

**International  
Institute of  
Social Studies**

The Erasmus logo is a stylized, handwritten-style script of the word "Erasmus" in a dark grey color.

**Navigating inclusion:  
Evaluating the internal and combined capabilities of children with  
cognitive disabilities in Bengaluru, India**

A Research Paper presented by:

**Shravya Sharath**

(India)

in partial fulfilment of the requirements for obtaining the degree of  
MASTER OF ARTS IN DEVELOPMENT STUDIES

Major:

**SPD**

Members of the Examining Committee:

Dr. Irene van Staveren

Dr. Roy Huijsmans

The Hague, The Netherlands December 2023

***Disclaimer:***

This document represents part of the author's study programme while at the International Institute of Social Studies. The views stated therein are those of the author and not necessarily those of the Institute.

***Inquiries:***

International Institute of Social Studies  
P.O. Box 29776  
2502 LT The Hague  
The Netherlands

t: +31 70 426 0460  
e: [info@iss.nl](mailto:info@iss.nl)  
w: [www.iss.nl](http://www.iss.nl)  
fb: <http://www.facebook.com/iss.nl>  
twitter: [@issnl](https://twitter.com/@issnl)

***Location:***

Kortenaerkade 12  
2518 AX The Hague  
The Netherlands

# Contents

<i>Acknowledgments</i>	<i>iv</i>
<i>List of Figures</i>	<i>v</i>
<i>List of Appendices</i>	<i>v</i>
<i>List of Acronyms</i>	<i>v</i>
<i>Abstract</i>	<i>vi</i>
<b>Chapter 1 – A life with dignity and freedom: Unlocking the capabilities of children with cognitive disabilities</b>	<b>1</b>
1.1 Site of the research	2
1.2 Inclusion criteria	3
1.3 The macro picture: The current state of children with cognitive disabilities	3
1.4 Theoretical background and the Capability Approach	5
1.5 The Research Objective	8
<b>Chapter 2 – Balancing agency and care: The transversality of childhood and disability research</b>	<b>9</b>
2.1 Sampling and data collection	10
2.2 Appraisal of the methodology: Multi-level post-structural approach to ethnography	11
2.3 Ethical considerations	12
2.4 Positionality	13
2.5 Limitations of the research	14
<b>Chapter 3 – Demographic mapping of cognitively disabled children and their households</b>	<b>16</b>
3.1 Contextualising the household of cognitively disabled children	17
3.2 Education and school enrolment	19
3.3 Chronological and social age	23
3.4 Household income and parental occupation	25
3.5 Gender disparity in the diagnosis and care of children with cognitive disabilities	28
<b>Chapter 4 – The evolving nature of valued capabilities</b>	<b>31</b>
4.1 Politics of the household	34
4.2 Influence of social institutions	34
4.3 The double economic burden of disability	35
4.4 Scope for further research	35
4.5 Reflexivity and conclusion	35
Appendices	37
References	42

## Acknowledgements

Working on this research paper has been a rollercoaster ride of emotions, reflections and learning. I have many people to thank and acknowledge for supporting me, keeping me accountable and helping me realise the vision I had. Firstly, I dedicate this research to late Dr. M. V. Ashok, my dear uncle, an accomplished Child and Adolescent Psychiatrist and an internationally acclaimed pioneer in a field of autism research, whose life was cruelly cut short earlier this year. His passion, compassion and zeal has always inspired me, and has been guiding light for this research. I would like to thank my aunt Dr. Vijaya Raman for her invaluable advice in framing appropriate questions for interviews, for her help in procuring the permission for me to conduct my research at St. John's Hospital and for always lending an ear to discuss my observations throughout fieldwork. I thank my parents - for always being my rock and allowing me to be and do everything I have ever wanted to.

Thank you, Irene, for your constructive and empathetic guidance as my supervisor. Your insightful feedback has helped me structure my arguments and has been crucial to helping me over the finish line. Thank you, Roy, for the ways in which you pushed the limits of my thinking and helped me embrace ethnography as my methodology. I have learnt so much in the Ethnographic Research and Child, Youth & Development courses that has given me the foundation for this research. Thank you, Karin, for your kindness and support throughout this Masters programme that has been more valuable to me than you could know. Throughout my life, I have been blessed with remarkable teachers who have guided and mentored me, and who I am today is a testament to their kindness and counsel. There are no words that can sufficiently convey my gratitude.

I want to thank my friends and colleagues at the ISS for the wonderful memories we have made together and all that I have learnt from them. I also want to thank my friends back at home, most importantly Nilanjana, who has proofread this research paper and always been a pillar of support for me, and Snehashis, who has kept me sane throughout all of this.

Finally, I am extremely grateful to the children and caregivers who trusted me with their stories and took a chance on me by participating in this research. I hope by representing the multiplicity of cognitively disabled children's lives to the best of my abilities, I have done justice to them.

