaa or fun) that circulated on a daily basis at Udaan. I also strive to document my role as an ethnographer who dipped in and out of experiencing fun and pleasure while attempting to keep up my appearances as a serious researcher and how that changed over time, as my relationships evolved, and became

more intimate. Anjaria and Anjaria (ibid 239) also make a case for dwelling on descriptions by stating that, “it holds off the scholar’s desire to sum up, reduce, and synthesize”, and can “broaden our audience.” Thus, in this chapter, I experiment with my well-rehearsed academic practices and move towards uncertain and open-ended ways of writing and analysis. I attempt to dwell on scenes of joy that I viscerally felt during my fieldwork. I background (not ignore) unequal relational dynamics and foreground moments of fun and joy; not because power and control are absent in such moments, but because the presence of fun and joy may produce affinities and intimacies (however temporary) that need to be attended to, on their own accord.

A majority of scholarship that engages with intellectual disability, especially in institutional settings, focuses on how institutions regulate and control intellectual disabled people’s bodies, social lives, work environments, and reproductive futures (Edgerton 1967; Gill 2005; Gill 2015; Wilson et.al 2011), although there is some recent anthropological scholarship that analyzes how institutional actors create conditions of pleasure for older people with dementia (Driessen 2018) and perceive intellectually disabled people as charismatic and unique actors (McKearney 2018; Zoanni 2018). Despite this, not much has been said about what happens if and when moments of enjoyment emerge within hierarchical institutions that cater to intellectually disabled people. I spend the rest of this chapter dwelling on such contexts of joy and think through what these moments may afford to both the special educators and intellectually disabled adults. Sarah Lamb in her ethnography (2022) with single women in India explores how despite facing systematic marginalization and hardships, single women, especially those with financial independence, had more fun and pleasurable experiences than their married counterparts did. In line with Lamb’s findings, I explore how despite being systematically excluded from mainstream society, intellectually disabled adults did not have to lead joyless and

“serious” lives as Sarika ma’am mentioned above, especially when non-disabled people in positions of authority intervened by imagining and creating fun environments and activities for them.

### **The Joy of Unstructured Spaces and Unregulated Time**

As mentioned in earlier chapters, I knew Sarika ma’am as the principal of the vocational school at Rainbow Foundation where I conducted my preliminary fieldwork in Summer 2019. She had been working there as a special educator for around 15 years. Sarika ma’am was friendly, enthusiastic, and open to conversations on sensitive topics, such as sexuality, marriage, and romance. She was an upper-caste (Brahmin), upper-middle class Maharashtrian woman in her 40s. She was also unmarried, which was unusual among special educators her age in Pune. In her words, she came to the field of special education by way of a, “lucky chance” in 1998. She had finished a bachelor’s degree in Home Science and a post graduate diploma in the field of Sports and Nutrition from a reputed, public, women’s university called SNDT University at Pune. She worked for a few years in hospitals and gyms as a dietician before getting bored and quitting to join a 6-month long bakery course, which was taught in the same premises as Rainbow Foundation. Once she was done with the bakery course, she was summoned by the founder of Rainbow Foundation, Mrs. Nene, a special educator who Sarika ma’am came to respect a lot over time (she had passed away by the time I came to do my fieldwork). Mrs. Nene offered her a job as a special educator at the recently opened vocational center at the Rainbow Foundation which offered classes in baking and cooking to intellectually disabled people over 18 years of age. While Sarika ma’am had no prior experience in teaching and she also had no exposure to intellectually disabled people, she decided to take the job. According to Sarika ma’am, at Rainbow Foundation, she was provided with on-the-job training lessons by her senior

colleagues who taught her concepts, such as, Intelligence Quotient (IQ) and various disability categories, such as, Down syndrome and autism; things she was not familiar with until then<sup>23</sup>. But she said that she learned how to interact with her students through experience. She also added that since when she started her journey, she was of a similar age as most people she taught, she developed a friendly and informal disposition as a teacher.

I observed that Sarika ma'am's approach to intellectually disabled adults appeared to be different from her colleagues at Rainbow Foundation. For instance, she was not a disciplinarian and often attempted to resolve conflicts among the attendees through friendly conversations instead of reprimanding them. Sahil sir joined Rainbow Foundation in 2017 as the music teacher. He had moved to Pune from Mumbai and belonged to a relatively privileged Gujarati family. Sahil sir told me that he had no exposure to intellectually disabled people before joining Rainbow Foundation. He had come to this job only as a music teacher with very little understanding of who he would be teaching. Soon after he joined Rainbow Foundation, Sarika ma'am and Sahil sir struck up a friendship. Both of them agreed that although their attendees were not particularly interested in learning math or English during their functional academics classes, they enjoyed playing instruments and performing musical and dance numbers during events and festivals organized by the institution.

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<sup>23</sup> Although I asked Sarika ma'am to elaborate on what she learned during these training sessions, she did not have any further details to share. However, I too underwent a week-long training course with special educators at Rainbow Foundation during my fieldwork in 2019. While the educators told me that they had updated this course several times, they had been teaching versions of this course to their incoming educators for the past 20 years. I was taught about different causes of intellectual disabilities, disability categories (learning disabilities, mental retardation, slow learners, autism), and teaching methodologies for different groups of students (multi-sensory approach to reading and writing, constant reaffirmation, reading aloud, helping children when they read, and using flashcards). They also gave me psychology lessons on different aspects of human personality and behavior. The special educators always referred to their own experiences teaching at Rainbow Foundation while they taught me and discussed topics such as, the ideal traits required of special educators, strengths and weaknesses of their students, and how urban parents refuse to cooperate with educators.

Sarika ma'am and Sahil sir wanted to create a platform wherein they could encourage these extra-curricular interests of their attendees. With this in mind, they started organizing an after-school music club which they called the "Fun Club". At the Fun Club, current as well as former attendees of Rainbow Foundation, who had aged out of the institution when they turned 25 years old, came together over activities such as music classes, salsa dancing, going for hikes, movies, and overnight trips. Sarika ma'am and Sahil sir had envisioned the Fun Club as a space where young adult men and women could mingle together more freely than they were able to at Rainbow Foundation, which they thought was a regulated and stifling environment, wherein adults wore uniforms, could not socialize freely with people of the opposite sex, and attended repetitive and regulated classroom sessions typical of schools meant for children (they shared these insights with me during my fieldwork at Udaan in 2021).

Thus, even during their tenure at the Rainbow Foundation, Sarika ma'am and Sahil sir shared a vision for intellectually disabled people, wherein they could participate in so-called enjoyable activities, such as music, dance, or even watching television. Unfortunately, I hesitated to attend the Fun Club while doing my preliminary fieldwork at Rainbow Foundation because I was worried about upsetting the higher administrators, especially the director, who surveilled my actions and did not appear to be too enthusiastic about my presence. I also never had the opportunity to meet Sahil sir during my time with Rainbow Foundation.

When I contacted Sarika ma'am from the United States in early 2021 while planning my dissertation fieldwork, I was surprised to find out that she had left Rainbow Foundation in 2019 and co-founded her own organization named Udaan with Sahil sir. Udaan was a continuation and expansion of the Fun Club and was a non-governmental vocational and arts center for intellectually disabled adults. Sarika ma'am and Sahil sir were also married now and did not



have any children. Udaan started with a focus on music and percussion instrument training for intellectually disabled adults, but quickly expanded to other activities, such as salsa dancing, visits to movies, restaurants, and malls, and camping trips, as they had also previously done. Soon after, Udaan also took up production activities, such as making and selling homemade soaps, diyas, bakery products, and gift-packages during Hindu festivals such as Diwali and Ganesh puja. In early 2020, Udaan collaborated with an outdoor gym, and started Sunday gym classes for their attendees. When I started my fieldwork in September 2021, Udaan was not yet registered as a charitable trust under the Indian Trust Act, of 1882 and did not have a stable source of funding; it depended on Sahil sir and Sarika ma'am's respective family and life savings as well as contributions from donors and involved parents with means for funding<sup>24</sup>.

I first visited Udaan on September 23, 2021. Unlike Rainbow Foundation, Sarika ma'am and Sahil sir's previous workplace, which was based in an official institutional building, Udaan was based in Sarika ma'am's and Sahil sir's rented apartment. Udaan was located in an upscale neighborhood in Pune. The street leading up to their apartment had large tree coverings and was tucked away from the noises and bustle of a major highway. It did not have classrooms, staffrooms, or separate sections for different vocational activities such as baking, sewing, binding, and so on. On my first visit to Udaan, I noticed that there were just three attendees present- Janani, Swarup, and Geeta. All three were Sarika Ma'am's former students from Rainbow Foundation. Aside from Sarika ma'am and Sahil sir, Sonali ma'am was the only other regular special educator (Udaan also had a few volunteers who offered their services intermittently for no money). Sonali ma'am was the vocational teacher in charge of arts and

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<sup>24</sup> By the end of my fieldwork period in September 2022, Udaan was registered as a charitable trust. The organization had also established a relationship with a wealthy Gujarati businessman who was willing to make a sizeable donation to them. However, I was unable to follow up and find out whether they had found a stable source of funding.

crafts and visited Udaan every Wednesday and Thursday. She was also a former special educator at Rainbow Foundation and decided to join Sarika ma'am at Udaan when she was offered the job. Udaan did not have a fixed number of attendees at the moment. Janani and Swarup were helping the couple clean the house. Geeta, on the other hand, was walking around the house, not making any noticeable contributions to the ongoing work. Soon after, she was bathed by Jyoti, a domestic worker who worked for both the organization and Sarika ma'am and Sahil sir's household. We discussed my life in Chicago, Udaan's plans and agenda, ate lunch together, and watched a recording of the organization's Independence Day celebrations. While Sonali ma'am was doing organizational work in one of the rooms, the mood was relaxed and a little chaotic. There was no fixed beginning or end to the day, no fixed lunch times, and no regular vocational training sessions or activities. I left confused and crestfallen- Would I get to observe a routine? Was every day going to be as uncertain and wayward as today, or was today an exception? Would I be able to do any "real fieldwork" here?

As I started visiting Udaan regularly, I realized that my first day was not an exception. Every day looked different here. Some days were slow, while some (especially those leading up to events or festivals) were abuzz with energy and excitement. Over time, I got used to the rhythm at Udaan, or lack thereof, and leaned into its nature as an unstructured and creatively charged space. While Swarup and Geeta were permanent attendees, others came and went. Many more attendees attended the Sunday physical exercise class, which was held in an open-air gym near Sarika ma'am and Sahil sir's apartment. The volume of attendees, employees, and activities increased around events or festivals. For instance, through my connections in the United States, Udaan participated in a cultural exchange program with a special school based in New York City. The attendees at Udaan performed various Indian beats on Djembe drums under Sahil sir's

guidance. For weeks leading up to the performance, many more attendees started pouring in and practicing hard with Sahil sir. The other phenomenon that took Udaan by storm was Diwali. Starting October, there was a flurry of activity around preparing snacks, gift-bags, and painting diyas. Attendees I had never seen before worked all day long, and Sarika ma'am hired two temporary employees in the kitchen to help with the bulk snack preparations. Sahil sir would regularly drive to Mumbai and take Swarup along for company to take meetings with corporate offices where he would make sales pitches, convincing them to buy Udaan's products as Diwali gifts for company employees. The atmosphere was charged with excitement, and it was impossible for me to not join in as well. At some point, I stopped worrying about what I was "getting" out of my fieldwork experience, and just started enjoying my time at Udaan.

In hindsight, the seemingly messy and unorganized ways of Udaan allowed me to participate in ways that was not possible in my other field-sites. For instance, after spending three months at Udaan, I conducted a three-month long stint at Sankalp, the government-aided workshop in Pune that I focused on in the previous chapter. Since Udaan was a young organization, with only one permanent employee, there was always more work to be done and help was always more than welcome. From managing their social media accounts, painting almost a hundred diyas over a weekend, to writing emails and brochures in English, and serving food to the attendees- I had done it all. I even recruited a friend of mine to assist with technology for their zoom-based virtual Djembe performance for the special school based in New York and my mom to manage the cash register during a Diwali exhibition where Sarika ma'am was selling the products made at Udaan. The ad-hoc nature of Udaan made for an excellent platform for my quick absorption into the organization. In contrast, at Sankalp, there was very little work for me to do. The daily routine and division of labor was already set in stone. I would awkwardly sit in

the corner of classrooms and workshops taking notes. Besides, even if there was work to be done, special educators hesitated to delegate to me, as they feared that the supervisor of the workshop would scold them later for making the “guest madam” do their work. Thus, my position at Sankalp led me, at least initially, to adopt the stance of the “scholar-as-appraiser” (Anjaria and Anjaria 2020, 237). However, given the all-hands-on-deck situation at Udaan, I never even had the time to watch from a distance- I was in the thick of it, as the English-speaking friend and researcher, who was always around. I felt excited to go to fieldwork, as though I was in some way contributing my small share to this yet-to-be-actualized project. The affinities that I as the ethnographer built at Udaan allowed me to feel both the pleasures and pains, in a much more visceral manner, than I felt at my other field-sites.

The unstructured nature of Udaan was not necessarily an intentional choice made by the founders. Sarika ma’am and Sahil sir routinely complained to me about their lack of funding as well as a lack of parental involvement and motivation. They had issues with parents not regularly sending their children to the center and not paying the fees and other expenses on time (or at all). However, even while sharing their financial woes and hoping for a more stable source of funding, the co-founders never made claims about changing their fundamental commitment to fun and becoming more work oriented. During the end of my fieldwork period, Sahil sir shared with me that he had spent his life savings on Udaan. He told me that he made extra money on the side by teaching music to older Gujarati people (he belongs to the Gujarati community), just so the attendees could go to restaurants twice a month. Talking specifically about Geeta, a 35-year-old woman attendee who I mentioned in the opening vignette of the introduction of the dissertation and who has been with Udaan from its very beginning, he said in a mix of Hindi and English, “Geeta needs to go to hotel...needs noodles. She is a foodie. Last week, we went to

Rahul hotel. We got rice. She got so annoyed! She wants noodles, broccoli soup, paneer chilli. We can't say no to her. We need funds”.

Although I am unsure about whether Geeta truly “needed” restaurant food and whether the organization truly did not have enough funds to provide her with this food, I want to stress that in the above quote, Sahil sir framed restaurant food as a need, instead of a luxury. Instead of approaching fun as something Udaan did on the side or in addition to their main vocational activities, Sahil sir here stated that the organization needed funds, so that they could continue intervening by creating pleasurable experiences for Geeta and other attendees in a more sustainable manner. Despite the stated financial instability, Sarika ma'am and Sahil sir's commitment to creating a fun environment for intellectually disabled adults, which they maintained by drawing on their familial wealth, life savings, and a few donors, kept Udaan operational as an ephemeral and event-oriented space. Considering its seasonal and unpredictable nature, Udaan, unlike the other institutions I observed, could not become a dependable, everyday institutional space for its attendees. However, it could provide excitement and novel experiences in a way that other institutions could not.

In the rest of the chapter, I aim to demonstrate how precisely because of its precarious and unstable nature, Udaan sustained itself as a space that offered intellectually disabled adults something unique- a space to be occupied in fun and pleasurable activities. Attendees watched television while having lunch and sat on beanbags to just “hung-out”. They joked around (fart-jokes and teasing each other about “girlfriends” were common joke categories). This is significant because in most institutional spaces that I observed during my fieldwork that were registered as trusts or had funding from governmental or non-governmental sources, the routine, behaviors, and expressions of intellectually disabled people were usually more supervised and

regulated. Special educators would often admonish their attendees for laughing too loud, for wearing western clothes, and for cozying up with people of the opposite sex.

At Udaan, intellectually disabled adults could freely laugh (most of the time- there were exceptions), wear jeans and tops (not just Indian clothes) and hang out in mixed gender groups. I wondered were Udaan was a more structured and regulated space, would the organization lose many of these qualities. Moments of spontaneity and fun emerged both because of Sarika ma'am and Sahil sir's explicit interest in "fun" as a category of experience for their attendees but also because of a lack of institutional accountability and norms. Considering that Udaan did not have trustees when I was doing my fieldwork, Sarika ma'am and Sahil sir were much freer agents than the other special educators I encountered during my fieldwork. Unlike my other interlocutors, they did not have to report to administrators, trustees, more organized parent groups, and senior colleagues. Given this, they were able to create a fun, young adult, consumption oriented, personhood for intellectually disabled adults who attended Udaan—who were apparently people who needed noodles. I next move to the ethnographic sections of the chapter by first examining everyday joys at Udaan.

### **Everyday Joys**

Everyday activities at Udaan, such as feeding attendees, doing production activities, and physical exercises, had an undercurrent of fun, which was largely shaped by the playful interventions made by Sahil sir and Sarika ma'am. The physical space echoed and enabled feelings of joy as well. While Udaan was home-based, Sahil sir worked hard to make the space as unique as possible. He placed real plants and artificial bamboo shoots and trees all around the apartment. He wanted Udaan to have a "Jurassic Park theme". By the end of my year of fieldwork in August 2022, he had implemented his vision, with plush monkeys, elephants, and giraffes hanging by

leafy creepers, soft lamps with bright pink flamingos painted on them, and framed photos of colorful birds on the walls.



Image description: A wall adorned with picture frames of flamingos and decorated with fake leafy creepers and plush toys hanging from them.

Even though the schedule changed from one day to another depending on the festival season and whether there was an upcoming Djembe performance to prepare for, Sarika ma'am and Sahil sir always made time to watch television, share their favorite food with the attendees, and chitchat with each other, the attendees, and me. If there was not too much work, Sahil sir and Sarika ma'am would just take a day off, ask the attendees not to come, and go for a hike or a movie with Geeta and Swarup- the two permanent attendees who often lived with them. While these last-minute changes to everyday schedule were probably disruptive to attendees who lived with their families as well as their families, they made possible moments of rest, respite, and pleasure for the co-founders and a select few attendees, such as, Geeta and Swarup, who lived with them.

Even the Sunday gym activities, oriented towards physical fitness, were filled with playful moments. Attendees were made to follow a routine of stretching, warming up, doing yoga poses, running, doing drills, and playing with balls, before winding down and meditating. However, nothing about this routine was joyless. Sahil sir would often come late to the gym (much to my righteous indignation), but his presence would always bring a smile to the faces of his attendees and co-workers. He would do “antics” such as throwing the ball at people’s butts instead of letting them catch it in their hands. As horrified as I was when I first saw this, Sarika ma’am and Sahil sir were pushing boundaries of appropriateness and creating new possibilities with their actions. One a rainy Sunday, instead of doing the usual routine, Sarika ma’am decided to change it up and made the attendees dance to a beloved Bollywood song Tak jhum jhum made famous also through the images of Shahrukh Khan and Madhuri Dixit (popular Hindi movie stars) dancing in the rain with children in the background. Every Sunday, once the attendees finished their physical exercises, Sarika ma’am and Sahil sir organized a lunch for everyone. The food was purchased from a relatively inexpensive Indian fast-food restaurant located right next to the gym. While some of the attendees would do the work of serving the food, and cleaning up the dishes, making the attendees work was not the focus here. The purpose of the activity was for everyone to take pleasure in eating delicious food together. I was amazed at the variety and the taste of food (sabudana khichadi, idli/sambar, vadapav- you name it) and would eagerly look forward to it.