## List of Figures

Figure 1.1: Achievement of valued functionings in the Capability Approach	7
Figure 3.1: Religion and caste of the participants	16
Figure 3.2: School enrollment in participating children	19
Figure 3.3: Chronological ages of participating children	24
Figure 3.4: Classification of household income of participants	26
Figure 3.5: Parental occupation of participating children	27

## List of Appendices

Appendix 1: 10 Central Capabilities	37
Appendix 2: Participant Information Form	39
Appendix 3: Questions with visual cues for children	40
Appendix 4: Questions for the child's caregiver or responsible adult	41

## List of Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CA	Capability Approach
DSM	Diagnostic and Statistical Manual of Mental Disorders
ID	Intellectual Disability
MLA	Member of Legislative Assembly
OCD	Obsessive Compulsive Disorder
OPD	Out Patient Department
PRICE	People Research on India's Consumer Economy
RPWD	Rights of People With Disabilities Act
UNCRPD	United Nations Convention of the Rights of Persons with Disabilities
UNCRC	United Nations Convention of the Rights of the Child

## **Abstract**

This research focuses on situating the experiences of inclusion of children with ASD and ID in Bengaluru, India. Claims and findings are attributed to primary fieldwork including ethnographic observation and semi-structured interviews with children with cognitive disabilities and their caregiver(s) at St. John's Hospital in August and September 2023. The paper seeks to make a methodological contribution to childhood disability by employing Capability Approach as an analytical guide to ethnographic research on what inclusion means to children with cognitive disabilities, what they value and enjoy, what capabilities are valued by caregivers, and how the household creates opportunities for the development of valued capabilities. The capabilities framework is not a totalising theory for assessing the capabilities and inclusion of participants but instead, it is used as a tool to navigate the complexity of cognitively disabled children's experiences and tack on to myriad theoretical understandings of disability and childhood.

The findings reveal the evolving nature of children's agency and capabilities, along with the evolving value placed by caregivers on different capabilities at different critical periods of development. The politics of the household meant that an alignment between caregivers and children on what is valued was associated with better outcomes, and fewer behavioural problems and higher language abilities in children themselves. The capability-constraining or enhancing influence of social institutions such as gender, age, education, healthcare and social attitudes on impairment, and how an income-using disability can exacerbate the existing income-earning handicap are discussed.

## **Relevance to Development Studies**

Policy and discourse on cognitively disabled children in India has been limited to inclusive education which has indeed led to greater inclusion in schools and employment. However, the social and environmental constraints that exclude cognitively disabled children from pursuing what they enjoy and value on an equal footing with their peers remain. This could be linked to the impossibility of separating an individual from society and a disabled child from its household, thereby providing a gap in research on locally contextualised understandings from cognitively disabled children and their caregivers on what inclusion means to them, what capabilities they value and what opportunities exist for the development of valued capabilities. By critically examining notions of inclusion and agency, and by considering disability as one axis of inequality, this research aims to use the Capability Approach to call attention to where cognitively disabled children's lives fall below the central requirements for a life with dignity.

## **Keywords**

Children; disability; Autism Spectrum Disorder; Intellectual Disability; inclusion; capability approach; ethnography; household

## Chapter 1 – A life with dignity and freedom: Unlocking the capabilities of children with cognitive disabilities

7-year-old Jeet<sup>1</sup> is a happy, well-mannered boy who enjoys playing cricket with friends, colouring and spending time with his 1-year-old brother. He is thoughtful, caring and likes to help around at home by wiping the dining table after a meal, unloading clothes from the dryer, filling his little brother's water bottles and watering the plants as he talks to them. While he might not be the best listener, he enjoys practical learning and watching videos on topics that interest him. He is popular with children his own age, his friends encourage him and seek out his company in class. For four hours everyday in school, a shadow teacher assists him as he learns numbers, writing and comprehension alongside his classmates. She gives him individual attention where he needs it and is often a bridge between Jeet and his classmates to ease his learning experience as a student with mild to moderate Autism Spectrum Disorder.

Jeet's parents gratefully recall his 1st grade teacher who allowed him to wander around the classroom and created a positive learning environment for him by explaining his condition to the other children in terms they would understand. Jeet is fortunate that he comes from an affluent household with well-educated parents who recognised the difficulties he was facing in time. He received a diagnosis when he was 4 years old and his father was quick to recognise the importance of early intervention in ensuring better outcomes for children with ASD. What makes Jeet's case unique among the participants of this research is the near-complete alignment of what he values and enjoys doing most and the capabilities his caregivers value most in his life. Jeet's happiness, independence to perform activities of daily living, ability to make decisions and "be reasonably okay" is the limit of his father's expectations for his life. His mother says:

*"We want education that allows him to go at his own pace. We want him to participate in extracurricular activities and become more independent. He has the capability to do it."*

His parents are aware that it will take a lot of effort for him to be in a place where he can eventually live independently. "Change takes time", says his father as he remembers how long it took for Jeet to start writing or to even toilet-train him. They would have to hold his hand and make him write, but now he writes on his own for several minutes at a time when he is in the zone. They never expected him to pick up writing so quickly. They know not to push him academically as they know how uncomfortable it makes him, he decides when he is done eating or when he is done with screen time. They believe that allowing him to make his own decisions will teach him how to control himself and fortunately, it has worked. Despite how positively this family has negotiated the practical implications of their child's disability, there have been difficulties. Finding the right school that is equipped to support him and accept him was not easy. They found that many schools that claimed to be inclusive were equipped only to support children with learning disabilities and not those with ASD or ID. The curriculum in schools is rarely modified to accommodate children with special needs, according to Jeet's mother:

*"He may learn one unit while other children learn five. Syllabus is never simplified for special kids. He cannot do everything that neurotypical kids do. He is forced to sit in class for long hours."*

---

<sup>1</sup> All names have been changed to protect the identity and privacy of participants.

*He is compelled to sit in Hindi and Kannada class although he finds it difficult to pick up new languages. Many schools refuse to accept special children. It is understandable when children have extreme behaviours, however, those on the moderate side should be accepted into normal schools”*

According to Jeet’s father, finances are a major pressure point:

*“Enormous amounts of money have been invested in speech therapy, occupational therapy and special education. The moment you say you have a special child, the rates shoot up. We have already spent more on his education than we spent on our own school and college educations. There are some families who simply cannot afford it.”*

Jeet’s story is one of a highly idealistic outcome for a child with ASD. Higher socioeconomic status, parental education and an alignment between the child and caregivers on what is valued has made it so. Higher maternal education, both parents living in the same household and higher family SES have all been associated with lower age of diagnosis, early treatment and amelioration of core symptoms (Dawson et al., 2011; Hrdlicka et al., 2023). However, even in this optimistic scenario, the social and environmental structures that have interacted with one's personal feature (impairment) to create barriers against those with cognitive disabilities are discernable. This study aims to impose the capability approach as an analytical tool to illuminate what ‘inclusive’ actually means to children with special needs, what capabilities they value along with their caregivers and how these capabilities may be developed. In this chapter, I will situate our sample of participants, define the criteria for inclusion, address the legislative and theoretical background for disability research in India before elaborating on how the capability approach framework helps us see disability’s relational aspects.

## **1.1 Site of the research**

St. John’s Centre for Children with Special Needs (also called The Unit of Hope) is a unique, multidisciplinary centre in Bengaluru, India. It was established in 2004 by St. John’s National Academy of Health Sciences with external funding from Christoffel Blinden Mission “to provide comprehensive, holistic care under a single roof to children with developmental disorders and disabilities including autism spectrum disorders, intellectual disabilities, genetic syndromes, cerebral palsy, visual/hearing/sensory impairments and neuromuscular disorders.” At the Unit of Hope, doctors from Paediatrics, Orthopaedics and Community Health join together to streamline rehabilitation services, provide assessments, short-term therapy, speech therapy, physiotherapy and special education services at a single site within the campus of the medical college hospital.

In keeping with the mission of St. John’s, the Unit of Hope aims to “reach the unreached” by subsidising the cost of services provided to families of children with disabilities and by providing cost concessions to deserving families. The centre “predominantly caters to families of children with disabilities from financially constrained backgrounds coming from remote rural areas of Karnataka, Tamil Nadu, Andhra Pradesh and West Bengal through subsidised cost for all services and provision of concessions for deserving families” (Unit of Hope, 2022). Beyond the Unit of Hope, a team of child psychiatrists, psychologists and medical fellows are available to provide diagnostic assessments,



psychological care and medical intervention where needed to children with cognitive disabilities in the OutPatient Department (OPD). The goal at the Unit of Hope is to “strengthen the inherent potential of every child and limit the challenges faced to help build a better quality of life for the child and the family.” (ibid.)

## 1.2 Inclusion criteria

The inclusion criteria for the sample was children in the age group of 6-18 years with autism spectrum disorders (ASD) or intellectual disability (ID).

DSM-5 provides three criteria for the diagnosis of intellectual disability:

- Deficits in intellectual functioning in areas like problem solving, reasoning, learning and planning.
- Adaptive life skill deficits in the conceptual, social and practical domains
- Onset of intellectual and adaptive deficits in the developmental period

DSM-5 criteria for an autism diagnosis includes impairment in social communication and restricted, repetitive and/or sensory behaviours or interests (American Psychiatric Association, 2013).

This study is limited to children with cognitive disabilities and hence the maximum age of participation was set at 18. Children with cognitive disabilities below the age of six were excluded from this study due to perceived difficulties in explaining the research process and questions, seeking assent and meaningfully engaging with children below six in an interview when their own ideas surrounding what they value might not be sufficiently evolved. ASD and ID are the two most commonly co-occurring neuro-developmental disorders (Mpaka et al., 2016). Recent research (Frega et al., 2020) shows that there may be shared or overlapping genes that link these two complicated disorders. In cases of comorbidity, separation of the two disorders and diagnosis is even harder. Besides genetic similarities, impairment in social communication is another area where autism and intellectual disability converge. The two disorders are sometimes similar, but not synonymous. Due to the similarities that the disorders share and the high tendency of individuals experiencing comorbidity, children with both Autism Spectrum Disorders and Intellectual Disability are included in this study under the banner of children with cognitive disabilities.

## 1.3 The macro picture: The current state of children with cognitive disabilities

### 1.3.1 *The Legislative framework for persons with disability in India*

The Rights of Persons With Disabilities Act, 2016 (RPWD), is some of the most recent legislation on the rights of the disabled in India in line with the United National Convention on the Rights of Persons with Disabilities (UNCRPD) which India ratified in 2007. The Act identifies 21 types of disability. For Children With Disabilities (CWDs), it provides the legislative framework for inclusive education as “a system of education wherein students with and without disability learn together and the system of teaching and learning is suitably adapted to meet the learning needs of different types of students with

disabilities” (Government of India, 2016, p.6). While this research found that children with disabilities and their caregivers did indeed value inclusive education, they frequently found that schools were inclusive in name only as they did not provide the necessary supportive framework for all children to have the same opportunities in all aspects of life. Besides, they also faced problems of poverty, social exclusion and stigma, and lack of access to information and resources. The most recent available nationwide statistics from Census 2011 which only identified seven forms of disability indicated that 2.21% of the population lives with a disability. This is significantly lower than the World Bank and WHO’s estimate that approximately 15% of any population lives with a disability (World Health Organisation, 2011). This discrepancy suggests a major backlog in diagnosis and care resulting from a lack of investment in understanding the needs of children with disabilities.