Unlike many of the other special educators, who often told me that, one has to treat “special” people with both love and discipline, at Udaan, the atmosphere was usually playful and unserious. Sarika ma’am, connected with her attendees by using her knowledge (based on years of experience gained teaching most of them at Rainbow Foundation) of their personal tastes and



social backgrounds. Instead of scolding Geeta for not finishing her food, Sarika ma'am would jokingly talk about how much of a foodie she was and her love for pasta and noodles with the rest of us, while coaxing her lovingly to finish the food on her plate. Instead of scolding attendees for not coming to Udaan on a regular basis, Sarika ma'am would entice them with a pleasurable activity. For instance, she tried convincing Nusrat to come to the center by saying that if she comes to paint diyas, they can watch her favorite television show together. She would jokingly ask Nusrat to bring festive food from home during Eid, since Nusrat was Muslim. Since she knew that Vaibhav's father owned a renowned bakery in Pune, she would often teasingly complain about how he never got any cakes or pastries to the center. In playfully referring to her attendees' likes and dislikes and their social connections outside Udaan, Sarika ma'am recognized intellectually disabled adults as persons with preferences and a social history. While many special educators I interacted with recognized intellectually disabled people as people by talking about their personality quirks, likes/dislikes, strengths and weaknesses, they would also usually refer to these qualities while talking to each other or to me. Sarika ma'am directly built a playful rapport with them in conversation. In being playful, she would put people at ease, and build temporary intimacies with them. For instance, Geeta would sometimes smile, sometimes facepalm, when Sarika ma'am called out her food preferences. Nusrat shyly smiled and said, "I will bring phirni (a rice and milk based traditionally Muslim dessert) next Eid, ma'am", and Vaibhav smiled and looked away before saying, "I always bring food from the bakery!" Thus, Sarika ma'am often engaged with intellectually disabled adults by using jokes and humor and in the process made them up as fun persons who could participate (unequally) in joyful conversations.

Daily conversations were laden with positive affect or humor. On a busy day leading up to Diwali, Sarika ma'am, Sonali ma'am, a few attendees, and I were sitting in a circle on the floor painting diyas at break-neck speed, when Samarth, one of the attendees, gave an audible burp. The other attendees started laughing. Sarika ma'am laughed along with them and jokingly said to Samarth that he should skip lunch today. On another occasion, Ajinkya's (an attendee) mother, Swati, a media professional, had organized for her employees to shoot a promotional video for the products the staff and attendees at Udaan made for sale during Diwali. During the shoot, the atmosphere was chaotic, and attendees were not complying with the instructions provided by the professionals (who did not seem familiar with intellectually disabled people). As the shoot ended at around eleven at night, the videographers wanted to take a photograph of all the attendees together. This seemed like an impossible task; everyone looked distracted and tired. Instead of just asking everyone to look at the camera, Sarika ma'am spontaneously started dancing and laughing to encourage attendees to smile for the photo. In both cases, Sarika ma'am demonstrated an ability to be playful- a quality that defined my time at Udaan.

Further, unlike the more structured field-sites I visited, there were more instances at Udaan, wherein intellectually disabled adults were left alone in groups, or with me, in the absence of any staff member. Especially during Diwali season, when all the staff members were busy making products for sale, there were times when attendees sat in circles, painting diyas, without any supervisor telling them what to do. I would often accompany attendees during these times, and while my presence was different from that of a "friend", I did not occupy the same position of authority in their lives as the special educators. During such times, those who used conventional language spoke to each other about things, such as what they ate for lunch, cracked fart-jokes, or asked each other to pass something to them or come closer. Those that did not use

verbal language either sat without explicitly participating in any way or expressed themselves through nods, smiles, and frowns. Being in the company of your peers without adult supervision is rare for intellectually disabled adults in India and a significant and ordinary source of joy for non-disabled adults. While I cannot comment on whether intellectually disabled adults at Udaan enjoyed this partially “alone-time” (partial due to my presence), in leaving their attendees alone, the staff at Udaan acknowledged their attendees as adults who did not always need supervision.

Sarika ma’am and Sahil sir also enjoyed and encouraged the quirks of their attendees. One such example is of Swarup, who was 31 years old and loved speaking in a Bihari accent (an accent from the state of Bihar, a north Indian state). He would rarely talk in a conventional manner, but often expressed himself by uttering a few phrases in a Bihari accent. Everyone would laugh when he spoke in this manner, and Sahil sir would respond to him in a Bihari accent. Sarika ma’am also told me that since Swarup loved Muslim people, she and Sahil sir would take him to Crawford Market (a Muslim dominated commercial and shopping district), when they visited Mumbai. There, he interacted with Muslim people, and they even purchased a traditional Muslim cap for him. Sarika ma’am referred to this as “good socialization” in English. By engaging with Swarup in a Bihari accent and intervening by helping him dress up in a Muslim garb, Sarika ma’am and Sahil sir actualized(what they interpreted as) Swarup’s desires and fantasies, albeit in a temporary manner. Thus, by occupying intellectually disabled people playfully through humor, jokes, and mimicry, in fun activities such as impromptu dance sessions, and eating delicious and fried food after physical exercise classes, Sarika ma’am and Sahil sir built a “new world” along with intellectually disabled adults (Anjaria and Anjaria 2020, 234). In this world, fun and enjoyment, instead of routine, discipline, and productivity, were the building blocks. Here, intellectually disabled adults were made up as fun people who could joke, have

desires, and indulge in fantasies, However, this personhood was temporary as it did not extend beyond Udaan, unpredictable and unreliable (given Udaan's on-and-off nature), and exclusionary because of its consumption-oriented nature.

### **Expanding Worlds**

While I am committed to talking about fun for the sake of fun, it is difficult for me to ignore the ways in which I saw fun's presence shape the lives of intellectually disabled adults at Udaan.

One such person was Geeta. Geeta's journey best demonstrates how fun, pleasure, and enjoyment are not just experiences that one has "on-the-side" or in "addition" to the important life experiences, but rather are the very experiences that make life worth living. As mentioned earlier, Geeta had been associated with Sarika ma'am since her days at Rainbow Foundation. Sarika ma'am recounted Geeta's story as one of degeneration. According to her, when Geeta was younger, she would dance, sing, and express herself freely. However, over the last couple of years, as her hearing deteriorated, she slowly became non-verbal. When I met her, she often refused to perform the tasks that she was asked to do and appeared to be in a bad mood most of the time. However, being non-productive never made her less valuable to Sarika ma'am and Sahil sir. Instead, they were closer to Geeta than their other attendees because she (along with a couple of other attendees) would stay over at their apartment for a few days every week. As Geeta's parents grew older, they became anxious about her future. They considered Sarika ma'am to be the best person to care for her once they were older and less capable of doing carework. However, instead of changing Geeta's life suddenly and permanently, they decided to make the transition slow and steady, with Geeta staying over at Udaan for a few days a week, and a few days with her parents.

Geeta's care needs were high, and she did not work much, unlike the other attendees. Not only that, but she also refused to perform small tasks (for herself and others) and often showed visible signs of anger and irritation. While I witnessed Sarika ma'am and Sahil sir scolding her, getting frustrated with her, and parents of other attendees labelling her as "attention-seeking", Geeta was the most stable and often most valuable presence at Udaan. In fact, she was the favorite. It was Sarika ma'am and Sahil sir's orientation towards fun and pleasure (instead of productivity) that made it possible for them to value Geeta on her own terms. While they nagged Geeta to participate in productive activities such as painting diyas, putting the Diwali kits together, and playing Djembe, she almost never seemed interested or able to participate on the same terms as others. She would often sit next to others as they continued doing their work, sometimes smiling, sometimes frowning. Instead of admonishing her for her refusal to be the same as others, Geeta was valued for being different. They achieved this by intervening in her life by creating moments of levity and organizing activities of enjoyment.

Geeta had a nickname, jaadi (fatty). While she was often teased using this name (by Sahil sir in particular), it was used as a term of endearment, which came from a sense of familiarity (something I will come back to later- the differences and overlap between having fun and making fun). A typical day at Udaan included Geeta sitting on a beanbag (a literal position of distinction) and watching television for hours, while everyone else sat on the floor, either working on some vocational activity, eating lunch, or also watching television. According to Sahil sir and Sarika ma'am, since Geeta enjoyed eating delicious food, they started a ritual of going out to the movies and then taking her out to eat pav-bhaji (an Indian street food delicacy made with vegetables and eaten with bread) at a restaurant. They shared a story with me of how they once visited a restaurant they frequented often with Geeta without her and their waiter

inquired about Geeta, referring to her as their daughter. Hearing this made them feel very happy and they shared that indeed, they saw Geeta as their own child. Thus, Geeta was valued above and beyond the other attendees, as kin. Even though Sarika ma'am and Sahil sir did not (and possibly could not) teach her how to play the Djembe and paint diyas, or motivate her to participate in games and sports, they made interventions in her life through the activities they thought she found enjoyable. As Sarika ma'am put it, "Geeta doesn't need money so we don't pay Geeta in cash, we take her out to hotels, because she loves that. Whenever we go to Matheran she takes a horse ride, we buy her a T-shirt. That is her way of enjoyment."

While it is presumptuous to state that Geeta did not need money, I present this quote to illustrate how Sarika ma'am connected with Geeta through (what she interpreted) as Geeta's interests and desires. Instead of forcing Geeta to do things she did not want to do, at Udaan, she could not only simply exist, but could also do things that according to Sarika ma'am and Sahil sir, she enjoyed. In providing opportunities for Geeta to indulge (a rarity for intellectually disabled people), Sahil sir and Sarika ma'am expanded Geeta's world- one TV show, one T-shirt, one restaurant meal, one horse-ride at a time.

### **Exposure to the Outside World**

Aside from spending time at the rented apartment doing production activities (and hanging out) and the Sunday gym classes, Udaan also focused on providing intellectually disabled people with opportunities to interact with the so called "outside world". When Sarika ma'am and Sahil sir realized that their attendees at Rainbow Foundation were interested in and good at music, they came up with the idea of having them do public performances. In Sarika's words in Marathi with a few words in English,

Can we take this forward, can we put on a show and as a by-product, can it be a source of income for them? This was the idea behind it. Then we thought through this they would

be able to form their own circle...they will have their own community and there they will feel free in that space. Then we thought, can they go out and have some fun, can they see the world? So, we started having camps.

Providing a platform for intellectually disabled adults to go out into the world to have pleasurable experiences was central to the inception of Udaan. While income was seen as a “by-product”, it was not the driving force behind the organization. By 2018, attendees at the Fun Club (many of whom transitioned to Udaan) gave their first Djembe performance through the Rotary Club. By now, they have performed 15 times, not just in Pune, but also in Mumbai (the financial capital of India), Mahabaleshwar, and Matheran- two important tourist locations in the state of Maharashtra. Sarika ma'am and Sahil sir considered these as big achievements, not just because their attendees performed for large audiences, but because leaving their home base helped them build their confidence and ability to adjust in different environments. Recounting one such instance of performing in Mahabaleshwar, Sarika ma'am said, “that was a unique experience for the children. Many people used to come up to them and talk to them. This was not just a performance. They gained confidence. The children used to tell them about themselves, about the organization. They were also looking after each other”.

Thus, Udaan was invested in not only building self-confidence of intellectually disabled adults, but also in them building relationships with each other and the “normal” world. Phadke (2020) and Kirmani (2020) analyze how women in urban centers in India and Pakistan respectively navigate highly masculine public spaces by engaging in fun activities, such as loitering, going for picnics, and taking selfies. Both authors argue that the feminist movement should seriously attend to these moments of fun and enjoyment and understand them as creating new and transformative possibilities for women within strictly patriarchal societies. In resonance with these authors, I propose that travelling to new places, seeing different sights, eating in

restaurants, living away from home, and interacting with strangers and each other in varied contexts could be viewed as transformative experiences for intellectually disabled adults whose everyday travels were usually restricted to the route from their homes to the vocational center and back. Considering that most institutions that cater to intellectually disabled often sequester and isolate them and keep them away from mainstream society (Gill 2005), Udaan's focus on exposing intellectually disabled adults to new people and experiences was unique and radical.

I want to end this section with a description of Udaan's trip to Mahabaleshwar in April 2022 as it demonstrates the transformative potential that travelling may have for intellectually disabled adults in India. In collaboration with the Rotary Club, Udaan had set up a stall selling its products near Venna Lake, Mahabaleshwar's famous tourist location. In the evening, the attendees, along with Sahil sir, formed a semi-circle in an open area near the lake and gave the tourists a Djembe performance. A donation box was set up in front of the performers. Swati, Ajnikya's mother (the parent volunteer/ally at Udaan) punctuated the performance by talking about the organization, its activities, and entreating people to donate. As the ethnographer-friend, I flitted between the stall where I interfaced with customers, sold the products, collected cash, and the performance, where I took videos and photographs, which were to be used for Udaan's sparse but growing social media presence on Facebook and Instagram. After the performance, attendees, educators, and a few Gujarati elders from the Rotary Club whose connections aided the set-up of the stall and performance, ambled around near the lake eating corn-bhel (a street food consisting of corn and other vegetables mixed with lemon and spices) and drinking lemon tea as the sun set. I had brought my parents along with me for the trip. They sat around with the attendees. Rahul, a young male attendee, engaged them in conversation and talked about how he helps his father out with their printing business. After hanging out for a while, we headed to the



hired bus, which took us all back to the guesthouse where the Udaan folks were living for the night (I was staying separately in a hotel with my parents, a few miles away). As soon as we got into the very crowded bus, Sahil looked at everyone and loudly asked, “Who wants strawberry ice-cream? Masala pan? Maggi party?”, His questions were met with loud cheers and clapping from everyone, including my family, the educators, and me.

Once we reached our destination, the attendees were assisted (by newly recruited assistant teachers) to their living quarters, where they cleaned up and changed into pajamas. Men and women slept in separate rooms, but everyone socialized together in outdoor spaces. While the attendees freshened up, Sarika ma’am, Rohini (a female assistant teacher), Swati, and Swarup got to work making a giant pot of Maggi (a type of instant noodles). Until the food arrived, intellectually disabled adults just relaxed outdoors with very little interaction with their teachers or the parents present. Even I decided not to make any field notes and just enjoyed the fresh, cold air- a rarity in Maharashtra. Some attendees sat together on a swing just hanging out or star gazing, while others walked around in the guesthouse estate in little groups or by themselves. Rahul, the only attendee with his own phone, sat away from others scrolling through his phone. After our dinner, Sahil sir dropped my parents and me off at our hotel in their car. Since there was space in the car, he took Rahul and Hussain along for the ride. Even though my parents and I could not fully understand Hussain’s speech, he kept talking during the whole ride.

The trip to Mahabaleshwar left a lasting impression on me, as this was the first time, I had ever seen people with intellectual disabilities outside their immediate familial or institutional settings, just “hanging out”. I acknowledge that Sahil sir and Sarika ma’am often dictated the larger terms of the ways in which intellectually disabled people interacted with the outside world and with each other. For instance, the attendees at Udaan were introduced as special children

during the concert (a problematic and patronizing terms for adults). Furthermore, men and women had to sleep in separate rooms at night. Significantly, this trip cost money and thus was only accessible to attendees who belonged to relatively well-off families. However, these limitations did not take away from the fact that Udaan made it possible for (a select few) intellectually disabled people to be in the outside world not for the purpose of work, but simply to have fun.

### **Having Fun/Making Fun**

In the last section, I want to address the culture of making fun or teasing at Udaan. During fieldwork, I had ambivalent, and even, negative, feelings about this aspect of “fun”. Many of the attendees had nicknames. Geeta was called jaadi (fatty), Swarup was called boodha (old), and Prathamesh was called baburao, the name of a beloved Bollywood comedic character who, much like Prathamesh, wore glasses with a high prescription. While everyone that used speech to communicate used these nicknames (which to begin with was a small number of people), the main driver/instigator of the nicknames was Sahil sir. Initially, I was taken aback by the nicknames and found them to be demeaning. I wondered what the attendees felt about these practices. Beyond nicknames, Sahil sir also loved teasing the attendees about their alleged romantic interests. For instance, Geeta and Swarup were labelled as husband-and-wife, and Sahil sir and Sarika ma’am would often teasingly ask them, “where is your wife?” or “what is your husband doing?” Prathamesh was teased about a woman whose last name was Shinde. Sahil sir often asked him about her whereabouts and whether she calls him. Prathamesh would alternate between looking coy and upset at this teasing. When I asked Sahil sir who Shinde was, he told me that full her name was Vaishali Shinde and that she was an attendee at Rainbow Foundation, who had once danced with Prathamesh on stage during a social gathering.

While teasing was a mode of conversation adopted by Sarika ma'am and Sonali ma'am as well, Sahil sir was the one most invested in this style of humor. He was introduced to me as a joker and a mazzakiya (humorous in Hindi) person by all the teachers and parents of attendees. Sarika ma'am often credited him for the fun environment at Udaan. However, I noticed and experienced a tension where the boundaries between having fun and making fun were blurred. I do not argue that having fun and making fun are different activities- in fact I see them as overlapping but not quite the same. This caused friction, because not all jokes and pranks always landed, especially those cracked at the cost of people's physical appearance, age, and so on. The teasing targeted not just intellectually disabled adults. Sahil sir would also goad Swati, Ajinkya's mother and Udaan's media resource person, into fights on several occasions. The fights would eventually be dismissed as "Tom and Jerry" fights (which I assume means unserious or fun filled fighting) but simmering beneath the teasing were real differences, which the co-founders often shared with me when they told me that Swati did not dedicate enough time to the organization.

I too became a regular target of Sahil sir's jokes because of my anxieties around doing my fieldwork during COVID-19 and adhering to certain safety protocols, such as wearing my mask when I was at Udaan. On my first day at Udaan, I discovered that Sahil sir had chosen not to get vaccinated against COVID-19. Knowing this escalated my anxieties. I would always wear my mask at the field-site and would nudge him to wear his and try to talk him into getting his vaccine. He would always make fun of me and say I was too scared because I came from the United States. There was an instance when he came into the living room wearing four masks and everyone (except me) burst out laughing. On another occasion, he wore a whole PPE kit and came up to me to ask if that made me feel better. I could not see the humor in any of his antics. If anything, I became angrier as he pushed my buttons. Our dynamic regarding his jokes around my

COVID practices came to quite a dramatic climax one day in late October of 2021. Just as I was leaving for home after a day of fieldwork that consisted of observing and participating in a soap-making workshop conducted by expert resource persons, Sahil sir's PPE kit (the one he never used) fell from the sofa and made a loud noise startling everyone. Sonali ma'am asked Sahil sir what it was, and Sahil sir said that it is for Shruti. Then he said something in Gujarati to Sonali ma'am (a fellow Gujarati) and laughed. I could not fully grasp it, but I understood it as something along the lines of, "She is so scared, she is the one who will get it (COVID)." I was livid and confronted him saying, "If you have something to say to me, say it in Hindi." He did not reply at all and busied himself taking photographs of the organizers of the soap-making workshop. Sonali ma'am looked at me apologetically and consoled me saying she will explain to me what he said. However, I was too upset to listen to anything, and left in a huff.

While I felt humiliated, this did not end my time at Udaan, or even mark it in a remarkable way. I went right back to the field the next day and continued being treated well by everyone (including Sahil sir). As confusing as it felt to be back as though nothing had happened, I counted my blessings, because I knew from experience and conversations with other ethnographers that fights and confrontations with interlocutors do not have easy resolutions. As I continued spending time at Udaan, I noticed that even though Sahil sir dished out most of the teasing, there was space for others to give it back to him. For instance, after a day of physical exercise one Sunday, Anju, an attendee, managed to tie her shoes successfully. Sarika ma'am praised her and jokingly pointed at Sahil sir and said in Marathi, "Now you can teach sir how to do it, he still cannot!" Sahil sir did not look upset at being the butt of the joke and took it graciously by smiling. Further, Sahil sir could also make fun of himself. An instance of this which brings my COVID-19 confrontation anecdote to a full circle, is when Sahil sir approached

me on a Sunday morning in February 2022 in an excited manner and let me know that he finally got his COVID vaccine, all because of me. He said that I finally convinced him and gave me a friendly high-five. I took this gesture on Sahil sir's end to be a form of acknowledgment and resolution of the months of simmering tension between us around the COVID pandemic.