The National Trust Act, 1999 was important legislation for people with Autism Spectrum Disorder, Intellectual Disability, Cerebral Palsy and Multiple Disabilities as the Trust was set up with the objective “to enable and empower persons with disability to live as independently as possible within and as close to their community as possible, to facilitate the realisation of equal opportunities, protection of rights and full participation of persons with disability and to evolve procedures for appointments of guardians and trustees for persons with disabilities” (National Human Rights Commission, 2022, p.23). Disha (an early intervention and school readiness scheme), Vikaas (day care scheme for persons with disabilities to develop interpersonal and vocational skills), and other schemes around health insurance, caregiver training and group homes for adults with ASD, ID, cerebral palsy and multiple disabilities were set up under the act. However, most of these schemes are dependent on non-governmental organisations registered with the Trust to set up centres and execute these interventions, aided by funding. In the present day, many individuals with disabilities are unaware of these schemes, there are limited centres across the country, and people with disabilities have to pay beyond their means even if they are eligible to benefit from a scheme.

### **1.3.2 *Navigating the domestic sphere***

Research by Forrester-Jones R, et al. (2006) suggests that inclusion of children with disabilities in rehabilitation, education, cultural and recreational activities are all important to promote self-esteem, confidence, mental health and happiness. Simplican et al. (2015, p.18) defines inclusion as “interaction between two major life domains: interpersonal relationships and community participation”. Households are the first instance where children form interpersonal relationships. The role of the household has been found to be increasingly important for inclusion of children with disabilities as the majority of their social relationships are mediated by members of their household (Masquillier et al., 2021; Amado et al., 2013). Especially in case of cognitive disability, the responsible adult or caregiver within the household plays a significant role in the inclusion of the disabled child and their experience of life. The UN Convention on the Rights of the Child recognises that a household with children or family “as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community” (UN General Assembly, 1989, p.1).

Reichman et al. 's (2008, p.690) research in the US revealed that family situation influences a disabled child’s well-being and the child’s disability in turn “can have profound effects on the entire

family” including detrimental changes to finances, careers, time allocations, and health. The household constitutes the essential unit of social organisation in daily life, “negotiating the social, economic and cultural meanings of disability” (Richard, 2014, p.308). Das et al., (2001, p.512) suggest that the “domestic sphere” is where families negotiate the practical meaning and lived realities of disability as presented to them in discourses of biomedical establishments, the state and the religious, cultural and economic context they inhabit. The household’s perception of a child with disabilities, influenced by all these externalities is what determines the child’s family life, access to resources and development opportunities.

### **1.3.3 *The need for inclusion: The impossibility of separating the individual from society***

Inclusion is a subjective construct, often discussed in opposition with exclusion, which refers to the “stigmatisation and marginalisation of groups of people based on characteristics like gender, race, disability, or socio-economic status” (Le Boutillier et al., 2010, p.137). Children with cognitive disabilities need to overcome many social, political and economic barriers to be meaningfully involved in society, make friends, participate in community activities, engage in leisure and play (Hill et al., 2004). Research on inclusion and participation in adults with disabilities by Hammel et al., (2008, p.1445) found that what they valued most was “the freedom to define and pursue participation on their own terms rather than meeting predetermined societal norms”. Children’s views may resonate at least to a certain degree with adult’s conception of inclusion.

While there is growing awareness about the need for inclusion at schools, jobs and recreation, there is a need to go beyond this to understand what inclusion means to children with cognitive disabilities. Amado et al. (2013) has emphasised the need for researching inclusion by focusing on the experiences and attitudes of community members and not only on individuals with disabilities. Research on inclusion of children with cognitive disabilities in Uganda (Masquillier et al., 2021) revealed that depending on the characteristics of the child, caregiver and household, the disability either causes an upward spiral towards visibility or downward spiral towards concealment or reinforcement of stigma within the household. This research aims to go beyond examining the effect of disability on household members by identifying what children with cognitive disabilities and their caregivers value, and to what extent they can have and be what they value. Mehrotra (2012, p.4) has suggested that the most important methodological issue in disability research is “the (im)possibility of separating the individual from society”. She advocates for building a knowledge base for pushing disability agendas in an increasingly globalised world by identifying disability as one axis of inequality and critically examining notions of exclusion, discrimination and empowerment. In an effort to do this, the study examines cognitive disability as one axis of inequality among the participants’ gender, age, class and caste.

## 1.4 Theoretical background and the Capability Approach

*“Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”*

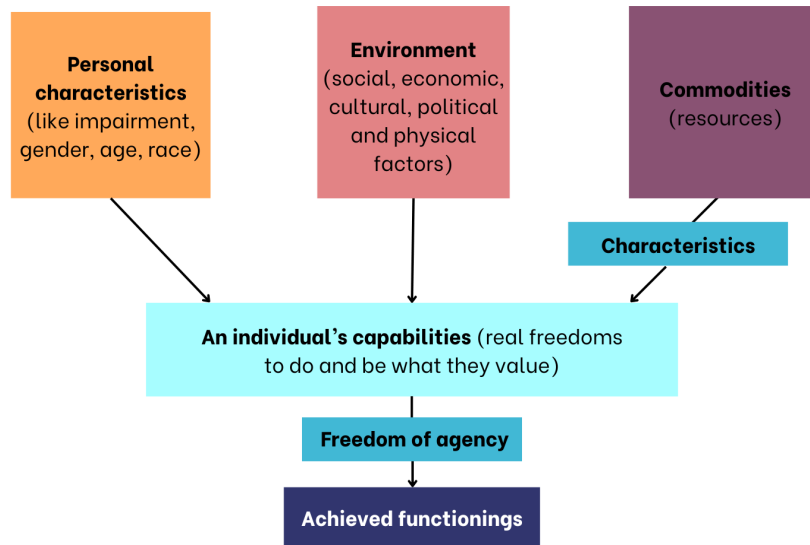
- UN Convention on the Rights of People with Disabilities (UN, 2006)

There are various theoretical perspectives on disability and these form the basis for policies designed to cater to people with disabilities and the practice of how people with disabilities are treated in the world. The social model of disability situates the problem of disability within society that excludes or devalues persons who do not fit into standards of normality (Skinner and Weisner, 2007, p.304). The biomedical model on the other hand, situates the problem of disability within the mind or body of the individual and places the burden of adhering to social norms on them (Landsman, 2005, p.125–126). In the biopsychosocial model, disability is both a medical diagnosis and social construction, involving interactions between the environment and the child’s health.

In this research, the egalitarian perspective of disability as emerging from the interlocking of personal, social and circumstantial factors provides the basis for conceptualising disability as an inability to function in a world that is not designed with the disabled individual in mind. Sen’s Capability Approach (1992) positions heterogeneity and human diversity as central to addressing equality, and evaluating individual advantages and disadvantages. Impairment is a personal feature that may affect certain functionings, and when it interacts with specific social and environmental structures, it becomes a disability. Functionings are what individuals achieve by being and doing. Viewing disability as a restriction of functioning and so, a narrower range of capability helps to see “disability’s relational aspect” with respect to impairment and the design of social and environmental arrangements (Terzi, 2005, p.458). Disability can also be viewed as deprivation of capabilities resulting from the interaction of the personal and external features (Mitra, 2006).

As per CA, an individual “converts the vector of commodities into functionings, and this is accomplished depending upon personal, social and environmental factors” (Nambiar, 2013, p.222). People seek commodities because they have certain characteristics that make a specific functioning possible. This can be understood through the example of the functioning of reading being made possible by using a commodity such as a book. The freedom of agency that individuals have to achieve functionings is undeniably constrained or enhanced by social, economic and political opportunities available to them. The way people react to opportunities presented to them depends on the habits that guide them. A series of responses need to be made or an individual needs to participate in society in specific ways for a capability set to be obtained. The extent of the individual’s participation can be inhibited or encouraged by the institutions that mould our social, economic and political activities. Hence, it may be said that it is institutions that constrain and enhance capabilities, and define the ‘capability space’.

**Figure 1.1:** Achievement of valued functionings in the Capability Approach



*Source: Author (2023) on the basis of Mitra (2006) and Nambiar (2013)*

In the Idea of Justice, Sen (2009) focuses on the real freedom a person has to be and do what they value being and doing. With this in mind, in this research, participants (children with cognitive disabilities and their caregiver/responsible adult) were encouraged to reflect on what inclusion means in the child's life. Questions for the semi-structured interview were created on the basis of the 10 fundamental human capabilities identified by Martha Nussbaum as "central requirements of a life with dignity" (Nussbaum, 2003, p.41) with the aim of understanding what the children valued being and doing. (See Appendix 1 for the Ten Central Capabilities defined by Nussbaum). Caregivers reflected on their child's physical health, education, social relationships, autonomy, self-expression, participation in decision-making processes, and opportunities for participating in activities the child valued. Children answered simple questions with visual cues to express what they valued being and doing. The institutions that govern the development of valued capabilities were discussed.

Nussbaum distinguishes between three different kinds of capabilities: basic, internal and combined. Basic capabilities are the necessary basis for developing more advanced capabilities. They include what individuals innately have, including the capability to see, hear, love, reason and so on. Internal capabilities refers to "the developed states of the person.... that is sufficient conditions for the exercise of requisite functions", which can include the bodily maturity or capability for freedom of speech or sexual functioning (Alkire, 2005, p.33). Combined capabilities are internal capabilities combined with the necessary social and environmental external conditions that allow the exercise of the function. The 10 Central Capabilities are combined capabilities that can be achieved by developing internal capabilities in an enabling social and material environment where they can be exercised.

## 1.5 The Research Objective

Children with cognitive disabilities represent those who are disproportionately left behind due to lack of diagnosis and access to care, poverty, exclusion, dependence on the household for navigating their interpersonal relationships and asserting their needs. In this research, I attempt to use the capability approach as an analytical framework to study children with cognitive disabilities like ASD and ID in the age group of 6-18 years, seeking care at St. John's Hospital, Bangalore, India. The research questions are:

1. What does inclusion mean to children with cognitive disabilities and their caregiver(s)?
2. What do children with cognitive disabilities value being and doing?
3. What capabilities do children with cognitive disabilities and their caregivers value, and what role does the household play in developing a child's valued capabilities?

The objective of this research is to use ethnography as a method and the capability approach as an analytical framework to make a methodological contribution to childhood disability research. By presenting the multiplicity of experiences of cognitively disabled children in Bengaluru, their capabilities and what inclusion means to them, I wish to call attention to where their lives fall below the central requirements for a life with dignity.

## **Chapter 2 – Balancing agency and care: The transversality of childhood and disability research**

For decades in childhood studies, childhood had been wrongly understood as “an enduring, historically consistent and universal construct” defined by immaturity, and a lack of rationality and adulthood (Goldson, 1997, p.19). This has only served to marginalise children and hide them from the public eye under the guise of protection and familialisation. The social construction of children as ‘human becomings’, rather than ‘human beings’ is inherently exclusionary of children (Qvortrup et al., 1994). Similarly, people with disabilities are positioned as non-abled bodied due to their impairment and are viewed as ‘lesser’ because of their dependence on caregivers/able-bodied people. In the social model of disability, the focus was moved from impairment to the social and environmental barriers impeding disabled people’s lives. Emphasis on the capabilities of disabled people has provided a political stage for disability rights agenda. This is not unlike the reconceptualisation of children as active agents in decision-making, which is closely linked with the UN Convention on the Rights of the Child (UNCRC). Researchers within childhood and disability studies have argued for a long time now for the recognition of people’s mutual interdependence. Viewing children as inferior to adults and disabled people as inferior to able-bodied people “ignores the realities of people’s interdependencies and the different types of ‘work’ done (whether paid or unpaid)” such as care work by children of disabled parents (Lewis, 2003; Watson et al., 2004; Tisdall, 2012, p. 183).