Moreover, intellectually disabled adults also had the opportunity to express their hurt at being taunted, without fearing any repercussions. Despite Geeta not being able to talk, I observed her face- palming and shrugging whenever Sahil sir called her jaadi (fat). I vividly remember an instance during peak Diwali preparation season, when Prathamesh was working on putting together Diwali kits in the make-shift crafts room, when we heard his nickname baburao being shouted from outside. Sahil sir came inside and said to Prathamesh that it was Swarup's doing. Prathamesh was convinced that it was Sahil sir. Prathamesh went back to work when Sahil sir (this time I saw it) shouted baburao again, and just pointed to Swarup accusingly. Prathamesh looked visibly upset and said to Sahil sir in Marathi, "You have spoiled Swarup." Although Sahil sir did not pay much attention to his statement and left the room to continue with his day, it took me by surprise. It demonstrated to me how Prathamesh understood the name-calling as something deeper- as a stance of favoritism towards Swarup shown by Sahil sir. Moreover, it was also an example of how Prathamesh could articulate his hurt without fear of punishment. This is significant because, people in positions of authority often expected intellectually disabled people to be obedient and compliant, and in expressing their hurt, the attendees at Udaan pushed the boundaries of their personhood.

By addressing how there was space to respond to Sahil sir's authority, I do not mean to justify the teasing. In fact, I wish that Sahil sir had attended to Geeta's and Prathamesh's dislike for the teasing and changed his behavior accordingly. However, my objective here is to

complicate “making fun” and frame it as a problematic and messy yet intimate act. At Udaan, making fun of each other was an expression of familiarity and comfort- not just plain bullying. Those who were most vulnerable were often targeted more than others, such as Geeta, who was unable to verbally express her dissent. However, intellectually disabled people had opportunities to talk back and show their discomfort (even with their body language and gestures). Further, even people in positions of power could (sometimes) be the butt of the joke. I also wanted to include “making fun” on the chapter on fun as it illustrates how no field-site, even one that focuses on enjoyment, is perfect. It shows how fun and pleasurable acts are not devoid of tension and conflict. Lastly, at Udaan the practice of “making fun” was deeply intertwined with the other fun and pleasurable modes of being- one could not “have fun” without “making fun”.

Having addressed how special educators intervening in the domain of “fun” created opportunities of pleasure and enjoyment for intellectually disabled adults at Udaan, after the interlude, I next move to exploring the specific domain of sexuality and trace the ways in which Sarika ma’am and Sahil sir made up a playful sexuality for intellectually disabled adults within the premises of Udaan. I demonstrate how by intervening through practices such as teasing, encouraging socialization along cross-gender lines, and going on make-believe dates, Sahil sir and Sarika ma’am shaped a playful, make-believe, and public sexuality for intellectually disabled adults. In particular, I address how Sahil sir and Sarika ma’am intervened in the lives of Geeta and Swarup by imagining, interpreting, and implementing a long-term sexual and romantic companionship for them within the premises of Udaan.

## **Interlude III: Intervening through Life Projects**

### **Is Marriage the Only Way?**

In July 2023, Anwasha Vijaykar and Varun Ramaswamy, two adults with Down syndrome, were married in India. Their three-day long Indian wedding, which included both Maharashtrian and Tamilian rituals, representing the bride's and the groom's heritages respectively, was covered widely by Indian print and social media, including NDTV and the Times of India. After the wedding, Anwasha, at 22 years of age, moved to Dubai to live with Varun and his family. On the surface, Anwasha and Varun appeared to be living the ideal regular adult life, having successfully achieved the heteronormative milestone of marriage.

However, this snapshot only scratches the surface, saying nothing about the amount of deliberate planning and strategizing that went into making this union possible. In January 2022, I met with Anwasha's mother, Tejal, and her twin sister, Ankita. Tejal was a pediatrician who had spent many years working in the United States and returned to India when her twins turned ten years old to set up her own special school and residential facility for intellectually disabled people. During our conversations, it became clear to me that both Tejal and Ankita were keen on arranging Anwasha's marriage and had invested time and resources to prepare her for the same. For instance, when Anwasha expressed a desire for marriage, Tejal sat her down for multiple conversations about how marriage involves everyday companionship. Instead of only talking about such matters, Tejal decided to take concrete steps to practically teach Anwasha the meaning of companionship by recruiting Ankita's male friends to take Anwasha out on "fake dates" for coffee, meals, and movies. Tejal wanted Anwasha to experience the world of dating, and in her words, "to have normal conversations and feel good".

Tejal also wanted Anwasha to achieve a basic level of independence, whether she decided to get married in the future or not. To teach her the same, as soon as Anwasha turned 18, Tejal found her an apartment, three kilometers away from their home, where Anwasha cooked, cleaned, and slept by herself. This arrangement only lasted for two months as it was interrupted by the COVID-19 pandemic, which forced Anwasha to move back in with her family, but according to Tejal, she truly enjoyed living by herself. Not only did Tejal and Ankita prepare Anwasha for an adult married life by teaching her social and everyday life-skills, in Tejal's words, they also "aggressively" looked for a match for her. Tejal was seeking a groom (disabled or non-disabled) whose family would be willing to team up with her to make their marriage work. Tejal said, "both the families will have certain responsibilities, we have to work together, it is not going to be a traditional marriage". She left no stone unturned and contacted networks in India and abroad to look for a groom for her daughter. Finally, it was Ankita who met Varun's sister and the two of them talked about their siblings and concluded that it would be a good idea to introduce them to each other. When I asked Tejal what kind of a future she imagines for Anwasha, she said that she would love for Anwasha to have a family, to be a mother, and she was confident that Anwasha would be the most loving and caring mother in the world. She shared, "Anwasha will raise the baby for twenty years, then the baby will take care of her once I am gone. That is my plan".

Tejal had a specific vision for her daughter Anwasha- she wanted her to experience marriage and motherhood. Tejal also had socio-economic and educational capital that positioned her well to implement her vision. From choreographing "fake dates", renting an apartment, actively searching for a match, to planning Anwasha's life trajectory after marriage, including her child's future caregiving duties, Tejal and Ankita were intimately involved in imagining and



realizing Anwasha's life trajectories. While marriage technically involves two individuals entering a social, sexual, and economic contract with each other, Anwasha's story demonstrates the effects of the interventions made by multiple actors. Anwasha's life-path was not imagined or implemented by her alone. She was not the sole agent of her desires- whether these pertained to dating, marriage, or motherhood. Instead, her life-path emerged through the intentions and actions of multiple actors.

While Anwasha's story presents like a normative success story at least for now and at least in terms of achieving the milestone of marriage, in the next two chapters, I examine, in contrast, nonnormative life-paths that stakeholders, such as parents and special educators, imagine and implement for intellectually disabled adults. I draw on Susan Reynolds Whyte's concept of "life projects" (2020, S132) to talk about these life-paths. In her essay that analyzes the role of rights-based development and humanitarian projects in the lives of disabled people in Uganda, Reynolds Whyte introduces the concept of life projects to discuss the long-term life paths imagined for disabled people (usually in collaboration with them) by their families and kin, such as education, housing, marriage, and raising families. According to the author, while development and humanitarian projects can sometimes aid disabled people's life projects (for instance, by providing them with cash benefits which they use to build a home), their intermittent and short-term nature often reduce their impact. As a result, these initiatives do not play much of a role in the life projects of disabled people, which usually span their life course and involve them growing and evolving as persons. There is a disconnect between the life projects that families and kin want and what the non-profits and development organizations can offer. While Reynolds Whyte discussed life projects designed by non-profits and development organizations for physically disabled people, many of whom could have at least minimal engagement or

involvement in deciding how to use these resources, in the next two chapters, I delve into life projects that were imagined for intellectually disabled people with little to no input or feedback from them.

During my dissertation fieldwork, I mostly worked with special educators who communicated with and occupied intellectually disabled people on a day-to-day basis. While some of them had visions or goals for the future of the intellectually disabled people they worked with, most of them were constrained by their limited roles. Given this, their interventions were usually temporary and limited within the institutional space of the workshops and vocational centers. However, I also had the opportunity to engage with interlocutors such as Tejal, who as Anwasha's mother had the authority and stake in Anwasha's life to intervene by imagining and implementing a long-term vision for her daughter in the form of the life project of marriage and possibly motherhood.

While Anwasha and her family implemented the more normative life project of marriage and motherhood, in the next chapter, I examine how the special educator couple, Sarika ma'am and Sahil sir, intervened in the lives of Geeta and Swarup, their long-term attendees at Udaan, by making up the life project of a playful sexual and romantic companionship for them. Finally, in the last chapter, I examine how Arun and Sujata, a married couple, intervene in their intellectually disabled adult daughter, Smriti's, life, by imagining and implementing a life project of building a workshop where she can experience all pleasures of life, including the joy of work as well as sexual companionship. However, I demonstrate how economic constraints and being in a rural environment makes them re-imagine this life project and instead create a life project which involves making up her personhood as a "single, happy, working girl". In each case, I explore the diverse ways in which kin, and in Sahil sir's and Sarika ma'am's case,

surrogate kin, imagine and work towards long-term life-projects for intellectually disabled people. In doing so, I compel us to think about the diversity of actors , kin and not, involved in enacting these life projects.

While this dissertation has addressed how non-disabled actors make decisions about the kinds of people intellectually disabled adults are, what their behaviors and actions denote, and what they can and cannot do, such as productive work, timepass, and fun, I have not yet discussed non-disabled actors who have long-term personal investments in planning and subsequently intervening in the futures of intellectually disabled adults. What are the futures imagined and actualized for intellectually disabled people in India? How do these life projects make up the personhood of intellectually disabled people? How do these futures articulate with the futures of organizations and institutions? To that end, I spend the next two chapters examining non-disabled actors who have personal stakes in intellectually disabled people's lives and how they imagine long term futures, such as marriage, romantic and sexual companionship, and happy-working-singledom for them. I examine the material and discursive circumstances that give rise of these life projects and the consequences of the same for intellectually disabled adults.

## Chapter 4: Making up a playful sexuality

### Introduction

It was October 2022 and preparations for Diwali were in full swing at Udaan. During lunch time, all the attendees took a break to sit on the floor and eat their lunches. While some had brought their lunches from home, others ate food prepared by Sarika ma'am and Jyoti, the domestic worker who worked at Sahil sir's and Sarika ma'am's home, which was both their home and Udaan's operational base. Sahil sir joined the attendees for lunch, although he was sitting on the couch, while the rest sat on the floor. As everyone was eating and engaging in chit-chat, Sahil sir turned to Prathamesh, a young man with Down syndrome, and said, "Prathamesh, Shinde had called". Prathamesh blushed and looked away. Sahil sir looked at me and said, "Prathamesh and Vaishali Shinde used to dance very nicely together at school functions at Rainbow Foundation to *Kamariya* and *Ek Chaturnaar* (names of popular Hindi movie songs). Prathamesh looked embarrassed at the disclosure of this information, but Sahil sir continued pressing him about Shinde, asking him whether he knew where she was and if he called her. Once done with lunch, everyone returned to their work posts to paint *diyas* or practice Djembe for the upcoming performance.

This was one of the many instances of Sahil sir and Sarika ma'am playfully teasing intellectually disabled adults over their supposed crushes at Udaan. As mentioned in the previous chapter, Sahil sir and Sarika ma'am met at Rainbow Foundation. During my preliminary fieldwork there, I had noticed that the director of Rainbow Foundation was particular about enforcing strict gender norms at the vocational center. Men and women had to sit separately, they were discouraged from socializing too closely, and they wore traditional Indian clothes. Special educators would interject if a man and a woman decided to sit together by asking them to

sit apart and they would always scold them, especially the women, if their clothes were not covering their bodies in a socially appropriate manner, by asking them sternly to cover up if their bra strap peaked out from underneath their clothes. Within this context, Sarika ma'am stood out as the friendly teacher, who joked with the attendees, high-fived them, and resolved their conflicts with a smile on her face, as she weaved in and out of the classrooms while managing her administrative duties as the principal of the vocational center.

As the principal, she was in a position of relative power compared to the other special educators (but not the director) and she used that power to make some changes, such as letting men and women sit together occasionally and organizing music and dance events in which they could dance together, an instance of which Sahil sir mentioned in the above quote. She was further emboldened to institute these practices at the Rainbow Foundation when Sahil sir became the music teacher there and supported her vision of the attendees being able to mingle together more freely, especially through dance and music. When I first met her in 2019 she was excited to learn that I was interested in studying the intersection of disability and sexuality and informed me that she organized an after-school club called the Fun Club (which I mentioned in the previous chapter), which was distinct from Rainbow Foundation and was meant specifically for intellectually disabled adults to do things they could not do freely within the institutional setting of Rainbow Foundation or at their respective homes. At the Fun Club, men and women were encouraged to socialize with each other by sitting next to each other, dancing and playing together, and even going on overnight trips together.

As mentioned in the previous chapter, I did not attend any sessions of the Fun Club. When I returned to conduct my dissertation fieldwork in August 2021, I was sure that I wanted to work with Sarika ma'am and was elated (and surprised) to find out that she had converted the

Fun Club into a full-fledged organization. While Sarika ma'am and Sahil sir did not talk very openly about this, I gathered that they had differences with Rainbow Foundation's administration over their approach, especially when it came to the institution's values around not permitting men and women to interact and socialize with each other. I have already spent a considerable amount of time discussing how Sahil sir and Sarika ma'am constructed a fun, young adult, and consumption-oriented personhood for intellectually disabled people wherein they could joke around with each other as well as engage with the so called "outside world" by going out to restaurants, movie theaters, malls, performing for non-disabled audiences, and travelling to locations other than their vocational center and homes. In this chapter, I explore how Udaan's prioritization of fun and pleasure also led them to make up a playful sexual and romantic personhood for intellectually disabled people at Udaan through practices such as the abovementioned teasing of Prathamesh over Vaishali.

I examine the ways in which Sarika ma'am and Sahil sir created an environmental bubble or a "new world" (Anjaria and Anjaria 2020) at Udaan within which intellectually disabled people were made up as people who not only enjoyed worldly pleasures, such as eating delicious food, and going on overnight trips, but also as people who could develop crushes, romantic feelings, and even sexual attractions. I call the sexual and romantic personhood that emerged within Udaan playful for several reasons. For one, Sahil sir and Sarika ma'am were highly imaginative and took many creative leaps of faith as they constructed stories of love and attraction for intellectually disabled adults. For instance, in the above example, it was Sahil sir and Sarika ma'am who intervened by setting up Prathamesh and Vaishali to dance together, interpreted their interactions during dancing as being indicative of Prathamesh's feelings for Vaishali, and subsequently teased Prathamesh about it for years to come to make up

Prathamesh's romantic personhood as someone who had a crush on the girl he once danced with. Secondly, this personhood was shaped through seemingly fun relational tactics, such as, teasing and make-believe; conversations regarding love, romance, and sexual feelings rarely became too serious. Finally, this personhood was also playful because it was low stakes as it never left the confines of Udaan. While Sahil sir and Sarika ma'am acknowledged, interpreted, and made interventions towards making up a sexual and romantic personhood for intellectually disabled adults within Udaan, it did not affect their lives outside Udaan, as other stakeholders, such as parents, were often not even aware of these relational practices.

Building on Kulick's and Rydström's (2015) framework of sexual facilitation, which I discussed in the introduction as well, I demonstrate that the sexual and romantic personhood that emerged at Udaan cannot be viewed as an individual phenomenon or as a "thing" that all individuals possessed, but rather as a constellation of opportunities and roles that emerged through interventions, which involved structuring and setting up the scene for sexual and romantic feelings and encounters to emerge. In their ethnographic study with cognitively disabled people and their sexual advisers in Denmark, Kulick and Rydström questioned the framing of sex as an individual right. In their words, "Because if sex is a right, what— or, more to the point, whom— is it a right to?" (2015, 19). Instead of framing sex as an individual right to sexual access, they approach it as a positive entitlement and urge for more interventions that, "facilitate disabled people's capacity to engage in a range of social and emotional relations with other people" (2015, 20). Their scholarship analyzed how professionals with formal training in sexual advising, who also worked closely with cognitively disabled people on an everyday basis, noticed that their cognitively disabled clients might want a sexual encounter or relationship and subsequently facilitated the same for them. Their book details examples of these professionals

coming up with systematic plans to actualize the sexual desires and needs of their cognitively disabled clients. In line with the sexual advisers researched by Kulick and Rydström, Sahil sir and Sarika ma'am also relationally made up the sexual and romantic personhood of intellectually disabled people at Udaan. However, this is where the similarities ended. As facilitators, the sexual advisers in Denmark communicated with cognitively disabled people about their sexual desires and collaborated with them to provide them support for the actualization of these desires. In contrast, Sarika ma'am and Sahil sir were not facilitators. They did not make systematic attempts to understand what intellectually disabled people were feeling or trying to say. Instead, they projected their own vision of youthful love and romance onto their attendees and came up with interventions (such as making people dance together and subsequently teasing them) which actualized this vision and, in the process, made up the sexual and romantic personhood of their attendees. Further, unlike the sexual advisers in Denmark who were apparently engaged in the project of capacitating or developing cognitively disabled people's ability to engage in sexual acts, Sarika ma'am and Sahil sir did not try to capacitate intellectually disabled people to make their own decisions around sexuality. Instead, they were the ones who always called the shots about what intellectually disabled people felt and could do.

Further, although Kulick and Rydström re-framed sexuality as emerging through relationships of assistance, they still approached it as a private activity that occurred between two or more consenting individuals who only required literal physical assistance with sex acts. For instance, sexual advisers would always leave the room when cognitively disabled people engaged in sexual acts, in order to give them their privacy. The authors explained that sexual advisers in Denmark followed state sanctioned guidelines that detailed best practices regarding the facilitation of cognitively disabled people's sexuality and come up with written contracts or



plans-of-action with their cognitively disabled clients. These clients articulated a desire to have sex (whether with their partner or paid sex workers). These contracts, according to Kulick and Rydström, helped maintain for sexual advisers the boundary between facilitating sex and having sex. Sexual advisers followed the terms of the contract, and only assisted when required, for instance, when someone needed assistance with putting on a condom or with laying down on the bed next to their partner. Thus, according to the authors, while cognitively disabled adults needed concrete assistance from expert sexual advisers, what counts as sex remained unquestioned and was framed as a private act between consenting mostly articulate individuals. However, the larger Indian context as well as the particular realities at my field-sites presented a rather different picture and made it nearly possible for the category of “sexual advisers” to even exist in India. To begin with, in India, unlike Denmark, sexuality is viewed as a problem unless it is actualized and contained within the confines of intra-caste, intra-religious, heteronormative marriage (Ramberg 2014; Lamb 2022). There are no state-sanctioned guidelines or even university level courses or certifications in India that direct professionals to appropriately engage the sexuality of intellectually disabled people. On an international level, although the United Nations Convention on the Rights of Persons with Disabilities, also known as the UNCRPD, recognizes disabled people’s right to marriage and family, it does not provide any guidelines on how intellectually disabled people could be facilitated or supported to achieve the same. The WHO and UNFPA guidelines that promote sexual and reproductive health of disabled people only mention that programs meant for intellectually disabled adults should be targeted to their level of understanding and be, “slower-paced and presented in a straightforward format, repeated, and reinforced” (2009, 19). Further, UNFPA and Women Enabled International (an international organization that focuses on disability and gender) (2018) published guidelines to

provide rights-based sexual and reproductive health services, which emphasize the utmost importance of obtaining informed consent from intellectually disabled people. Even if a person is determined unable to provide consent, the guidelines suggest that service providers should involve them to the greatest possible extent in decision-making processes. While the document does not specify what informed consent means, it iterates that even if it takes a long time to obtain consent, especially in case of people with communication difficulties, service providers, nonetheless, need to obtain consent. Thus, international documents regarding intellectual disability and sexuality do not provide any systematic guidelines on how to facilitate the sexuality of intellectually disabled people and instead focus on the provision of sexuality education or sexual/reproductive health services. Significantly, these guidelines also emphasize the importance of informed consent, which locates consent within the individual, which was a difficult concept to apply to my field-sites wherein intellectually disabled people did not communicate using conventional or linear language and it was perfectly acceptable for special educators to interpret and decide what intellectually disabled people felt and needed in various domains of their life.