On the other hand, excessive focus on rights-based discourse and the agency of children has also been found to have deleterious consequences as children are still “vulnerable and dependent beings that need to be nurtured with love and affection.” Arneil (2002) recommends an ‘ethic of care’ which highlights responsibilities over rights, rather than viewing children as proto-adults with complete autonomy. She believes that by only framing and analysing what children are saying and by selecting quotes, the researcher merely manages to curate children’s voice, repeating what they have to say. Further to this, Tisdall et al. (2009) has argued that viewing ‘voice’ as “the property of a rational, articulate, knowledgeable individual, capable of speaking for herself such as the researcher” further marginalises children by privileging verbal communication over other forms. This can be exclusionary of children and cognitively disabled people who do not use speech. Children’s voice has helped gain political attention to children’s issues, however, it is important to move beyond verbal and written communication to include multiple mediums of communication including visual, sound and multimedia wherever possible. In this study, children were asked a set of simple questions with visual cues to decipher what activities they enjoy and what they value most. Being aware of my positionality as an adult, able-bodied researcher, I was consciously observant of both the behaviours and emotions of the participants, and of the varied power constructions between researcher and participants. I will revisit my positionality towards the end of this chapter.

Priestley (1998, p.214) has made astute observations on the commonalities between childhood and disability research by drawing attention to the preoccupation with impairment and vulnerability in both areas of study. There is also a tendency for children/disabled persons to be treated as service users, for disabled children to be categorised as a single administrative unit. There is a fine line to tread, as homogenising the lived experiences of cognitively disabled children could obscure the complex and multiple identities that they could possess like other children do, while pathologizing childhood disability

imposes a unitary identity of a ‘disabled child’ thereby excluding other equally or more important aspects of a child’s identity. In this study, I attempt to find a balance between promoting children’s agency and an ‘ethics of care’ approach to children with cognitive disabilities. Disability and age are two axes of inequality along with gender, race, class, caste, sexuality and geography. The resulting differences need to be carefully examined to determine the role of each. Participating children with cognitive disabilities are perceived as beings with evolving capabilities who are learning to assert their agency and explore what they value.

## **2.1 Sampling and data collection**

Ethnographic observations were conducted in the Unit of Hope and OPD at St.John’s, over a four week period between 7th August and 3rd September 2023. Dr. Vijaya Raman, Professor and Child Psychologist at St. John’s hospital, introduced me to the site and helped procure the necessary permissions for my presence at the hospital. She guided me in developing age-appropriate questions to gauge what children value, and in structuring the flow of the qualitative interviews with caregivers. My first task was to gain understanding of the sample population of children and caregivers visiting the hospital by having discussions with the medical fellows, child psychiatrists and psychologists at the hospital. All the medical professionals and practising fellows were informed of the purpose of my research and the inclusion criteria so that they could highlight any potential participants to me. On Tuesdays, Wednesdays and Saturdays, I was present at the back of the OPD, waiting for the doctors and psychologists to find children that fit my inclusion criteria. On Thursdays and Fridays, there were other opportunities to find participants visiting one or more of the specialists at the Unit of Hope. While I waited, I observed diagnostic assessments by psychiatric fellows and had conversations with them about the children they were treating. On numerous occasions, I interacted with my participants in a small set-up on children’s chairs surrounding a children’s table. A box of toys, coloured pencils, clay and other supplies sometimes present at the OPD helped put some children at ease and made them feel safe and comfortable enough to participate. At other times, there was a cubicle or room available where I could interview the participating children, their caregiver(s) and in a few cases, their siblings.

18 children with cognitive disabilities were selected for this research on a rolling basis. Qualitative interviews were conducted with children and at least their primary caregiver or responsible adult. All participants fitting the inclusion criteria were approached to participate. There were several cases of children and caregivers who refused to participate due to time constraints or not wanting to be the subject of research. It was integral for me to acknowledge the agency of every participating child, by explaining the purpose of the research and including them in decision-making. Consent, privacy and confidentiality were discussed with participants before the responsible adult signed an informed consent form. Every child who was 16 and above was given the option to sign the consent form. All participants were informed that their participation was voluntary and they could refuse to answer any questions they were uncomfortable with. I assured them that I would maintain the confidentiality and privacy of the information they were sharing with me by anonymising names. Participants were encouraged to ask me any questions they might have about the purpose and process of research. Conversations between participants and the researcher were majorly in Kannada and English, but sometimes interspersed with Hindi or in a combination of these languages. A Participant Information Form containing the child’s name, gender, age, parents’ names and occupations, number of siblings, religion, caste, income, current or



highest grade completed, school/other facility, mother tongue/ other languages spoken and diagnoses was filled by the caregiver or by the researcher on behalf of the participant (See Appendix 2 for Participant Information Form). During the interviews, I was hypervigilant in observing the participants to ensure their ongoing assent.

Two weeks into the data collection process, I had interviewed eight participants but had not been able to find a single female participant. This had been a point of concern since the early stages as a general observation of the visitors to the children's OPD revealed very few girls. The doctors at the OPD also confirmed the skewed gender ratio of children seeking mental health care at the hospital by attributing it to parental gender bias in investment in healthcare due to sociocultural factors and lower prevalence of neurodevelopmental disorder in girls. I will return to this conversation in Chapter 3.5 by dialoguing with research on the prevalence of cognitive disabilities in different genders and parental bias in help-seeking.