In this context, wherein intellectually disabled adults never clearly articulated their desire for sex, and institutional stakeholders did not follow any systematic guidelines to obtain their informed consent, Sahil sir and Sarika ma'am intervened in the domain of sexuality by interpreting and ultimately deciding what "counted" as sexuality. For instance, going back to the opening vignette, it was Sahil sir and Sarika ma'am who set up Prathamesh and Vaishali for a dance performance, based on which they decided that Prathamesh had romantic feelings for Vaishali. Here, Prathamesh's sexuality was neither individual nor private. Further, his sexuality was also not normatively legible in the form of physical sex acts. Rather it was a moving target

(involving practices such as, partner dance performances and teasing) that was fixed in place by Sarika ma'am and Sahil sir, who were in a position of relative authority in his life. Thus, Prathamesh's sexual and romantic personhood was not just made up in a relational manner but was also publicly interpreted and declared by Sahil sir and Sarika ma'am. By examining ethnographic data from participant observation and in-depth and informal interviews, I examine how the sexual and romantic personhood(s) that emerged at Udaan challenged the framing of sexuality as a private inner desire that existed within individuals. Instead, at Udaan, love, romance, and sexuality were constructed through relational practices and pronouncements that were public and involved multiple actors.

Aside from examining the public and relational nature of the sexual and romantic personhood that emerged at Udaan, I also showcase the affordances and limits of this personhood for intellectually disabled people. On the one hand, I demonstrate how Sahil sir and Sarika ma'am proactively implemented relational practices, such as teasing, playing make-believe, partner dancing, and even more normatively sexual practices, such as cuddling and kissing at Udaan, through which they created tangible opportunities for intellectually disabled adults. . However, I also demonstrate how this personhood was limited because of its low stakes and often make-believe quality. For instance, does partner dancing with someone of the opposite sex count as sexuality? Does going on a make-believe date with your teacher count as a romantic date ? While I do not have answers to these questions, I hold on to the tension of this personhood as being both expansive, creative, and perhaps limiting at the same time because of its playful nature. I also want to note that, in all likelihood, Sahil sir and Sarika ma'am would not have been able to implement a more permanent and serious sexual personhood for intellectually disabled people. As mentioned earlier, it would be difficult for Udaan to gain

socio-cultural acceptance in mainstream Indian society if it openly advertised and advocated for sexual and romantic relationships among its attendees. Further, as I gathered from interviews with special educators, it would have been challenging for Sahil sir and Sarika ma'am to convince most parents to be on board with any plans to develop the sexuality of their children (although I cannot be sure of whether parents truly felt so averse to matters of sexuality since I did not engage with many parents during my dissertation fieldwork).

Another tension I hold on to is that the ideas of sexuality and love that emerged at Udaan were both nonnormative and heteronormative at the same time. While the sexuality that emerged here was de-individualized and relationally interpreted, making it nonnormative, Sahil sir and Sarika ma'am also enforced heteronormative norms, by always pairing people off in heterosexual duos. Despite the highly imaginative quality of sexuality and love at Udaan, Sahil sir and Sarika ma'am never imagined a same-sex couple. This was the case even though they once witnessed two of their male attendees touching each other during an overnight trip. While the couple did not admonish the men for their acts or even scold them, they never encouraged a relationship between the two men and framed it as a physical and hormonal release (while talking to me as well as during sexuality workshops) and not as a sign of affection or attraction towards each other. Finally, an important feature of the public and playful sexuality that emerged at Udaan was that Sahil sir and Sarika ma'am were the central actors choreographing and shaping the sexuality of intellectually disabled people (with little to no apparent or obvious input from them). This led to the main tension that I grappled with during my fieldwork which I make explicit- I was never certain whether intellectually disabled people were "on the same page" as Sahil sir and Sarika ma'am about their supposed sexual desires. However, I want to hold on to this tension and still present Udaan as a field-site that did sexuality and love differently, or even

at all, and in doing so, presented an alternative to the western, individual, private sexuality model.

As mentioned in the introductory chapter, my preliminary research at various institutional sites, such as special schools, vocational centers, and respite-care facilities in India revealed that special educators often apprehended the sexuality of intellectually disabled people as an individual problem behavior in need of regulation, control, or even erasure. Even when I returned for my dissertation fieldwork in 2021, I observed that most of my special educator interlocutors worked towards either curtailing, ignoring, or re-directing the supposed sexual or romantic urges of their students. For instance, they would often openly discourage intellectually disabled people from exploring their own or other people's bodies by scolding them whenever they touched themselves or others. Special educators also often instructed intellectually disabled people to use filial kinship terms, such as, *bhau-bahin*, (brother-sister in Marathi) for each other to discourage them from viewing each other as sexual or romantic partners (even though they framed themselves as being more open-minded than other actors such as parents). This risk-averse approach to sexuality was exemplified succinctly by Kulkarni maushi's words, a special educator at Sankalp workshop, who once during a focus group discussion said to me, "If we don't bring it up then it will not cross their minds" (it being matters of sex).

However, Udaan presented a drastically different picture. Here, matters of sexuality were not ignored, discouraged, or re-directed, unless the actors practiced same-sex intimacy. Rather, Sahil sir and Sarika ma'am often playfully and proactively noticed, interpreted, and discussed the supposed sexual desires and needs of intellectually disabled people. At Udaan, Sarika ma'am and Sahil sir encouraged their attendees to call each other friends (using the English word friend, the

Hindi word *dost*, and the Marathi word *mitr*). At Udaan, men and women were friends, not siblings.

Having examined the general environment and practices, I zoom in on Sahil sir and Sarika ma'am's interventions with Geeta and Swarup, the oldest attendees at Udaan, who were known as the "husband-wife" (*navra-baiko* in Marathi) duo at Udaan. Geeta and Swarup, unlike the rest of the attendees, had a long-term relationship with Sahil sir and Sarika ma'am and even lived with them as their surrogate children, which allowed the couple to make sustained and more "serious" interventions in their sexuality, by setting up structures that made it possible for them to kiss, cuddle, and live together. While most intellectually disabled adults at Udaan only came to the institution during the day Geeta and Swarup were permanent members of Udaan and almost like Sahil sir's and Sarika ma'am's children. As such, Sahil sir and Sarika ma'am were invested in imagining and planning their life trajectories which they did by implementing the life project (Reynolds Whyte 2020) of sexual and romantic companionship for them. Thus, not everyone was treated the same by Sarika ma'am and Sahil sir and different intellectually disabled people were made up as very different types of sexual and romantic persons. While most people's sexuality was made up in a temporary and fleeting manner, as people who could flirt and dance with members of the opposite sex and get teased by their peers and educators for the same, Geeta and Swarup were made up as persons who could live as romantic and sexual companions within the premises of Udaan, under the supervision of their educators. However, before delving into Geeta's and Swarup's story, I examine how Sahil sir and Sarika ma'am created the social aspects of a college experience at Udaan.

### **Udaan as a stimulation of a college-experience**

See, when these kids come to me, they are 18-20 years old, so they are like college goers. When we used to attend college, we were not serious all the time. So, why can't they

have some fun? Why can't we make them look good? If they look presentable, we also feel good. They are teenagers, why should they listen to boring lectures? At Rainbow Foundation, I talked to them about Shah Rukh Khan movies and TV shows instead. I also wanted them to wear different kinds of dresses. So, I started planning different kinds of days, such as, Saree Day and Traditional Day. We also celebrated "Rose Day" and asked them to give the rose to someone they liked. Some people were not very happy with these decisions, but I never bothered too much with formal permissions.

Sarika ma'am shared this with me when I asked her about whether there was anything unique about working with people over 18 years of age. As mentioned in the previous chapter, Sahil sir and Sarika ma'am were committed to providing intellectually disabled people with a "college experience". By this, they did not mean providing them with a higher education, but rather the pleasurable social experiences of being an upper-middle/ middle-class urban college going youngster in India. While none of practices seem overtly sexual, by creating a space for intellectually disabled people to talk about entertainment and encouraging them to wear nice clothes, and openly give a rose to someone they like, Sarika ma'am enabled intellectually disabled people to inhabit the role of a "college-goer"; a role that had connotations of sexual possibilities and promise within the urban Indian context.

While at Rainbow Foundation Sarika ma'am could only implement such practices occasionally given that she was not the one in charge, at Udaan, intellectually disabled people could always be "college-goers". There was no dress code at Udaan that mandated them to dress in traditional or conservative Indian clothing, unlike most of the other institutional sites where I conducted fieldwork. Intellectually disabled people would wear colorful western clothes and would be praised by Sarika ma'am if they wore a striking pair of earrings or bangles. Further, men and women were encouraged to sit together while doing activities or even just relaxing. They were not asked to call people of the opposite sex their brothers or sisters. Instead, everyone was encouraged to view each other as friends. There were fewer rules and regulations (compared

to the Rainbow Foundation, where most of the attendees had attended the special school and vocational center before coming to Udaan) and people could do “adult” things such as wear their clothes of preference and go out for activities of enjoyment. Thus, Udaan, while not a real college, was an attempt at a simulation of the social aspects of a college experience. It is within this environmental bubble and in simulated role of a “collegegoer” that intellectually disabled people at Udaan were exposed to the sexual and romantic opportunities at Udaan. It is important to note the class dimensions of Udaan before proceeding to the next section. Sahil sir and Sarika ma’am’s vision of a “college-experience” reflected an urban upper-middle Indian experience. Accessories, colorful, and attractive clothing, and going out to restaurants and movies for fun cost money- something that only intellectually disabled adults from middle, upper-middle, and upper-class families could afford. Thus, while Sarika ma’am and Sahil sir constructed a social simulation of a college experience at Udaan, they could only extend it to select intellectually disabled adults who belonged to middle or upper-middle class families, since those were the people most likely to attend Udaan.

### **Choreographing crushes and relationships**

As mentioned in the opening vignette of Sahil sir teasing Prathamesh over Vaishali Shinde, teasing intellectually disabled people over supposed crushes was a common occurrence. While Sahil sir was usually the instigator in most cases, intellectually disabled people would also tease each other. For instance, right after Sahil sir teased Prathamesh about Shinde, Prathamesh proceeded to tease Swarup asking him, where his *baiko* (wife in Marathi) was today. I was again taken aback since I had assumed that Swarup was not married. Sahil sir jumped in again to decode the situation and let me know that Prathamesh was referring to Geeta since Swarup liked her. Soon enough I became used to playful teasing of this nature and learned that Sahil sir and



Sarika ma'am were invested in pairing some of their trainees with each other as a couple or even just as people who liked each other. But I wondered- how did Sahil sir and Sarika ma'am come to their conclusions? How did they know who likes whom? As I tried more to get to the bottom of this by incessantly asking them questions (much to their annoyance) such as, "but, how do you know that Prathamesh liked Vaishali Shinde?" Their answer surprised me, as it was not based on a verbal confirmation from Prathamesh that he indeed liked Vaishali. Instead, they told me that they felt that Prathamesh had a lot of fun dancing with Vaishali, which made them believe that he liked her.

To give another example, Sahil sir and Sarika ma'am often talked about the love triangle brewing between Geeta, Swarup, and Virat and teased the three about the same. They shared with me that Virat and Swarup both had feelings for Geeta, but Geeta had her eyes set on Swarup. I was perplexed by their confident claims and asked them how they knew what each person in the equation felt, especially given the fact that none of them used conventionalized language to communicate. Here are some excerpts from my conversation with the couple where I asked them to share how they reached their conclusions:

Shruti: When did you first observe that there was something between Geeta and Swarup?  
Sarika ma'am: I don't remember the exact details, but earlier when she used to speak, she used to call Swarup her best friend. Now she does not talk, but she gets shy whenever Swarup's name is mentioned. You take anyone else's name, there will be no reaction on her part.

Shruti: What about Swarup, how did you know he likes her?

Sahil sir: He understands lesser than Geeta, but we see him being protective towards Geeta. We used to ask him if he liked other girls, and he would always say no. And once I asked him if Prathamesh could take care of Geeta, he replied by saying-I will beat him! That's what gave his feelings away...

Shruti: And how do you know about Virat's feelings?

Sarika ma'am: Once we had asked everyone to choose dance partners and dance with them. Swarup and Virat both picked Geeta. She refused to dance with Virat, and you know what she said? She said, you are so thin, go away!

In resonance with Prathamesh's example, in this case too, Sahil sir and Sarika ma'am did not have verbal confirmation from Geeta, Swarup, or Virat about their feelings. They interpreted and decided that cues, such as Geeta's calling Swarup her best friend, her supposedly shy expressions, Swarup's acts of care towards Geeta, and Virat choosing Geeta as a dance partner, were indicative of their feelings (or lack thereof) of attraction. Sahil sir and Sarika ma'am did not spend a lot of time confirming or making sure that their claims accurately represented what intellectually disabled people felt. This was not their priority. Instead, they were invested in seeing and presenting (to themselves, the attendees, and me) intellectually disabled people as sexual and romantic beings. Sahil sir and Sarika ma'am made up the sexual and romantic personhood of intellectually disabled adults by creatively imagining, telling, and consolidating stories of romances and crushes through relational acts such as teasing. They intervened in their lives by creating scenarios and activities, such as, dance performances, in which they paired female and male attendees and made them relate and interact with each other, based on which they often built a story about their feelings of attraction towards one another. Further, they also shared these stories with others, such as me or new employees and volunteers, which reinforced their value as institutional lores.

At Udaan, the priority was not to facilitate relationships initiated or articulated by intellectually disabled people. Instead, Sahil sir and Sarika ma'am choreographed interactions, interpreted specific interactions as being indicative of feelings of romance and attraction, and then made pronouncements which solidified these stories of love and romance. As shown in the examples above, Prathamesh, Geeta, Swarup, and Virat were not articulate private individuals who were agents or drivers of their own story. Their desires were relationally and publicly imagined, interpreted, and acted upon by Sahil sir and Sarika ma'am. Further, these stories also

reflected the limits and normativity of the imaginations of the special educators. For instance, they could never imagine two men or two women falling in love with each other. Further, they did not view intellectually disabled people as complex people who could have conflicted feelings for each other or have feelings for more than one person. Finally, they did not take into consideration the possibility that intellectually disabled people could have feelings that could not be accessed, interpreted and known by them. As *special mula*, Sahil sir and Sarika ma'am made them up as persons whose romantic and sexual feelings were easy to interpret, understand, and subsequently act upon. Intellectually disabled people did not have space to reject the interpretations made by their special educators.

The fact that Sahil sir and Sarika ma'am made up these stories of love, romance, and crushes in a teasing and unserious register gave these a playful quality. Moreover, the sexual and romantic personhood that emerged within Udaan was playful also because of how low stakes it was. The stories of attraction and love rarely left the premises of Udaan. For instance, stakeholders, including most parents, did not acknowledge the sexuality of intellectually disabled adults just because Sahil sir and Sarika ma'am saw them as sexual and romantic beings. Except for Geeta's mother and Swati (a parent and media professional who helped Udaan with its operations), none of the parents were even aware of the ways and the extent to which Sahil sir and Sarika ma'am discussed matters of love, romance, and sexual attraction at Udaan.

Along with teasing, making up make-believe scenarios was an important everyday practice enacted by Sahil sir and Sarika ma'am. As mentioned in the previous chapter, Swarup and Sahil sir almost exclusively spoke to each other in a Bihari accent. While neither of them belonged to the state of Bihar, Swarup rarely spoke using conventionalized language and used only a few phrases in a Bihari accented Hindi to communicate verbally. Instead of trying to make

him talk in a more normative manner, Sahil sir and Sarika ma'am would engage in make-believe and put on fake Bihari accents while talking to him. These communicative exchanges were also accompanied by laughter and amusement. The tendency to intervene through make believe scenarios also extended to matters of love and romance, exemplified by the following anecdote of Sarika ma'am going on a "date" with one of her male attendees. Sarika ma'am shared with me the story of a young intellectually disabled man, Shishir, who came up to her when his brother got married, asking her if he will ever get married or have a girlfriend. He confided in her that he wanted to go on a date, like actors and actresses do in movies. Instead of either placating or dismissing Shishir, Sarika ma'am engaged with Shishir by listening to his desires. However, instead of facilitating his desires by helping him find a girlfriend, Sarika ma'am decided to intervene by orchestrating a date for Shishir and herself. Since she rode a motorbike, she asked him to sit behind her on the bike and hold her as she took them to their destination- a park. She said that she and Shishir sat on a park bench, just like couples do, and chatted for a while. Sarika ma'am said that she went on the date because she wanted Shishir to experience "normal" things, like other young people do. When I heard this story, I had many questions- how did Shishir like the experience? Did it fulfill his desire for a date? What if he wanted a long-term relationship and not a "fake date" with his teacher? While these questions are still unanswered, what stood out to me was that Sarika ma'am created an experiential bubble within which she and Shishir went on a make-believe date which included a motorbike ride and sitting on a park bench, both elements of a regular date for many college going students in Pune.

When viewed through the lens of societal norms, which idealize and center heteronormative sexuality articulated within monogamous heterosexual marriage for the purpose of procreation (Rubin 1984), the romantic and sexual practices that transpired at Udaan did not

meet the standards of a socially acceptable or recognized sexuality (no one outside Udaan was even privy to them). Moreover, even when viewed through the perspective of Disability Studies scholarship, Udaan's interventions do not appear to be enlightened or unproblematic; some of their actions, such as teasing or going on make-believe dates can be seen as forms of infantilization or de-sexualization of intellectually disabled people (Gill 2015; Kafer 2013).

However, drawing on anthropologist Annelieke Driessen's (2018)'s work in Dutch residential homes that analyzes the ways in which caregivers craft and create conditions of pleasure for elderly people with dementia (such as drawing soothing baths while playing gentle music in the background), I propose that Sarika ma'am and Sahil sir can also be seen as creating conditions of pleasure for intellectually disabled people within which they became "appreciating subjects" (Driessen 2018) capable of feeling attraction and going on dates. In this model, intellectually disabled people did not inhabit a rational, individual sexuality (which was clearly articulated, long-term and valid according to societal norms) and were instead granted a playful (often transient and temporary) sexual personhood shaped through non-normative relational practices. However, the asymmetry in these relational practices cannot be minimized. Sahil sir and Sarika ma'am called the shots- they decided who liked whom (based on behaviors and actions that stood out to them). To what extent intellectually disabled people "experienced" pleasure through these practices remain unknown to me. However, Sahil sir and Sarika ma'am were certain that their interventions were based on the desires of intellectually disabled people. In the next section, I address the case of Geeta and Swarup- the only long-term couple that emerged within Udaan and demonstrate the ways in which Sahil sir and Sarik ma'am built and shaped Geeta's and Swarup's relationship through playful practices that brought them together in various relational contexts.

### **Geeta's and Swarup's story: What is the origin story?**

Of all intellectually disabled adults at Udaan, Sahil sir and Sarika ma'am were most invested in Geeta and Swarup, both as individuals, and as a couple. At the ages of 35 and 31, Geeta and Swarup respectively were also the oldest attendees at Udaan and had the longest association with the co-founders. Both had been Sarika ma'am's students at Rainbow Foundation. They had known each other for over ten years (Sarika ma'am and Geeta had known each other for almost twenty years). After Sarika ma'am quit the Rainbow Foundation and started Udaan, both Geeta and Swarup started coming regularly to Udaan. As I mentioned in the opening vignette of the introduction chapter, Sarika ma'am had been interpreting and making decisions around Geeta's sexuality since her time at the Rainbow Foundation. The opening vignette in the introduction chapter describes how Sarika ma'am talked about replacing Geeta's habit of using a glass bottle near her "pee-hole" with her holding a young man's hand during the sexuality workshop that she and I co-organized for the special educators at the Rainbow Foundation in Summer 2019.

While discussing Geeta's case at the workshop, Sarika ma'am said that she had observed how Geeta looked happy whenever she held hands with a specific boy during their group activities at the vocational center. This is what clued her in to the fact that Geeta liked the texture/touch of the boy's hand, which is why Sarika ma'am went ahead and orchestrated occasions during which Geeta held hands with this boy. When I heard Sarika ma'am mention Geeta's example at the sexuality workshop, I was eager to learn more and had so many questions: how did she know that Geeta was happy holding a man's hand? How did she know that Geeta was no longer using the glass bottle near her "pee-hole"? However, I could never ask those questions at Rainbow Foundation, due to time constraints as well as my level of comfort

with Sarika ma'am at that time. Given this, I was happy to be doing fieldwork at Udaan, hoping to resolve some of my queries.

Upon starting my dissertation fieldwork at Udaan, I realized that the man Sarika ma'am decided Geeta liked to hold hands with was Swarup. Thus, Sarika ma'am had been thinking about, interpreting, and making interventions around Geeta's and Swarup's sexuality for a long time, even before they started Udaan. Geeta and Swarup were the resident couple at Udaan and were lovingly referred to as *navra-baiko* (husband and wife in Marathi) by everyone, including the founders, special educators, involved parents, and the attendees. But when did this begin? When and how did Sarika ma'am know that Geeta and Swarup liked each other? While the sexuality workshop story indicated that it was Geeta's habit of using the hard glass-bottle that led Sarika ma'am to notice how she looked happy when she held Swarup's hand, was that the whole story? When I interviewed Sarika ma'am and Sahil sir and asked them how they "knew" that Geeta and Swarup liked each other, this is what they said,

Shruti: When did it all begin between Swarup and Geeta?

Sarika ma'am: I do not remember any particular incident, but in our shows at Rainbow Foundation, when they danced, they only wanted to be each other's partners.

Sahil sir: Oh, and remember, when we went to Matheran, and we asked everyone who wants to sleep next to whom? And Swarup chose Geeta.

Sarika ma'am: And when we went to the mall, they would hold hands very comfortably. When we take naps in the afternoon, she will tickle his toes. Then she will kiss and look at us!

Sahil sir: They also have feelings, why would she not kiss him?

The interview excerpt above is from one of the multiple conversations I had with Sarika ma'am and Sahil sir regarding how they "knew" about Geeta's and Swarup's liking for each other. Their answers would always be of this nature: they were never able to trace their claim back to an exact time or event (a eureka or aha! moment), unlike Sarika ma'am's claim during the sexuality workshop, which traced it back to the glass-bottle incident. Instead, they would count non-

normative cues, such as holding hands and dancing as indicative of their feelings, just as they did with many of their other attendees. However, they also mentioned more conventional and “bolder” forms of sexual expressions, such as kissing and intimate touching, while talking about Geeta and Swarup. This intrigued me a lot, since there was no other field site at which I had heard special educators talk about such sexual practices. How did Sahil sir and Sarika ma’am pull this off? How did they manage to allow or even encourage acts such as cuddling and kissing?

As I spent more time at Udaan, I found out that while other attendees came to the vocational center during the day to do vocational activities and to practice for Djembe performances and returned home in the evenings, Geeta and Swarup often stayed over for multiple days with Sahil sir and Sarika ma’am. In fact, as Geeta’s parents grew older, they came up with a plan to slowly transition her from living with them to living full-time at Udaan. By 2022, Geeta was spending most of her time at Udaan, going back to her parents’ home only for the weekends. While Swarup’s mother was not as systematic with her transition plans for Swarup, he too spent many evenings and nights at Udaan. While Geeta’s parents paid Udaan a per month fee of Rs 3000, Swarup’s mother was struggling financially and could not pay the fee. On most days, Sahil sir, Sarika ma’am, Geeta, and Swarup lived together, sharing their meals, watching movies or cricket matches at night, and frequently going out to restaurants and malls. Thus, unlike the other attendees, who Sahil sir and Sarika ma’am did not spend much time with and whose parents were the most important stakeholders in their lives, Geeta and Swarup were largely under their supervision.

They told me that they had already discussed Geeta’s and Swarup’s feelings for each other with Geeta’s parents, who were supportive of their interventions but uninvolved. Swarup’s



mother, a widow, on the other hand, was painted as an unsupportive parent by them, who not only denied her son's status as an adult with sexual feelings (by still bathing him despite being repeatedly told not to), but also neglected him, by not talking to him when he was at home and locking him up when she went out to do her chores. Given Swarup's apparently difficult conditions at home, Sahil sir and Sarika ma'am felt like they were his real guardians, even though technically, they were not yet official guardians for either of them. Thus, unlike Geeta's parents, Swarup's mother was not in the know about Geeta's and Swarup's apparent relationship. Despite having different equations with the two sets of parents, they felt responsible towards Geeta and Swarup. Other attendees came and went, but Geeta and Swarup were permanent members of Udaan. Sahil sir and Sarika ma'am were not planning on having their own biological children. Thus, within this scenario, they treated Geeta and Swarup as their surrogate children, even referring to Geeta as their daughter. They imagined a future in which Geeta and Swarup would permanently reside with them and be an integral part of their family unit as well as Udaan- both inseparable entities given that Udaan was a home-based organization. It is in this dual role as surrogate parents and special educators that Sahil sir and Sarika ma'am felt emboldened enough to implement a life project for Geeta and Swarup which involved making up their sexual and romantic companionship in a more sustained manner than one-off instances of teasing or "fake dates".

### **Interpreting Geeta's and Swarup's attraction and love for each other**

As mentioned in the previous chapter, in most everyday scenarios, Geeta appeared to be upset, facepalming, pacing up and down, and refusing to participate in any of Udaan's endeavors. Sahil sir and Sarika ma'am often treated her exclusively as an "appreciating subject" (Driessen 2018) who enjoyed going out, eating at restaurants, and watching television, rather than someone who

could also be trained to learn the Djembe or paint diyas as a productive person, unlike the rest of the attendees. While significant, these activities were still limited (and highly consumption oriented) and did not involve capacitating, skilling, or developing Geeta's abilities in any manner. Aside from viewing Geeta as an appreciating subject who enjoyed food, television, and traveling, they also saw her as someone who appreciated Swarup. I noticed the first sign of this very soon into doing my fieldwork, when I saw everyone at Udaan frequently teasingly ask Geeta in Marathi , "Where is your husband?" Geeta's answer to the question was always the same- she would clasp her hands together, smile mischievously, and point with her eyes to another room. The first time this occurred, I turned to Sarika ma'am for an explanation who told me that Geeta was referring to Swarup as her husband with her coy gestures and expressions. I wondered, "Was that truly the case? Where did Geeta learn to do these gestures? Did Sarika ma'am teach or prompt her to gesture in this manner?" I would quickly check my thoughts, feeling guilty about being patronizing. Of course, Geeta could come up with these gestures on her own! I would scold myself and return to my field-notes.

However, the nagging feeling of what came first remained in my head. Over time, I started noticing that Sahil sir, Sarika ma'am , the other educators, and Jyoti, the domestic worker, would often ask Geeta this question and whether Swarup was at Udaan or back home. Geeta would always answer the same way: by clasping her hands together, smiling mischievously, and pointing with her eyes to another room. Her enthusiastic response would cheer everyone up, including me. While seemingly routine, I came to understand this call-and-response practice as a playful, albeit limited, way of relating to Geeta as a person and acknowledging her communicative, sexual, and romantic personhood. Through the playful intervention of teasingly questioning Geeta about her husband, Sarika ma'am and Sahil sir checked-in on her. In doing

so, they included or enveloped her into the everyday functioning of Udaan, instead of either scolding her for not participating in the work activities or completely abandoning her given her lack of interest in the everyday programming of Udaan. By teasing her about her husband Swarup, they not only made her up as a sexual and romantic being (who could have a husband, albeit a fake one) but also constructed her as a person who could communicate through gestures and facial expressions which were interpretable to them. It was Geeta's idiosyncratic mannerisms (which included her lack of ability to reject the meanings imputed to her behaviors) that made it possible for Sahil sir and Sarika ma'am to playfully build a story about Geeta and Swarup. However, this playful teasing was very limited. While the other attendees at Udaan participated in vocational and recreational activities of various kinds and were asked questions about different domains of their life, including, their families, work, popular culture, and so on, Geeta was often only asked this one question. For instance, even though Swarup was teased as much as Geeta about his "wife", educators at Udaan also gave him instructions to do errands and asked him to participate in vocational activities. They also talked to him in a fake Bihari accent and indulged his curiosity about Muslim people by taking him to a commercial area populated by Muslims, encouraging him to talk to people there, and buying him traditional Muslim garb.

Aside from the playful teasing, Sahil sir and Sarika ma'am claimed that they had noticed Geeta and Swarup express their attraction for each other through their behaviors, such as wanting to spend time together and choosing each other for activities. I was not sure if I could confidently make the same claim. For instance, I noticed Geeta and Swarup both orienting towards each other as well as actively rejecting each other's presence. There were times I noticed Swarup feeding Geeta unprompted. Whenever we went out for events or overnight trips and had to navigate traffic and crowds, Swarup would always hold Geeta's hands without anyone having to

tell him the same. However, I also noticed instances of the two of them actively rejecting each other's presence. For example, there were times during Sunday morning gym sessions when the volunteer sports teacher, Vimla ma'am, would ask Swarup to hold Geeta's hand and run, but he would not follow the instructions, because he appeared to be socializing with other male attendees who only came to Udaan for the Sunday activities. Similarly, Geeta too rejected her educators' plea to play a game with Swarup or even sit down for a meal with him (especially if it was healthy food, something she appeared to not like at all). However, what remained constant despite Geeta's and Swarup's changing orientation towards one another were Sahil sir's and Sarika ma'am's attempts to pair the two of them together in a variety of contexts.

For instance, Swarup was often asked to feed her, which he usually did without any complaints. Whenever there was a difficult physical activity to be done during gym classes (such as climbing a tire or running swiftly) Vimla ma'am would ask Swarup to assist Geeta with these activities. There appeared to be an unspoken agreement among the educators at Udaan that Swarup, while everyone's helper, was Geeta's protector and caregiver. However, it was never clear to me whether Swarup always wanted to occupy this role or not.

One of the most striking cases of Sahil sir and Sarika ma'am pairing Geeta and Swarup occurred at the very end of my fieldwork period. On April 30<sup>th</sup>, 2022, Sahil sir and Sarika ma'am organized a surprise farewell party for Mr. Shah, an older Gujarati retired businessman, who had recently agreed to come on board at Udaan as a trustee. Mr. Shah was leaving for New Jersey for six months to spend time with his daughter and Sahil sir and Sarika ma'am wanted to send him off with celebrations. I arrived at the venue at 4 pm to help set up by organizing the chairs in an orderly manner, adorning the room with flowers, and preparing the food and beverages table. At around 5 pm, Mr. Shah and his family arrived. After cutting a cake, eating a delicious *pav-bhaji*

meal, and cracking way too many jokes about the Gujarati community, it was time for the main event- a dance performance by Geeta and Swarup. Before the performance, Sarika ma'am introduced the dancers saying, "Now, our children, Geeta and Swarup, have prepared a small performance for you." She proceeded to play *Mere Haath Mein* (your hands in my hands) , a rather romantic Bollywood song that picturizes the actor and actress dancing intimately in the rain, as Geeta and Swarup took to the stage, hand in hand. They swayed to the music holding hands, with Swarup directing Geeta's steps and turning her in different directions. While Geeta characteristically alternated between facepalming while looking upset and smiling widely and Swarup did not necessarily follow the beat of the music, the audience, which comprised of intellectually disabled people, special educators, and older Gujarati folks, appeared to be enjoying themselves, clapping along, and encouraging the pair. The performance ended with Swarup lifting Geeta off the ground, a dance move that received resounding applause.

This incident left a mark on me because this was the first time during my fieldwork that I had witnessed intellectually disabled people perform a partner dance to a sensuous Bollywood song. Usually, across my field-sites, special educators would select either devotional, children's', or patriotic music while choreographing dance performances. Further, these dances would never feature both men and women dancing together (let alone touching or lifting each other). While I never explicitly asked special educators questions about their choice of music, I observed that educators were often encouraged (by administrators) to see intellectually disabled people as "innocent" children and Bollywood music with explicit romantic connotations may have been considered inappropriate and even corrupting for their innocent minds. In contrast, within Udaan's world, intellectually disabled people were *bacche* (children), innocent, loving, and non-threatening, but also deserving of the sexual and romantic opportunities of a college-going youth,

as long as these were orchestrated and supervised by Sahil sir and Sarika ma'am. Within this world, Geeta and Swarup, while being introduced as children to the audiences, could also partner dance to romantic music as "colleagegoers". I understand this move as a part of Sahil sir and Sarika ma'am's playful approach to sexuality, which challenged the boundaries of child, adolescent, and adult sexuality. Moreover, partner dancing under supervision was also a low-stakes, non-threatening, and fun, almost festive, looking activity, which further added to its playful nature.

### **Orchestrating sexual intimacy**

Shruti: How did you decide to give them alone time in the afternoon?

Sarika ma'am: This was Sahil's decision, but I don't know how we made the decision. One afternoon, we were all here, and Sahil asked everyone to just lie down and relax for some time.

Sahil sir: And the thing just happened...we did not suggest anything.

Sarika ma'am: We saw it.

Sahil sir: We were also scared and feeling awkward, but we knew there would be no serious repercussions. I stopped Sarika from interrupting them. Let them do whatever they want. There is nothing wrong with it. It will not result in conceiving. Their minds will get relaxed, even if it is for a second.

Continuing my conversation with Sahil sir and Sarika ma'am about Geeta's and Swarup's love story, we eventually landed in the territory of sexual intimacy. While in the interview Sahil sir and Sarika ma'am were unclear about the kind of intimacy Geeta and Swarup engaged in, at other times, they had told me that they preferred to cuddle and kiss when left alone and did not do much else. In the quote above, several details of the relational arrangement (as understood and told by Sahil sir and Sarika ma'am) come to the fore: Firstly, Sahil sir and Sarika ma'am went out of the way to clarify to me that they did not "suggest" anything to Geeta and Swarup, but rather things happened organically, driven by Geeta's desires, and their role was just to not interrupt. Secondly, their anxieties regarding Geeta's and Swarup's intimacy were managed by

the fact that Geeta could not conceive, referring to Geeta's hysterectomy, a decision that Geeta's parents took around ten years ago. Lastly, it became clear that while Sahil sir and Sarika ma'am wanted them to do "whatever they wanted", they kept an eye on them as well. Although they saw themselves as open-minded bystanders who just did not get in the way of Geeta's and Swarup's desires, I argue that this was not the case. I contend that rather than being bystanders, Sahil sir and Sarika ma'am proactively intervened by orchestrating their sexual encounters: by announcing naptime, letting them sleep next to each other, and keeping an eye on them while they kissed and cuddled. Ironically, Geeta's hysterectomy, a procedural tactic often used by state institutions and families of intellectually disabled women to control their sexual and reproductive capacities (Block 2002; Stri Kruti et.al 1994; Kafer 2013) emboldened Sahil sir and Sarika ma'am to be okay with Geeta and Swarup being sexually intimate.

According to Sahil sir and Sarika ma'am, Geeta and Swarup would often be physically intimate in private (under their watchful eye). They also shared with me that while Swarup was more innocent than Geeta, his mannerisms had changed after the second COVID-19 lockdown. Sarika ma'am said, "Before Swarup did not even know how to touch his organ, but after the lockdown, he had undergone a sea of change, we noticed that he gave her a tight hug, lied down with her, and kissed her in a way I had never seen before". I never witnessed Geeta's and Swarup's sexual intimacy- I only have Sahil sir's and Sarika ma'am's word regarding the same. However, what becomes clear is that Sahil sir and Sarika ma'am viewed Geeta and Swarup as people capable of having sexual and romantic feelings and intervened by setting up situations for them to express their desires while also keeping tabs on them. I admit that I was uncomfortable about Sahil sir and Sarika ma'am watching Geeta and Swarup being intimate and having close knowledge about their evolving desires for each other. However, I also reminded myself of the

fact that other special educators too often tracked behaviors such as public erections and masturbation and intervened by re-directing or reprimanding these behaviors.

As mentioned in the introduction, my central tension as an ethnographer was with the leaps of imagination Sahil and Sarika took with their interpretations regarding the sexual and romantic feelings of intellectually disabled people. Throughout my time at Udaan, I often heard myself say, “really?” to a lot of the claims made by Sahil sir and Sarika ma’am. Was it really the case that they noticed Geeta’s and Swarup’s liking for each other, which they encouraged? Or was it that they decided that Geeta and Swarup were a couple (with no input from them) and intervened in ways that eventually made them develop “feelings” for one another? Did Geeta and Swarup really have feelings for each other? To go back to the very beginning- did Geeta really prefer holding hands with Swarup over the glass-bottle? Despite repeatedly asking questions and closely observing people’s mannerisms and behaviors, I did not get any closer to establishing a clear linear timeline of their love-story. However, I realized that in obsessing over getting to the bottom of it all, I was still holding on to the idea of sexuality was an inner, individual desire and was looking for any overt signs or gestures that confirmed to me that- yes, these were indeed their inner individual desires and not something else that was constructed through Sarika ma’am’s and Sahil sir’s interventions. However, Sahil sir’s and Sarika ma’am’s interventions presented a different way of doing sexuality- by de-individualizing sexuality and making it their concern, they made sexuality and romance a relational, public, and playful phenomena. They intervened in Geeta’s and Swarup’s lives through practices of observing, imagining, interpreting, choreographing, and publicly pronouncing sexual and romantic feelings on their behalf. In which case, maybe the question to ask is not whether Geeta and Swarup really liked each other, but it is



to ask: whether Sarika ma'am and Sahil sir successfully made up Geeta and Swarup as sexual and romantic persons with feelings for each other?

### **What if the bubble bursts?**

In the interlude, Anwasha expressed a desire for marriage to her mother, Tejal, who attended to the desire, made it a life project for Anwasha, and proactively worked towards helping her fulfill this desire by arranging her marriage. Tejal, much like Sarika ma'am with Geeta, relationally made up her daughter's sexuality. However, Tejal's life project was normatively legible and successful on a societal level. Anwasha's marriage was recognized (and celebrated) by normative society, unlike Geeta, who was married only within the world of Udaan. To take another example, while Prathamesh was acknowledged as a sexual person at Udaan by being teased about his supposed affection for Vaishali Shinde, I do not know how and if at all this affected his life in a substantial way outside Udaan. Further, I doubt if these practices of teasing made any difference to Vaishali's life, as she did not attend Udaan at all. Also, what would happen if intellectually people left the world of Udaan? Did they stop being sexual and romantic persons? Prathamesh stopped coming to Udaan by the end of my fieldwork period because his mother had started a home-business making diyas and envelopes and wanted Prathamesh to work with her at home. I wondered, did Prathamesh stop being a sexual and romantic person now that he no longer attended Udaan? Given that his mother did not have a collaborative relationship with Sahil sir and Sarika ma'am, I doubt that they felt comfortable sharing their insights about his feelings and desires with her.