Simple questions with visual cues were used to determine what children value and enjoy. (See Appendix 3 for the list of questions and visual cues for children). A few of the participating children were non-verbal or had limited language skills. In these cases, caregivers assisted by translating and interpreting the gestures, expressions and limited vocabulary of their child. The behaviours of participating children and their caregivers, the parent-child relationship, and the child's relationship with their siblings if present were keenly observed. A semi-structured interview was conducted with the child's caregiver(s) with questions constructed on the basis of the 10 fundamental human capabilities to ascertain which capabilities they valued and what inclusion meant to them in the context of their child's life. (See Appendix 4 for the list of questions for caregivers)

## **2.2 Appraisal of the methodology: Multi-level post-structural approach to ethnography**

Ethnographic research on disability can have contradictory agendas. Emancipatory research which aims to create structural change is linked to policy and political agenda while counter hegemonic writing can dilute the political strength of the disability rights movement and be confined to culturally relative story-telling if the focus is on difference. For this study, I have chosen a 'multi-level post-structural approach' to ethnographic research (Davis, 2002) as the method to make meaning, using reflexive participant observation and qualitative interviewing. Ethnography is also a favoured methodology for studying childhood as children are actively constructing their social lives and the societies they live in (Prout et al., 1990).

Bourdieu's notions of culture and structure are central to his concept of 'Habitus' (1986). In his critique of cultural nobility, he characterised culture as the capacity to produce classifiable practices, words and ways of being. When this interacts with judgement of taste, or the capacity to categorise and appreciate various practices, the social world as we see it is created. Habitus is located and defined in the relationship between these capacities. Post-structuralist research shows that individuals alter behaviours to suit different fields or social settings. It is possible to identify groups of people based on their behaviours and the relationship between their behaviours and the structures within which they are embedded. When individuals move through social settings, they draw on the fluid identities they possess. The concept of

unitary identity has been argued against in anthropology, queer theory, disability studies and many other fields (Asad, 1986; Seidman, 1998; Corker, 1999).

Davis (2002) has proposed that ethnographers can learn how people react to the individuals, cultures and structures they encounter on a daily basis by examining uniform notions of identity, culture and structure. In the same vein, in this research with cognitively disabled children, I want to present varied understandings of how children navigate impairment and their diverse understandings of oppression and inclusion. I wish to provide faithful accounts of individual children's experiences and link this to the collective experience of cognitively disabled children without erasing individual differences, so as to not reproduce hegemonic exclusion. By embracing and legitimising the fluidity of participants' experiences, by being reflective and perceptive of power relationships during fieldwork, by not privileging or projecting my own experiences over participants, it is my humble aim to both contribute to the counter hegemonic discourse and represent the multiplicity of the lives of children with cognitive disabilities.

Following the Nussbaumian approach to CA, the 10 fundamental human capabilities form the theoretical basis for conceptualising the central requirements of children with cognitive disabilities to live a life of dignity. However, data collected and analysed as part of this research does not serve to merely illustrate theory as there is the risk of "imposing prefabricated, theoretical models on the rich complexity of everyday life" (Cerwonka, 2007, p.19) when totalising theories are used in ethnographic research. Instead, I seek to use the CA as an analytical tool to gather complex narratives of inclusion, and its lack thereof, in the lives of cognitively disabled children. In Chapter 3, I will move reflexively between ethnographic observations, dialogues with participating children and caregiver/s, and differing theoretical perspectives on cognitive disability in childhood by discussing the influence of factors like household's perception of impairment, education, age, gender, household income and parental occupation.

## 2.3 Ethical considerations

This research has adopted the six ethical practices prescribed by Jenkin et al. (2019) as best practices, based on the review and summary of academic literature on principles and ethics in child participatory research and disability inclusive child research. Below, I have described how the ethical principles have guided this research:

1. **Respect:** The Convention on the Rights of People with Disabilities (CRPD) highlights that respect affirms the 'inherent dignity and individual autonomy including the freedom to make one's own choices' (UN, 2006: Article 3a), alongside 'respect for the evolving capacities of children with disabilities' (UN, 2006: Article 3h). I have been honest, accountable and respectful of the experiences of all participants. It was my intention to value the inherent dignity and autonomy of every child participating in the research along with their caregiver or responsible adult.

2. **Trust and time:** Cognizant of the fact that children and their caregivers might be initially distrustful, I have provided them with the space to feel comfortable and participate. I have taken the time to build

trust and rapport with the children and their caregivers to ensure ongoing, informative communication with all participants.

3. **Focus on strengths:** Appreciating the capabilities, ideas and experiences of children with disabilities, and focusing on potential rather than limitations complements the CRPD's acknowledgement of the 'evolving capacities of children with disabilities' (ibid.) I choose to focus on children's strengths and recognise that they have something valuable to communicate despite their disability or how it may limit their capabilities.

4. **Inclusive of diversity:** Diversity in children can include their age, gender, impairment, language, personality, caste, cultural identities and individual interests. To accommodate for this heterogeneity in the research process, I have carefully observed children's communication skills, by taking note of verbal and non-verbal language and cues, allowing them time to make decisions, and engaging with the caregiver or responsible adult to interpret/assist communication.

5. **Listening:** I have listened to the experiences of children with cognitive disabilities in the effort to value and legitimise these experiences, paid attention to their facial expressions, bodily gestures, movements, vocalisations and other signals. The caregivers' assistance has been useful in adding context and interpreting the child's mode of communication.