Unlike Tejal, who has the authority to be involved in planning and executing all the important decisions in her daughter's life (such as what happens if and when Anwasha has a baby) Sahil sir and Sarika ma'am did not have such decision-making power in anyone's life,

except for maybe Geeta, (considering that Geeta's parents were thinking of making them her official guardians in the near future), which made their interventions low-stakes. The relational practices that emerged at Udaan only had validity within the social world of Udaan, which constrained the founders' ability to be "experimental" beyond a point (for fear of pushback from parents) and limited the social affordances of this playful sexual and romantic personhoods in the outside world. Further, considering that Udaan had not found long-term and ongoing funding (except for Mr. Shah, they did not have any funders) its future as a stable center as well as a home for Geeta and Swarup remained in question, making the futures of these personhood(s) uncertain. However, that does not take away from the romantic and sexual opportunities, roles, and relationships, however transient or temporary, and maybe even fantastical, that were created at Udaan.

Having explored an organization that created a bubble, I next move to the Ananda Foundation, which took the opposite approach, and aimed at integrating with and responding to the larger socio-cultural context of their institution which was based in the village of Karkamb in Maharashtra. What happens when an urban couple dreams of opening a family-centric workshop in a rural environment only to find out that their vision is illegible to the residents of the village? What happens when their dreams of building a workshop are closely intertwined with securing a future for their intellectually disabled daughter within the institution? How do they adjust and change their ideological values and programming in accordance with the needs of their audiences? How do they re-evaluate their own value as a workshop? How do they re-imagine a new future for their daughter within their new context? In the next chapter, I explore these questions by examining Asha's and Jayant's story, a couple from the city of Pune, who intervened in the rural Indian context by setting up a workshop for intellectually disabled adults

in Karkamb. I shift from the contained bubble of Udaan to Ananda Foundation to explore a very different institutional model, in which Asha and Jayant re-imagine their institution's purpose and their daughter's future in response to the needs and values of their audiences.

## Chapter 5: Re-imagining life projects

### Introduction

We visualize a picture of how our lives after retirement and Smriti's life after twenty-five could go hand in hand. We would have a family containing both of us, Smriti and a few other children like Smriti, and perhaps, a few parents of such children. There would be a workshop where these children would work productively. There would be a small farm or a garden where the children could play and work. They would have a separate room full of gadgets of entertainment and a library. The children would work as per their ability and choice. They would perform and enjoy songs, dances, plays etc. They will enjoy *all* sorts of pleasures of life. The real challenge lies in the pregnant word *all* as it implies sexual pleasure as well. Understandably, these children are deprived of many pleasures due to their innate limitations. We feel it's cruel to keep these children away from the fulfillment of sexual bliss which is as important as food and water. It's hypocrisy to keep these children away from sexual pleasure.

This is an excerpt from the Marathi book, *Amche Anokhe Prayog*, later translated into English as, *My Unique Experiments*<sup>25</sup>, written by a couple named Asha and Jayant Lokhande, and published in 2010. The book chronicles the couple's experiences raising their daughter, Smriti, who has Down syndrome, excerpts of which I discuss in the first interlude of the dissertation. In the book, Asha and Jayant note how Smriti's birth completely changed their life's trajectory. They shared the different ways in which their experimental parenting strategies shaped her into becoming a talented and capable adult. They detailed the many ways in which they not only supported Smriti's normative development by teaching her to read and write, but also shared how they exposed her to the arts, such as, music, dance, and theater. They wrote about the arts being equally, if not more important, for her overall development and happiness. Along with talking about the experiences of raising her, the couple also shared their envisioned life project for themselves and their daughter's future. As demonstrated in the opening quote, they imagined

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<sup>25</sup> I am unable to share the name of the book because doing so would compromise the anonymity of my interlocutors.

building a space which would look like a family, comprising of the three of them and other “children” like Smriti and their parents. They also wanted to build a workshop for Smriti where she and her peers would participate in productive as well as pleasurable activities. Along with pleasures such as music, dance, and plays, the couple also mentioned sexual pleasure and framed it as being as essential a need as food or water. In the book, the couple also talked about how they did not think that marriage was a responsibility that intellectually disabled people could take up. However, they suggested the alternative of companionship, describing it as follows,

They won't be able to carry out marital responsibilities, that's a fact. So we don't want them to tie the knot of marriage by religion, morality or even by law. The main intention is to provide them with an opportunity to have companionship. Physical relationships are merely a part of this companionship. That too depends on the children's desires, necessities, and circumstances. In this family, children should get happiness from love, caring, touching, each other confidently, being with each other at difficult moments, doing small titbits for each other and of course, fighting with each other. Depending on the situation, it will be decided by the invigilating adults how and when assistance would be given to these children. This would be flexible. However, we need to keep aside all traditional and hypocritical concepts of morality and immorality! We should help these children with an open mind. We need the support of like-minded parents to make this possible.

Jayant and Asha had reflected on what they meant by companionship. They were for the belief that intellectually disabled people deserved companionship, which they understood to be an ability to love, care, touch, and support each other. They viewed physical intimacy as only one aspect of companionship and wrote that the decision to actualize it would depend on the specific child's desires. Significantly, the model of companionship suggested by Jayant and Asha involved support from other parents or adults who would supervise and assist the companionate relationships among intellectually disabled adults, which was very different from Sahil sir and Sarika ma'am's approach, which most often did not involve collaborating with parents when it came to their interventions regarding matter of love and sexuality at Udaan. In resonance with

Rapp's and Ginsburg's (2011) parent interlocutors based in New York who talk about how the presence of disability leads to the complete overhaul and re-configuration of their familial and kinship roles, structures, and expectations and compels them to re-imagine their futures, Jayant and Asha also shared how their lives changed overnight with Smriti's birth. Smriti's birth and her specific support needs led to a rehaul of Jayant's and Asha's life trajectory, which eventually led them to the life project of building a family-centric workshop, with desires to connect with other families and expand kinship networks. Within this imagined workshop, providing companionship for their daughter was a central priority.

I first met Asha and Jayant Lokhande in 2019 during my preliminary fieldwork. Asha and Jayant were a middle-class Maharashtrian couple who lived in a two-bedroom apartment in the city of Pune. However, neither Asha nor Jayant grew up in Pune. Asha belongs to the weaver community (classified under the Other Backward Castes or the OBC category by the Indian state) and grew up in Karkamb, a relatively large village in the Solapur district of Maharashtra in 1970s. Back then, the population in Karkamb was around 12,000 and it had only one high school, where the principal was Asha's father. The village did not have a college, so Asha left for Solapur, a small city close to Karkamb to pursue her higher education (a Bachelor of Education, B. ED). She was the second girl from her village who went to the city to receive a college education, the first one being an upper-caste Brahmin girl. In Solapur, she met Jayant, her future husband at college. Jayant was from the city of Solapur and belonged to the Vishwa Brahmin caste, whose representatives claim that it is an upper-caste, but the claim is often rejected by other upper-caste groups. He was training to be a Marathi language journalist. They married after dating for five years, against the wishes of their families, because they belonged to different

castes. They lived in Solapur where Asha worked as a high school teacher and Jayant as a journalist.

Smriti, their first daughter, was born in Solapur. However, soon after they realized that she had Down syndrome, they started travelling regularly between Solapur and Pune, a much larger and more urbanized city, to access medical services for her. In the year 2000, when Asha became pregnant again, she visited Sasson Hospital in Pune to undergo pre-natal testing to make sure that the fetus did not have Down syndrome. The tests were negative (meaning that the fetus did not have Down syndrome) and soon Sunaina, their second daughter, was born. In 2003, when they realized that no special school in Solapur was up to their standards, they moved to Pune and enrolled Smriti in Rainbow Foundation- the institution where I conducted preliminary fieldwork in 2019. When I met with them in 2019, Smriti had already finished her schooling at the special school affiliated with Rainbow Foundation and after doing a short stint at the vocational center there (which at that time was overseen by Sarika ma'am), decided to quit and stay at home instead. During this meeting, Jayant and Asha shared with me that they were having serious discussions as a family about moving from their urban residence in Pune back to Karkamb, the village where Asha grew up, to set up their own workshop- one they had dreamt of nine years ago in their book. They had chosen Karkamb because Asha's family still lived there, and her father had gifted a piece of land to the couple to build the workshop (over the years, the families had resolved their initial conflicts with the couple). As soon as I met them, I noticed that the couple were different compared to most of my other parent interlocutors. For one, they never sent Smriti to another room or talked about her as though she was not present, something that often happened when I interviewed parents of intellectually disabled people. Smriti would move freely through the house, using the kitchen, doing her chores, or simply watching television, as I

chatted with her parents. Moreover, Jayant and Asha claimed not to subscribe to traditional gender roles. At the time I met them, Asha was an ex-high school teacher working as a teacher trainer at the Maharashtra State Department of Education in Pune and Jayant was a journalist. He had started working nightshifts when Smriti was born, to care for her during the day, so that Asha could continue doing her paid work. They had had an inter-caste love marriage and talked freely about it. The couple also told me how they supported Smriti's sexual health, desires, and curiosities. They shared with me the efforts they had made to explain the menstrual cycle to Smriti when she was younger and told me that Jayant would even buy sanitary napkins for her if the need came up. They also mentioned the story of the time when Smriti's grandma caught her watching porn on Jayant's phone and how instead of reprimanding Smriti, Jayant told off his mother for scolding Smriti for exploring her natural curiosities. They understood Smriti's sexual desire as something that was evolving with time. According to them, when she was younger, she would get excited and looked aroused when she watched intimate scenes on television. However, as a grown up, she acted like a grandma (*aajibai* in Marathi), by rolling her eyes and facepalming at such scenes and saying phrases, such as, "Oh god, they have started up again!" Asha and Jayant appeared to perform a liberal openness with me and framed themselves as accepting, open-minded, educated, and to some extent even "cool" parents. I was excited about their aspirations- both with respect to their future organization and their daughter's sexual future-futures that were entangled in their imagined life-project.

It was during this meeting that they asked me if I would be willing to edit the English translation of their book that chronicled their journey with Smriti, extracts from which were shown at the beginning of this chapter. I was excited to collaborate with them and learn more about their life-journey and future life goals. It was while reading the book that I realized that the



couple had spent a considerable amount of time thinking about and articulating a vision for their future family centric workshop, which included developing their daughter's as well as other intellectually disabled people's sexuality as well as broader connections with others. This peaked my excitement, especially because I was particularly interested in examining how they would set up structures in their future institution to encourage companionship to emerge among intellectually disabled people. With this in mind, I decided to focus on them and follow their journeys.

When I returned to India in 2021 to conduct my dissertation fieldwork, I was happy to learn that Asha, Jayant, and Smriti had taken the plunge at the end of 2019 and moved to Karkamb, a village in the southeast region of Maharashtra, to set up their workshop- Ananda Foundation. Ananda Foundation was located on the outskirts of Karkamb, around 5 kilometers from the main village square. Most Karkamb residents lived in and around the village square. Asha had spent the first seventeen years of her life in Karkamb, migrated to the closest city of Solapur for her higher education and employment, and later to Pune for her daughter, only to come back full circle to Karkamb with hopes of securing a future for her daughter and herself by building a workshop. According to the 2011 census data, Karkamb's current population is approximately 17,000, in contrast to Pune, which had a much larger population of 3,124,458. Karkamb is situated within a larger rural area, surrounded by other smaller villages like Nematvadi. The closest city, Solapur, is approximately hundred kilometers away. Jayant and Asha told me that while Karkamb is drought-prone, it receives irrigation from Ujani Dam. This makes it possible to practice farming there, which is the major occupation for its residents. Karkamb's economy is primarily agrarian, in contrast to Pune's, which is driven by manufacturing, industrial, and information technology sectors. Being primarily a rural area, not

too many city dwellers migrate here. Jayant and Asha were somewhat exceptional, and it was Asha's familial networks and access to land that led them back here.

According to Asha, Karkamb is famous for its grape production. While I could not find much demographic information on the village through researching government archives and websites, Asha informed me that people of all caste and class backgrounds live in the village. She told me that only 10 to 15 % of the population are landowning rich farmers and around 40% of the population are poor daily wage workers, who either work on farms (by doing tasks such as cutting sugarcane), or as masons. She said that these people work whenever a need for their labor comes up and are often unemployed for as long as six months at a stretch. Additionally, there are few people who run grocery stores and work as vegetable or fruit vendors. She also informed me that Karkamb opened its first mall in 2021, within which several villagers opened small shops selling shoes, clothes, and fabrics. Asha also told me that the village is spatially segregated based on caste. She said that there are separate lanes, especially for those who belong to lower castes (these castes are often marked by their occupation which is passed on from one generation to another). Thus, people belonging to the potter caste (*kumbhar*), the goldsmith caste (*sonars*), or the weaver caste (*koshti*) live in their separate lanes.

When I visited Karkamb in February 2022, in the middle of the Omicron COVID-19 wave, the workshop was catering to six attendees, including Smriti. All the attendees were Karkamb residents. Most of their parents came from lower class backgrounds and worked as daily wage workers or community health workers. One of the attendee's family owned a small roadside tea stall. Only one of the attendees came from a middle-class family as his father was the principal of one of the local high schools. The workshop was a spacious room on the first floor of a two-storey building, the ground floor of which was occupied by the Lokhande family

as residence. Upon spending a few days at the workshop and having multiple conversations with the Lokhandes, I realized that the workshop was far from the space they had imagined in their book. While the couple had wanted to build a family-centric livelihood project, they were not even close to actualizing this vision. A major reason for this was that they were still grappling with fitting in with and becoming legible to the residents of Karkamb village.

Ananda Foundation was the first institution of its kind in the village, which had never had a workshop that catered to intellectually disabled people before. Jayant and Asha had ventured into the unknown territory of rural Maharashtra and were thus struggling to engage and communicate with the village residents. Their struggles included convincing rural parents of their value as an organization so that they would send their adult children to the workshop- adults who often had a social role in the village community and economy. In conversations with me, Jayant and Asha expressed their concerns about the ideological differences between them and the Karkamb residents regarding what intellectually disabled people should be doing with their lives. Marriage was a point of contention. While Jayant and Asha believed intellectually disabled people should have access to sexual pleasure and companionship, they thought that intellectually disabled adults were not capable of comprehending and undertaking the responsibilities of a marriage. In contrast, according to Jayant and Asha, Karkamb residents thought of marriage as an acceptable life-path for their intellectually disabled children.

Moreover, they were also facing problems with procuring funding, recruiting educators, paying stipends to their attendees, and providing transportation to and from their homes to the workshop. Thus, within the rural context of Karkamb, with limited social and financial capital in hand, Jayant and Asha were faced with challenging and unfamiliar socio-cultural and discursive realities, which contrasted with their more recent lived experiences in the city of Pune, where

had they raised their daughter Smriti. Under these circumstances, their initial vision of setting up an institutional space, in collaboration with other families, which would provide them with social, work, and romantic opportunities under the same roof, remained a distant dream.

In the rest of the chapter, I explore Jayant, Asha, and Smriti's journey with Ananda Foundation to examine what happens when people re-imagine and re-articulate their life-projects in response to their socio-cultural and economic circumstances. I demonstrate how, over time, Asha and Jayant adjusted their life project, for both the organization and their daughter, in response to their larger social context. By focusing on Ananda Foundation, I ask- What happens when a disability-centered life project cannot be implemented because of its larger contextual realities? Specifically, what happens when an urban intervention, such as a workshop that caters to intellectually disabled people, is set up in a rural context? How does it gain recognition and legibility? What role would it have to serve to become useful to rural intellectually disabled people (and their families), who have never encountered such an institution before, and who already have social roles and understandings of personhood(s) within their families and the rural economy? What happens to Jayant's and Asha's imagined future for Smriti, including their abstract vision of actualizing companionship within the workshop, when faced with the rural context of Karkamb? While this dissertation has thus far approached interventions as relational practices enacted by special educators while interacting with intellectually disabled people, in this chapter, I frame Ananda Foundation as an institutional intervention made by Jayant and Asha in the rural context. Much like how special educators intervened in the lives of intellectually disabled people in a top-down manner by interpreting and deciding what they felt, thought, and needed, Jayant and Asha intervened in Karkamb's socio-cultural context by deciding that the intellectually disabled people and their families within the village needed this

workshop and its services. However, this top-down intervention did not quite work, and Jayant and Asha had to change the nature of their institutional intervention. By responding to the needs of the residents of Karkamb, Jayant and Asha transformed Anand Foundation from a top-down, urban intervention into a more engaged and responsive intervention.

To be clear, I am not making a strict binary between urban and rural. Indeed, according to Asha, Karkamb had changed considerably since her childhood. There was now a mall, three high schools instead of one high school, and a major national highway connecting Karkamb to the cities of Solapur and Pune in the state of Maharashtra. Thus, my intention is not to essentialize Karkamb as a static/backward rural area, where no development occurs. Instead, drawing on Vandana Chaudhry's concept of "rurality" (2019), I want to capture how Jayant and Asha respond to the specific, "material, relational, and social realities of rural lives, worlds, and sociality" (Chaudhry 2019). According to Chaudhry, whose scholarship focuses on the effects of large-scale neoliberal development life-projects of disabled people in rural Telangana in India, "theorizing disability from the perspective of rurality allows for the disruption of dominant liberal binaries and, in doing so, provides new vantage points from which to conceptualize disability and access" (Chaudhry 2019). In her ethnographic research, Chaudhry (2019) examines how disability in rural Telangana is experienced within under-resourced environments (lack of electricity, bad roads, and so on) and through kin-relations. For instance, she notes how during her fieldwork, she never met blind people who used a cane to navigate public spaces. Instead, they would be escorted by family members. In resonance with Chaudhry's concept of "rurality", I examine how Karkamb's social, material, and relational realities led Asha and Jayant to repurpose their life project. I demonstrate how the couple abandoned many aspects of their

original life project for both the organization and Smriti in response to the needs of Karkamb residents.

While Asha and Jayant changed many aspects of their original vision, this does not mean that their work at the Ananda Foundation was any less valuable. In fact, in adapting to the needs of the people of Karkamb over time, Asha and Jayant adopted a more responsive, rather than a top-down approach, and in doing so, became more valuable, and less invasive/intrusive within their larger village community. They negotiated with their initial vision and ideals. Thus far this dissertation has mostly looked at organizations within the city of Pune, a highly urbanized environment. Pune, unlike Karkamb, has a dense network of special schools, vocational centers, workshops, and residential facilities. Transitioning from special schools to vocational centers or workshops was a reality familiar to most of the urban parents I met. Considering that paid employment was not a realistic prospect for most of the intellectually disabled adults I met during my fieldwork, such institutions were valuable spaces where intellectually disabled adults spent a considerable amount of their day. They followed a routine, participating in vocational activities, which often looked similar across different sites, such as painting *diyas* (an activity almost synonymous with such organizations). In an urban environment, such institutions were familiar to urban parents and served a role in their lives. These institutions provided opportunities for intellectually disabled adults to do busy-work, participate in rest and respite, and sometimes even fun. They also provided parents with respite from their care-giving duties.

In no way do I indicate that these organizations did not face challenges. Conversely, I also do not suggest that these organizations were perfect in responding to the needs of urban

intellectually disabled adults or their families<sup>26</sup>. However, they did not face the issue of appearing legible and valuable to their audiences. Even if an organization was new, it did not have to take up the task of explaining its core purpose to its audiences. For instance, Udaan, despite being as new as the Ananda Foundation, did not struggle with communicating its purpose and role to its parent audience. In contrast, for Ananda Foundation, the rural environment did not afford it the same legibility and recognition that was afforded to its urban counterparts. In brief, in the rest of the chapter, I first demonstrate the problems Ananda Foundation encountered while establishing its own value in a rural environment, where intellectually disabled people already had social roles. Next, I analyze how the organization re-imagined and re-purposed itself, by being responsive to their rural environment. I specifically focus on how Jayant and Asha eventually come to embrace and work with the social roles and forms of personhood(s) ascribed to rural intellectually disabled people by – 1) changing its own vision, from a livelihood project to a respite/social home and 2) by adjusting their opinion on the place of marriage in the lives of intellectually disabled people. Further, I also demonstrate how in adjusting their opinion on marriage for other intellectually disabled people, they also adjusted their own perspectives and reflections on marriage as a life-path for Smriti, their own child.

Further, I illustrate how while Asha and Jayant had hoped for the Ananda Foundation to be a space where Smriti and her peers find sexual pleasure and companionship, the couple abandoned their abstract vision and forged a new personhood for her, wherein they made her up as a happy, single, working girl. While not normative (such as marriage or even companionship), I demonstrate how this re-imagined personhood also opened multiple avenues

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<sup>26</sup> As mentioned in the introduction, administrators and special educators in urban institutions often complained about how parents of their attendees either pulled their children out or often did not send them to the institution on a regular basis. Urban institutions also struggled with issues of funding and resources.

of experiencing pleasures for Smriti. I draw on ethnographic observations, multiple interviews, and conversations between 2019 to 2023 with Asha, and excerpts from Jayant's and Asha's book to illustrate Ananda Foundation's journey from an imagined life project in 2010 to their current context-responsive intervention at Ananda Foundation in 2023. I now move to the ethnographic section that explores the challenges that Asha and Jayant faced while building the Ananda Foundation, the most fundamental of which was convincing rural parents of their organization's value.

### **Issues of Legibility and Value**

Asha and Jayant were invested in building a workshop that provided livelihood to intellectually disabled adults. They were always clear about not wanting to set up a residential center which caters to urban families who drop their charges off at the center and visit infrequently- an institutional model that is common in India. Sahavas, a respite care facility based in Wada, a village three hours away from Mumbai, where I conducted fieldwork was one such institution. Here, urban parents from Mumbai and Thane would drop their adult charges off on Monday. From Monday to Friday, intellectually disabled adults would spend time at the respite-care facility doing vocational activities, such as beading necklaces, exercising regularly, and doing activities, such as watching television, going for long walks, singing songs in the evenings. On Friday evenings, a bus would take them back to their respective homes for the weekend. The purpose of the respite-care model was to provide a break to urban parents from their caregiving duties<sup>27</sup>. However, this was not the vision that Jayant and Asha had for their institution. They

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<sup>27</sup> Sahavas is a private institution that has received funding from multinational corporations (i.e., Lubrizol corporation), charitable trusts run by politicians and philanthropists in Mumbai (i.e., SK Patil Trust), public sector companies such as Life Insurance Corporation of India (LIC), and individual donors. Sahavas also charges Rs. 5000 (USD 60) a month to the families of its residents which helps with the maintenance costs. However, the administrators often reduce or waive off this monthly fee because parents struggle to pay them the full amount. This



aspired to integrate with the village community and recruit intellectually disabled people from within the Karkamb village area. In their book, they wrote about wanting to create a space where intellectually disabled adults, with support from staff and parents, would engage in income generating activities, such as farming. However, when they built the organization in 2019, their reality was far from this imagined vision. Asha and Jayant struggled to pay salaries to their three educators, one of whom also worked as the van driver who picked up and dropped off the attendees. The only income generating activity performed at the workshop was painting and selling diyas to acquaintances and friends in Pune. This activity barely made a profit and was not enough to either meet the expenses of the organization or to pay a decent stipend to the workshop attendees, something that Asha and Jayant desired to do.

The other vocational activities performed at the Ananda Foundation involved making paper-bags (to be sold to medical stores), braiding *dupattas* (long flowing scarves/shawls) and crushing peanuts. None of these activities brought in an income and were geared towards providing fine motor skills to intellectually disabled people. While there was a small farm right next to the workshop building, only Jayant tended to it and the produce was used for sustaining the Lokhande family; it was not a source of income. In a conversation with me during my field-visit, Asha shared with me that according to her, a person needs Rs. 2000 per month (USD 24.09) to live in Karkamb; an amount she would like to eventually provide to intellectually disabled adults. But they could only afford to provide a Rs. 20 (USD 0.24) stipend per day, which she paid by dipping into her savings, given the lack of funding. Thus, between 2019 and 2022, Ananda Foundation was not a source of livelihood for intellectually disabled adults and functioned more like an urban vocational center, in which intellectually disabled adults, instead

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was especially true during the COVID-19 pandemic and its immediate aftermath when many families were struggling on the financial front.

of becoming productive workers, would forever remain attendees. I provide these institutional details here because these form the context for the struggles Jayant and Asha faced with establishing legibility and legitimacy for the Ananda Foundation in Karkamb.

Along with struggling with establishing the Ananda Foundation as a livelihood project, the couple were also struggling with establishing their relevance to the uninitiated audiences of Karkamb village, since people in Karkamb had never heard of an institutional workshop that catered specifically to intellectually disabled people. According to Asha, Karkamb residents referred to Ananda Foundation as a school or *shala* in Marathi. While finding people with intellectual disabilities was not very difficult (given the relatively small population and dense social networks) what followed in terms of convincing families of the value of the institutional space was much harder. Asha and Jayant shared with me that spreading the word about the Ananda Foundation was relatively easy. While Asha made active efforts at disseminating information about the institution by visiting mainstream schools in the village, she also shared with me that given how well known her family was in Karkamb, (considering that her father was the principal of the only high school back in the 1980s), people found out about Jayant's and Asha's arrival and Ananda Foundation mostly through informal social networks.

Asha shared that once the word about Ananda Foundation was out, they quickly had a list of thirteen people. Unlike the vocational centers I visited in Pune, wherein children with intellectual disabilities had to undergo psychological testing and obtain a disability certificate from a government hospital before joining the center, here, Jayant and Asha met their disabled attendees through word-of-mouth and had to trust the judgment of their fellow village community members. However, despite obtaining a list of "disabled children", convincing families to send their children regularly to the center proved to be a much harder task. In Asha's

words in Marathi, “Initially they (parents/families in the village) say- Oh you have come from Pune and are doing so much work, and this is really good, and we will send the kid. When we meet and talk this is the standard response but later, we call, then they say-today is not the right time for him.”

In both Asha’s and Jayant’s opinion, a reason for the inconsistent and confusing communication was that they were facing difficulties in conveying their vision to rural parents, whose intellectually disabled children already had social roles and duties in the larger rural community. Asha shared with me that people with intellectual disabilities did work, such as, watching over cattle in the fields, helping around the house by cleaning and cooking, and even simply staying at home to receive visitors when other members of the family were not at home. Considering that intellectually disabled people had social roles in Karkamb, parents did not see much value in sending their children to a center for the entire day when they could instead be doing important work at home (as far as I gathered, most of them went to mainstream schools just for a few years as children before dropping out because of how hard it was for them to keep up with studies). Thus despite Jayant and Asha making several social visits to families to convince them to send their children to Ananda Foundation, most families remained unconvinced of the institution’s value. While many just refused to send their children, others attended irregularly, causing a high rate of absenteeism, which also contributed to the center facing challenges with coming with regular programming and applying for funding.

Aside from social roles, the issue of marriage also emerged as a matter of tension between Jayant and Asha on the one hand and the larger Karkamb community on the other. Many rural parents considered marriage to be a viable option for their intellectually disabled children- an aspiration that did not align with sending them to the workshop. For instance, Asha

recounted the story of two sisters named Meghana and Sheetal, whose parents agreed to send Meghana to the workshop, but did not want to send Sheetal, because they hoped that they would be able to find a suitable match for her. According to Asha, while Meghana had mental retardation, Sheetal had a milder and less clear mental disability, which had caused her previous marriage to end. Sheetal also had leukoderma, a skin infection that causes white patches on the skin. Their mother had hopes that Sheetal would have a second marriage and therefore did not want to send her to the Ananda Foundation. She thought it would decrease her prospects on the arranged marriage market because she felt that the organization would be perceived as a *vedyanchi shala*<sup>28</sup> (phrase for crazy people's school in Marathi)- a tag she wanted to distance her daughter from. Over time, Sheetal's family could not find a marriage prospect for her, and Asha convinced her mother to send her to the workshop. At present, both Meghana and Sheetal attend the workshop. However, it was not an easy or quick process because of the negotiations around the question of marriage.

In another instance, Shivaji, a young, enthusiastic man with Down syndrome and an attendee at the workshop, stopped coming regularly over 2022 and eventually left by the end of the year. According to Asha, the reason for this was that his father wanted him to get married and did not think that the workshop was a suitable place for him. Asha was not convinced that marriage was the right path for him because she was not sure if Shivaji understood the responsibilities that came along with marriage. Jayant and Asha even visited his home and tried talking to his parents into sending Shivaji to the workshop, which they believed he enjoyed.

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<sup>28</sup> Vedyanchi shala is a term that often came up during conversations with special educators when they talked about how their special schools, vocational centers, or workshops were perceived as “a school for crazy people” by members of the society who were not familiar with intellectual disability. Special educators and founders would often share with me how they would have to explain to these people that their organization did not cater to “crazy people” but instead to people whose brains did not work as quickly as others.

They also tried having a conversation with them about marriage and asked them if they had ever talked to him about what it meant to be married. They never received a straight answer about either him coming back to the workshop or his plans for marriage. According to Shivaji's father, it was Shivaji who had lost interest in the workshop. At present, Asha does not know whether Shivaji got married or not, but she still feels a deep sense of loss. While there is no certainty about whether Shivaji's parents truly wanted him to be married, Shivaji's example demonstrates that there were tensions between Ananda Foundation and the larger Karkamb community (at least as perceived by Jayant and Asha) about whether intellectually disabled adults could get married.

Thus, there was a divide between the life projects imagined for intellectually disabled people by people in Karkamb and Ananda Foundation. Those who belonged to the village of Karkamb approached and made them up as people who could participate in work at home and on the farm as well as marry. In contrast, Ananda Foundation was offering them a limited or restricted personhood within the workshop, which included spending their day at the workshop doing vocational activities, playing cricket, having lunch together, and listening to the radio. While Jayant and Asha were genuinely committed to turning Ananda Foundation into a space where they could eventually earn, as of now, there were no promising prospects on the horizon. In this context, going to the workshop, instead of being helpful to families, could prove disruptive to their families' everyday routine and cost them economically. Thus, Ananda Foundation was in a fix. In the next section, I demonstrate how the organization adopted a more context responsive approach by embracing the realities of their socio-cultural environment and in doing so, created value for their institution.

## **Working with what you have**

When I visited the Ananda Foundation in February 2022, Jayant and Asha were still in conversation with each other and me about how to “convince” rural families to send their adult children to the workshop. They were also struggling for funding, figuring out how to arrange transportation to and from the workshop, and trying to hold on to the six regular attendees. They even seemed a little nostalgic about Pune’s urban environment, its “open-minded” people, and the support their vision could have possibly received in a city as opposed to a village. Once I returned to the United States in September 2022 to write my dissertation, I continued keeping in touch with the couple, because I wanted to keep up with the trajectory of the institution. When I called Asha in June 2023, she was delighted to tell me that there were three new regular attendees at the workshop. She informed me that none of them were from Karkamb, but instead came from the adjacent village, Nematvadi. Nematvadi borders Karkamb on the side close to the Ananda Foundation (which is located on the outskirts of Karkamb). People travel two to three kilometers from their homes in Nematvadi to reach the Ananda Foundation, making it closer than most homes in Karkamb, which are approximately five kilometers away from the workshop. Nematvadi is similar to Karkamb in the sense that it too is a primarily agrarian village. However, it is smaller and less developed than Karkamb (for instance, Nematvadi does not have a mall). All the attendees who came from Nematvadi belonged to families whose income depended on daily wage labor.

Two of the three new attendees were a sibling duo named Bhushan and Mahima. According to Asha, no one in Nematvadi knew about their father’s whereabouts and their mother was an alcoholic, who often left them alone for days, during which time neighbors would take them in, and provide them with food. Given their circumstances, Asha shared with me that she

thought the priority was to provide them with shelter for a few hours a day and their afternoon lunch, which was prepared by her in her kitchen right below the workshop. Asha did not prioritize vocational training or teaching functional academics to Bhushan and Mahima. Instead, she responded to their need for shelter and food which transformed Ananda Foundation from a livelihood project into a social home. In doing so, Jayant and Asha repurposed the Ananda Foundation in response to those who inhabited their larger rural environment.

Ethnographic studies that focus on disability in rural Global South (Chaudhry 2016; Chaudhry 2018; Reynolds Whyte 2020) demonstrate the limitations of rural livelihood projects aimed at disabled people. Reynolds Whyte (2020) through her ethnographic research in rural Uganda examines how livelihood projects implemented by international humanitarian and development agencies rarely provided long term or sustainable income to disabled people, who often relied much more on their relationships with their families. In a similar vein, Chaudhry (2018) in her ethnographic study of disability microfinance projects of the World Bank in rural Telangana in India shows how microfinance loans, which were meant to encourage entrepreneurship among disabled people through the formation of self-help groups (SHG), often only benefited disabled people from privileged class, caste, and gender backgrounds. This was because microfinance loans, given out at low interest rates to those who wanted to use the money for income generation activities, were usually taken by disabled people who had pre-existing resources or family businesses, in which they funneled this money. In contrast, internal loans, given out at high interest rates, were taken by the more marginalized disabled members of the self-help groups who needed money, not for income generation, but for marriage expenses, food, education, and other basic needs. Thus, not only did rural livelihood projects fail to generate

income in a sustainable manner for disabled people, but these also exploited the most marginalized disabled people in India.

Even in Karkamb, the livelihood project (in the form of a workshop) was proving to be an ineffective intervention for the residents. In moving away from the life project of a livelihood project and embracing the possibility of Ananda Foundation being a social or respite home for some intellectually disabled people, Asha and Jayant demonstrated flexibility in the face of unfamiliar circumstances. Asha even framed rural communities as empathetic people (instead of backward or ignorant people in need of an education) while talking about the neighbors of their new attendees, Bhushan and Mahima. She shared with me that despite being unmarried, Mahima, a 35-year-old intellectually disabled woman, was dressed by her neighbors in the traditional attire of a married woman. She told me that Mahima would wear a saree, a *mangalsutra* (auspicious thread tied around a bride's neck during the wedding ceremony), and *jodve* (toe-ring worn by married women). When Asha asked Mahima's neighbors why she dresses like a married woman, they told her that they dress her this way for her own safety. They said that in a married woman's attire, men will leave her alone and will not try to take advantage of her. While she appeared to be amused when she shared this with me, she did not attempt to change anything about Mahima's attire or question the decision of her neighbors to dress her as a "married woman". Instead, she repeatedly praised them for caring for her and said, "No one in a city would have just taken in these two people and taken care of them the way these people did". Instead of lamenting about how they would have been valuable, legible, and connected to like-minded parent communities in an urban environment like Pune, by appreciating rural communities as kind and empathetic, Asha accepted and even embraced her current socio-cultural realities.



## **Surprising encounters with marriage**

Aside from re-imagining the Ananda Foundation as a social/respice home and shifting their attitudes toward Karkamb residents, Asha and Jayant also shifted their attitudes toward marriage in their recent encounters with one of their new attendees, Prakash. . Prakash was married and had a nine-year-old school going daughter. Asha was told by Prakash's neighbors that he was married at a young age to an orphan girl for "financial reasons". When Asha visited Jayant's home to recruit him, she noticed that he did not want to talk to his wife and kept gesturing to send her into the other room. She also found out that he sleeps at night with his mother. However, while recounting her visit to me, she did not dwell too much on Prakash's marriage. Instead, she told me that despite Prakash being a slow learner with significant communication issues, she was excited for his attendance. And the reason for her enthusiasm was Prakash's daughter, who according to Asha, was supportive of her father's attendance at the workshop and accompanied and assisted him whenever she had vacation from school.

In contrast to Shivaji, whose prospect of marriage had caused tension between Ananda Foundation and his family, in the case of Prakash, Asha and Jayant were flexible. They embraced rural ideologies and practices regarding marriage and personhood, which differed from their own values regarding intellectually disabled people's ability to marry. In framing Prakash's daughter as an asset instead of a burden, Asha accepted rural ideologies and practices of marriage. She did not enforce her own ideals regarding marriage- as something that needs to be consented to and rationally understood- and instead, accepted the relationship that these particular rural intellectually disabled people and their families shared with marriage. In the next section, I shift attention to the other aspect of Jayant's and Asha's life project, which was

securing companionship for Smriti within the workshop. What happens to Smriti's sexual and romantic personhood and future in Karkamb?

### **We didn't do enough: Reflections by Jayant and Asha on Smriti's sexual life**

“We are not closed to the idea of Smriti's marriage, but what she sees around here at Karkamb are traditional ideas of marriage. If we were in Pune, we could have done something, but here the dream feels far away”. Asha said these words to me over a Whatsapp call in July 2023. I had called her when I heard the news of Anwasha Sawant's and Vignesh Krishnaswamy's wedding—the wedding I mention in the third interlude. Asha knew Tejal, Anwasha's mother, from support groups and networks for parents of children with Down syndrome in Pune, and I was curious to know what she thought about the wedding. Comparing herself to Tejal, Asha said that replicating Tejal's story would be very hard for her. We went on to discuss Tejal's favorable material circumstances—her privileged financial position, strong familial networks, and experience and exposure to the United States. We then reflected on how Asha and Jayant did not have access to any of these perks. However, given that Asha knew of the ways in which Tejal systematically planned for Anwasha's marriage, she felt that she had fallen short in preparing Smriti for marriage. In her words, “Anwasha lived alone; we couldn't do it. There is so much to learn. To become stern and make them independent. We cannot even leave Smriti alone for more than two to three hours...we get worried. We see our limitations. We have to communicate on her behalf to let others know what she wants to do or say”.

Asha self-reflexively considered her own shortcomings in capacitating Smriti with the skills she thought were necessary to sustain a traditional marriage: independent living and normative communication. While the Lokhandes acknowledged their daughter's right to sexuality and even developed it at a young age by affirming her sexual curiosities as “natural”,

according to Asha, they did not (and could not) consider what it would mean for Smriti to articulate normative and relational forms of sexuality as she grew older. Unlike Tejal, who encouraged her daughter to “date”, however non-sexual the nature of this dating may have been, Asha and Jayant did not spend much time developing Smriti’s relationships outside their inner circle of cousins, aunts, uncles, and grandparents. Thus, Smriti, now a 28-year-old, had never experienced close intimacy with anyone outside her joint family. Additionally, unlike Anwasha, while Smriti was adept at helping her parents out with chores at home (she made tea, washed, and dried utensils, and folded laundry), according to her parents, she could not live by herself for long periods of time or communicate with outsiders without her parents being present. Thus, the world that Jayant and Asha had built for Smriti did not involve her socializing with outsiders and was oriented towards Smriti spending time with her immediate family and relatives. Incidentally, Smriti’s world was not that different from the worlds of some of her rural counterparts in Karkamb, who also spent most of their time at their homes, doing chores and socializing with their families.

Given these circumstances, Asha felt that Smriti was not prepared for the expectations of traditional marriage. While Jayant and Asha had accepted marriage to be a life-path for rural intellectually disabled adults, they did not think it was the right life-path for Smriti. Further, even though Asha never articulated this clearly, the socio-cultural, linguistic, and class differences that existed between the Lokhande’s and many of the families residing in Karkamb perhaps made it difficult for Jayant and Asha to imagine Smriti getting married to someone who was born and raised in Karkamb. While in their book written in 2010, Jayant and Asha had proposed the option of “companionship”, given their current rural realities in 2023, in the absence of like-minded parents, who were willing and able to assist relationships between

intellectually disabled people, Asha had concluded that actualizing the model of companionship seemed like a “distant dream”. She believed she and Jayant had fallen short as parents for not being able to figure out either marriage or companionship for their daughter and thought that they did not plan her sexual future in a systematic manner. Despite desiring and imagining a relational, companionate sexual personhood for Smriti, Asha thought that her lack of foresight and planning (around either getting her married or facilitating her companionship) as well as her perceived lack of socio-economic and urban privileges (compared to Tejal, who was upper class and had strong familial connections in Pune) had left Smriti in a situation where she could not experience sexual pleasure with others. Asha’s critical self-reflection resonates with Disability Studies scholarship that frames sexuality as a source of distress and exclusion (Finger 1992; Shakespeare 2000) for disabled people, especially disabled women, who are not considered responsible or capable enough to carry out the normative duties of marriage and motherhood (Ghai 2002; Addlakha 2007).

Indeed, unlike Anwasha, Smriti was not married. Further, unlike Geeta and Swarup, whose romantic and sexual companionship was constructed by Sarika ma’am and Sahil sir at Udaan, Smriti did not have a companion or partner at Ananda Foundation. However, I argue that viewing Smriti’s intimate life, only through the lens of “failure” or a lack is an incomplete analysis. Instead, it is important to note how Tejal’s life project for Anwasha and Sahil sir’s and Sarika ma’am’s life project for Geeta and Swarup were qualitatively different from the one imagined by Jayant and Asha. While Tejal’s and Sarika ma’am’s and Sahil sir’s projects were focused on actualizing marriage and companionship respectively, Jayant and Asha had imagined a two-pronged project, which involved securing Smriti’s future, including her sexual and romantic future, within their own workshop. While companionship was one of their life projects,

it was subsumed under the larger project of creating a workshop space. Further, while Tejal, Sarika ma'am, and Sahil sir appear to have implemented their life projects somewhat successfully, Jayant and Asha encountered many difficulties in setting up their workshop space and had to re-configure their imagined workshop space in a way that no longer afforded the option of companionship. Within these new circumstances and in the face of a so-called failed life project, I illustrate how Asha and Jayant created a new personhood for Smriti which entailed her being a "single, happy, working girl". In doing so, they made another adjustment to their original life-project. I demonstrate that singledom does not necessarily denote a lesser life. Instead, it can be viewed as a non-normative life-path with its own affordances.

### **Single, Happy, Working Girl as a new life-project and an alternative form of personhood**

When I met Asha and Jayant in 2022 in Karkamb, along with talking about building the Ananda Foundation, the couple was also eager to discuss a topic close to their heart- Smriti's sexual and romantic life. The couple shared that over the past couple of years, Smriti noticed her cousins getting married and started asking them when it would be her turn. They said that they were taken aback by her questions. In response to Smriti, Asha said in Marathi, "See, Smriti, you will have to cook for your husband and see how much married people fight! You can make friends in the workshop instead and work here. Single people are happier anyway". They talked to Smriti about marriage as an undesirable option, involving responsibilities and unpleasant experiences such as fights. Further, they also presented the alternative future of working at the workshop, a space where she could be single, happy, and surrounded by friends as being more desirable, although this was not the original vision they had.

Indeed, Asha and Jayant worked towards making up her personhood as a "single, happy, working girl", in Asha's words. For instance, in July 2023, Asha shared with me that the couple

had made the decision to get a Wi-fi connection at home. It was a significant monthly expense for them, given that neither of them was earning a steady income any longer. The decision was taken keeping Smriti in mind because they wanted her to be able to watch her favorite television shows on her mobile phone freely and privately. Further, they installed the wi-fi connection to also enable Smriti to take Casio and *Bharatnatyam* (an Indian classical dance) classes on zoom. Asha told me that while Smriti regularly did extra-curricular classes in Pune, they had to abruptly discontinue them when they moved to Karkamb. She was happy to see Smriti engaging in dance and music again and felt that these were significant avenues of happiness for her. Aside from seeing to it that Smriti could comfortably access entertainment and recreation, Asha and Jayant also wanted to train her to become a teacher at the Ananda Foundation in the future. They had trained her in skills such as using the computer and typing in Marathi. She was adept at carrying out the different vocational activities at the workshop. Recently, Asha had started teaching her how to sew using a sewing machine, because she was adding the activity of sewing towels and making towel bouquets for sale at the workshop (apparently towel bouquets are a popular gift item in the smaller town and cities in Maharashtra). Asha said that sewing was a difficult task for Smriti, given that she had Down syndrome and could not use her hands and fingers with ease. However, she was happy to report that Smriti was learning at a fast pace. Asha and Jayant intervened in different ways to occupy Smriti's time with meaningful activities.

Moreover, although Jayant and Asha were not comfortable leaving Smriti alone in their home for long periods of time, they were proud of the fact that she regularly visited Asha's sister's home, which was nearby, and even spent ten or more days there, by herself. She also shared that her sister appreciated Smriti's company because, unlike her sons, Smriti helped around the house, by doing chores, such as washing dishes and making the bed. Smriti also often

accompanied Asha during her work and personal trips to Pune, where she tagged along with her mother to sell the workshop's diyas to family and friends, conduct workshops on disability awareness, and social events, such as, weddings and birthday parties. She even performed at dance and music festivals that were organized by parent support groups and networks of special schools in Pune. Thus, Asha and Jayant had intervened with the intention of enriching Smriti with a full life. This life did not look the same as the future they had imagined in their book in 2010, wherein Smriti would have a companion among her intellectually disabled peers. However, within their current environment in rural Karkamb, which included Ananda Foundation grappling with establishing itself as a valuable organization for its residents and considering Smriti's specific support needs, Jayant and Smriti were working with what they had. They had adjusted to the personhood of a single, happy, working girl for Smriti.

While this personhood did not include relational sex acts, companionship, or marriage, , it included Jayant and Asha opening multiple avenues of pleasure and stimulation for Smriti, such as, learning new skills, pursuing artistic hobbies, watching television of your choice privately, attending, and performing at social events, and bonding with your extended family. I argue that although nonnormative, Smriti's life and its pleasures should not count as a lack of sexuality. Instead, it should be viewed as an unconventional and open-ended form of sexual personhood. In doing so, I expand the category of sexuality beyond the "charmed circle" (Rubin 1984) of hetero-normative sexuality to add "single, happy, working, girl" to the list of nonnormative, peripheral, and invisibilized sexual personhood(s). To analyze Smriti's status as a single, happy, working girl, I draw on recent scholarship in the field of "single studies" that highlights the ways in which singledom can be a satisfying and empowering life-path, especially for women (Lamb 2022; Chowkhani 2022). Sarah Lamb in her ethnography (2022) with single

women in India explores how despite facing systematic marginalization and hardships, single women, especially those with financial independence, had fun and pleasurable experiences. Lamb engages with single women with various sexual and romantic arrangements, ranging from those who have sex with their male lovers, queer women, and those who do not have sex at all. Unlike Smriti, the single women in Lamb's ethnography articulate themselves as "single" women. However, I argue that precisely because of Smriti's non-normative communication and her support needs, it is valuable to recognize her as a single woman capable of experiencing pleasures as well.

I was left with many questions about Smriti's sexual desires. I wondered- maybe Smriti still watches porn on her phone now that she has an wi-fi connection at home? Or maybe, just like her parents observed, she is no longer interested in watching physical intimacy on screen and rolls her eyes if she comes across such a scene? I was left wondering whether Smriti enjoys performing in front of a larger audience. Whether she experiences pleasure when she attends social events in Pune? While I do not have answers to these questions, Jayant and Asha had made up a world, within Karkamb, in which it was possible for Smriti to experience multiple pleasures, sexual or otherwise.

When I visited the Lokhandes in 2022, I observed Smriti as embodying the role of a single, happy, working girl. She appeared to be at ease with her life at the workshop and in Karkamb. She would do her assigned household chores (which involved making tea and wiping and arranging washed dishes), meet with her relatives who visited them often, watch her favorite television shows, and do the activities at the workshop that she most enjoyed as she listened to old Hindi songs on the radio. On my last day in Karkamb, Smriti came up to me and asked me, "So, did you like our workshop?" I understood Smriti's usage of the term "our" as reflecting her



stake in Ananda Foundation. This was not just Jayant's and Asha's life project; it was also Smriti's. While it was not what Jayant and Asha had imagined, they had managed to secure a very different future for themselves and Smriti in Karkamb.

## Conclusion

### **Reckoning with unrecognized and lost possibilities**

I want to end by going back to the very beginning of the dissertation: to Sarika ma'am's interventions with Geeta. I want to consider what was lost when Sarika ma'am noticed Geeta's behavior of using the glass bottle near her genitals and, after experimenting with possible interventions, ended up deciding that the best of course of action would be for Geeta to hold hands with Swarup. While Sarika ma'am's decision to pair Geeta and Swarup had long term consequences for them given that, within Udaan, they were framed as a "husband-wife" duo who held hands, lived together, and even cuddled and kissed sometimes, I cannot help but wonder what possibilities were lost for Geeta when Sarika ma'am replaced her self-directed behavior with a companionate relationship. What if Sarika ma'am had replaced the glass bottle with a safe but similarly hard or rough textured sex toy? What if she had come up with a comprehensive sex education plan where she talked to Geeta about masturbating in private spaces and facilitated the same for her? Would that have been more in line with Geeta's desires?

While there is no way for me to know for certain whether the romantic and sexual companionship made up by Sarika ma'am for Geeta was better or worse than the option of providing her with a sex toy, I bring up this alternative to point to the fact that when special educators intervened to make up specific personhood(s) for intellectually disabled adults, they also closed possibilities in the process. In shaping a romantic companionate life-path for Geeta, Sarika ma'am might have foreclosed the possibility of Geeta exploring her sexual personhood further and in a different way. Throughout my fieldwork, across various field-sites, I noticed special educators interpret what intellectually disabled adults felt, thought, and needed. There

were many times I questioned their judgement. Despite these doubts, instead of focusing on how their interpretations were perhaps imperfect, I chose to focus on the consequences of their interventions and document the kinds of personhoods these produced. However, in the conclusion, I want to make space to attend to what was lost or what could have been by imagining alternative possibilities. What if instead of intervening in a top-down manner wherein they called the shots regarding who intellectually disabled people were as persons and what they could or could not do, special educators had intervened in different ways? How would that have affected intellectually disabled people's personhood and the opportunities presented to them? I want to consider both liberal and individualistic models that arise from a disability rights perspective as well as seemingly non-liberal models that prioritize fostering relationships of care and dependence.

For instance, taking Geeta's and Swarup's example further, I want to consider what would have happened if Sahil sir and Sarika ma'am had adopted a rights-based approach which saw Geeta and Swarup as self-advocates who could determine the course of their own lives? Would they have spent more time trying to understand what Geeta meant by putting the glass bottle near her "pee-hole"? Would they have provided her with more choices, instead of deciding that she wanted to hold hands with Swarup? If Sarika ma'am and Sahil sir had attempted to facilitate her autonomy, would Geeta have refused the intervention of holding hands with Swarup?

Further, I could not help but wonder whether Sahil sir and Sarika ma'am could have come up with ways to intervene in Geeta's life that did not involve teasing her about Swarup or taking her out to restaurants and movies. While significant, these were intermittent and limited interventions. There were many moments on an everyday basis that Geeta spent pacing up and

down the rooms at Udaan by herself, looking visibly unhappy and irritated, while the rest of the educators and attendees continued working on their vocational or artistic tasks. What would have happened if Sahil sir and Sarika ma'am had dug a little deeper and tried to find out if there were any activities, aside from eating and watching television, that Geeta enjoyed? She did not seem to enjoy painting diyas or playing the Djembe, but maybe they could have provided her with more choices to find out if she enjoyed some other form of work or recreation that would have kept her occupied alongside her peers at Udaan. Although Geeta was approached as an "appreciating subject" (Driessen 2018), would capacitating her with skills instead of only indulging her, produced opportunities for her that kept her occupied in ways that made her less restless and even more joyful? (although to be clear, Sarika ma'am and Sahil sir shaped Geeta and the other attendees as well as themselves as joyful and fun people)

I also think about Darshan, the nonverbal autistic man at Sankalp in Sandhya maushi's class, who appeared to enjoy grabbing Sandhya maushi's mobile phone, playing a specific ringtone, and running up and down the classroom giggling. Initially, Sandhya maushi used to laugh whenever he grabbed her phone. However, she had to eventually stop him from doing the same because she was afraid that a donor might see Darshan behaving in this manner and have a bad impression of Sankalp. She would scold him and instead ask him to fold dusters or recite the alphabet. What would have happened if Sandhya maushi had allowed Darshan to continue grabbing her phone? In contrast to Geeta, Darshan was not allowed to be an "appreciating subject" and was approached through the framework of productivity and discipline. Further, there were many intellectually disabled attendees at Sankalp, who were categorized as "children who sat," who sat and napped most of the day at Sankalp. Although sitting and napping were forms of occupation through which people accessed rest, respite, and social connection, what

would have happened if the administrators at Sankalp considered the possibility of expanding their vocational activities beyond sewing and folding dusters and shredding paper, and introduced activities that people who otherwise sat or napped could proactively participate in? Would that have completely changed who was categorized as a “good child” and who was viewed as a “child who sat”? Would these categories have stopped existing altogether?

Finally, turning to the last field-site, Ananda Foundation, I imagine what would have happened if Jayant and Asha had still actively pursued the facilitation of Smriti’s sexual and marital life instead of making her up as a “single, happy, working girl”. What would have happened if they had assimilated further with the residents of Karkamb and had tried to arrange Smriti’s marriage with someone within the village? Would that have created different kinds of life opportunities for Smriti? Would a married life in Karkamb been more aligned with Smriti’s desires for marriage?

Aside from these liberal possibilities, I also want to consider what would have happened if special educators approached intellectually disabled people as dependent recipients of care? For instance, what if instead of making up intellectually disabled people as productive, disciplined and obedient workers at Sankalp, special educators made them up as recipients of care who did not have to work to be accepted at the institution? What if the special educators at Sankalp were trained to care for the bodies and minds of their attendees and were explicitly asked not to discriminate among them based on their abilities? How would that impact the kind of persons intellectually disabled people would become in these institutions?

While I do not intent to say that these alternative possibilities that I imagine here are better or more effective than the ones provided by special educators at my field-sites, I want to draw attention to the fact that intellectually disabled adults were almost never offered multiple

possibilities in these institutions. They could not occupy multiple positions and roles at the same time. They could not inhabit complex forms of personhood, wherein they could be productive, appreciating, and problematic, all at once. For instance, if they were categorized as good children who were productive, they were instructed to spend most of their time on sewing machines, without much respite. Or if they were slotted as problematic, such as Anu at Sankalp, they were only viewed through the lens of their supposed problem behaviors. By noticing, interpreting, and making decisions about their lives, special educators made up intellectually disabled people as persons who could communicate, work, do timepass, have fun, flirt, and even cuddle and kiss. However, the terms of these opportunities were decided by special educators and were restricted to the institutions. In creating these personhood(s), special educators also foreclosed multiple possibilities for them. To be clear, I recognize the work that special educators did in shaping opportunities and life-paths for intellectually disabled adults. As I have documented in the dissertation, I often observed special educators make generous and creative interventions, wherein they attended to the nonnormative articulations of intellectually disabled adults, listened to what their families needed or wanted for their futures, and made available opportunities for them to work, rest, socialize, and have fun. However, I suggest that the constrained environments within which special educators worked, wherein they often had to do multiple tasks at the same time, be answerable to administrators and parents who did not take their expertise seriously, do their work for low salaries, and run their organizations without ample funding, influenced the kind interventions they made.

For instance, if Sandhya maushi did not fear being reprimanded by her administrators, she may have been able to allow Darshan to continue grabbing her phone to listen to the ringtone and run around. In another example, I think of Shalini, a young woman at Sankalp, who often

repeated the phrase, “Will you go to Bal Kalyan? I will be singing there!”, only to be routinely ignored by Kulkarni maushi, the special educator in charge of her section. Whenever Shalini said this phrase, Kulkarni maushi was usually working on finishing a quota of sewing dusters, writing in the diaries of her attendees, delegating work to the *madat-nis* ( helper or assistant) or instructing one of the other twenty women attendees who were in her section. Granted there were also times during which Kulkarni maushi appeared to be doing “nothing”, sitting around, and looking at her phone when Shalini said this phrase. But she usually took this time off because of how overscheduled the rest of her day was.

I cannot help but think of the possibilities that could emerge if special educators were given fewer work responsibilities. For instance, if Kulkarni maushi had less tasks and more time to spare, would she have interpreted Shalini’s words as being indicative of her interest in music? Would she have pursued this line of thinking and made available opportunities for Shalini to explore her interest in music? Or in another example, if Udaan had more financial resources to hire more staff members (at present Sonali ma’am is the only regular staff member aside from Sahil sir and Sarika ma’am), would Swarup’s helper duties be reduced? If Swarup had lesser chores to do around Udaan, would he be able to develop other interests or simply spend some time resting and hanging out with friends? Additionally, even though it is significant that special educators learned most of their skills on-the-job from their colleagues and from experience, I wonder how they would have interacted with intellectually disabled people if they were exposed to an academic curriculum which introduced them to different ideologies and strategies of engagement? What if special educators in India were exposed to ideas of disability rights and self-advocacy? Would they abandon their top-down interventions in favor of a more collaborative and facilitative approach?

While I cannot know with certainty that providing special educators with more resources, time, recognition, and training would result in intellectually disabled adults having more diverse opportunities and social roles, I suggest that it is important to think about the two groups as being interconnected and interdependent. It is vital for policymakers, institutional administrators, and parents of intellectually disabled people, to take seriously the ways in which special educators shape the life-trajectories as well as day-to-day lives of intellectually disabled adults and to capacitate them to make innovative, creative, and sustained engagements which could open up multiple possibilities for intellectually disabled adults

Further, even though this dissertation has focused on the relational context between special educators and intellectually disabled people within institutions, I want to reflect on possibilities beyond these segregated spaces, which include the integration of intellectually disabled people within mainstream society. As I mentioned in the introduction, intellectually disabled people live on the peripheries of mainstream Indian society, wherein they usually cannot access decent educational or employment opportunities, exist in public spaces without supervision, or participate in social institutions, such as marriage or parenthood. Thus, along with thinking of ways to improve segregated institutions of special education, it is also important to develop strategies and policies (both within institutions and outside) which assure that intellectually disabled people have options outside vocational centers, workshops, and residential facilities. This is not a task that can be taken on just by these institutions in isolation. Instead, there need to be collaborations among policymakers, non-government institutions, academics, and families of intellectually disabled people. Importantly, these collaborations must involve intellectually disabled people as well. While it is important to acknowledge the fact that as it stands, intellectually disabled people in India may have to spend the rest of their lives within



segregated institutions, I want to imagine possibilities wherein these spaces are not inevitable, and people can leave these institutions to become different and complex kinds of persons who exist and thrive in diverse public spaces and occupy complex social roles.

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