6. **Choice and comfort:** I have consciously allowed children to decide the degree of participation they are comfortable with. I have offered ways to participate that are relevant, comfortable and appropriate to each child, to the best of my abilities.

*Source: Author (2023 based on Jenkin et al. (2019))*

## 2.4 Positionality

Having been introduced to my potential participants by psychologists and doctors, who are trusted medical professionals in 'positions of power' who can "inhibit or promote the self-emancipation of disabled children from the bounds of culture and structure" (Rabinow, 1986, p.236), I was aware that they could perceive the researcher as a highly educated adult in a position of influence over their medical care. To minimise this distance and build rapport with children and their adult caregiver(s), I explained the nature of my research and emphasised that my masters thesis was not affiliated with the medical institution they were visiting but instead was an academic and counter hegemonic effort to put forward a true representation of cognitively disabled children's experiences and capabilities, and investigate where their impairment comes into conflict with cultural and structural barriers. It was made clear that while participants would receive no direct benefit from the research, it was an opportunity for both the child and the caregiver to reflect on what they find valuable, what inclusion means to them, which capabilities are important and discuss how opportunities presented themselves within the household for the child to develop valued capabilities.

I was also aware of the inherent hierarchy of adult-child relationships, which results in the child's voice being silenced, both in observing the children's relationship with their caregiver and in my interactions with children. As prescribed by Thomas et al. (1998, p.342), I was intent on "being open to

children’s agenda” by ensuring that the questions were relevant to their own concerns and by giving them “control over the process to value what they had to say” in the limited time I had with them.

16-year-old Ritesh was towering over everyone at the entrance to the OPD. Already over 6ft tall, his shy demeanour was far removed from his imposing exterior as his father guided him into the room by his shoulder. His eyes were downcast and he initially refused to meet my eyes. His school teachers who were worried about his poor memory and inability to remember all the alphabets, had advised his parents to bring him to the hospital for a diagnostic assessment a few years ago when he was diagnosed with Intellectual Disability. When Ritesh was silent in reply to my question on how he likes to help other people, his father attempted to urge him and soon grew frustrated at his lack of response:

“ಮಾತಾಡೋ, ಅಕ್ಕ ಏನು ಮಾಡಲ್ಲ. ಏ! ಮಾತಾಡೋ!”

Translated from Kannada: “*Speak to her, she is just like a sister. Answer her now, why won't you?*”

Noticing that this admonition seemed to overwhelm Ritesh, I intervened to let him and his father know that he did not have to answer if he did not want to and was met with immediate gratitude on his face for not being forced to answer. He preferred instead to walk across the room and look out of the windows at parked cars and passersby. By the time I had finished interviewing his parents, Ritesh had returned to the table and I circled back to him in a conversation about cricket where he expressed his ability and interest as an all-rounder. The rapport we had established meant he was more willing to participate and answer my questions. He was the first participant I enlisted for this research at the beginning of the observation window on 8 August 2023.

The very conception of disability that positions people as ‘able’ or ‘disabled’ reveals the power politics and ableist conceptions that create exclusionary or discriminatory situations for people with disabilities. Throughout this study, I was aware of my positionality as an able-bodied individual or outsider, utilising sensory experience to comprehend and research the social reality of children with cognitive disabilities. Overcoming the distance created by this difference required not privileging my own experiences over that of disabled children and their caregivers and finding ways to communicate with non-verbal children by understanding their modes of communication. Children with limited language abilities still manage to express their needs and emotions through gestures, pointing, physical touch or imitation of sounds. They may have limited vocabulary and unique expressions to communicate with their caregivers and educators. Cognitively disabled children may also have highly developed receptive language skills where they understand what is being said to them, comprehend simple jokes and visual ideas, and respond when they are addressed. In cases where participating children were non-verbal, I sought to understand their preferred modes of communication. Questions were broken down to generate simple answers. The assistance of the caregiver(s) was sought to translate or rephrase questions, and to understand expressions and gestures.

## 2.5 Limitations of the research

Firstly, this research initially sought to collect photographs of cognitively-disabled children engaged and being included in activities they enjoy and pursuing valued capabilities as stimuli for qualitative

interviews and alternate source of data. However, many potential participants were hesitant to participate if they had to share photographs. They were worried for their safety, despite being assured that their privacy and identities would be protected by blurring faces in photographs and changing names. The ethical principles guiding this research include: a) respect which means recognising individual autonomy to make decisions and b) comfort and choice which includes consciously allowing participation in ways that are relevant, comfortable and appropriate to each participant. Recognising the participants' choice to participate on terms they were comfortable with and following the delicate ethical deliberations that have to be made in research on childhood disability, I chose to not include photographs in this research.

Secondly, only one out of 18 participants in the study was female. During the observation period, I noticed many adolescent girls and young adult women seeking care for behavioural issues, depressive disorders and generalised anxiety disorders at the Psychiatric OPD and a few girls with physical disabilities consulting with orthopaedic and paediatric doctors at the Centre for Special Needs. After an initial period of not enlisting a girl child between the age of 6-18 with a cognitive disability such as ASD and ID, I informed the doctors, psychologists and fellows of this gap in the sample and requested them to keep a sharp lookout for girls fitting the inclusion criteria. I also considered enlisting participants from another location in Bengaluru, Deepika School for Special Needs. This idea was not pursued due to the difficulties in defining another research site, creating equal grounds for ethnographic observation, and time constraints around conducting multi-sited ethnography during the limited observation window. Failing to capture the diverse experiences of girls with cognitive disabilities is a major limitation of this research. In Chapter 3.5, I will elaborate on the experiences of the one female participant in this research to decode the structural and cultural constraints that inhibit the diagnosis and care of girl children with ASD and ID.

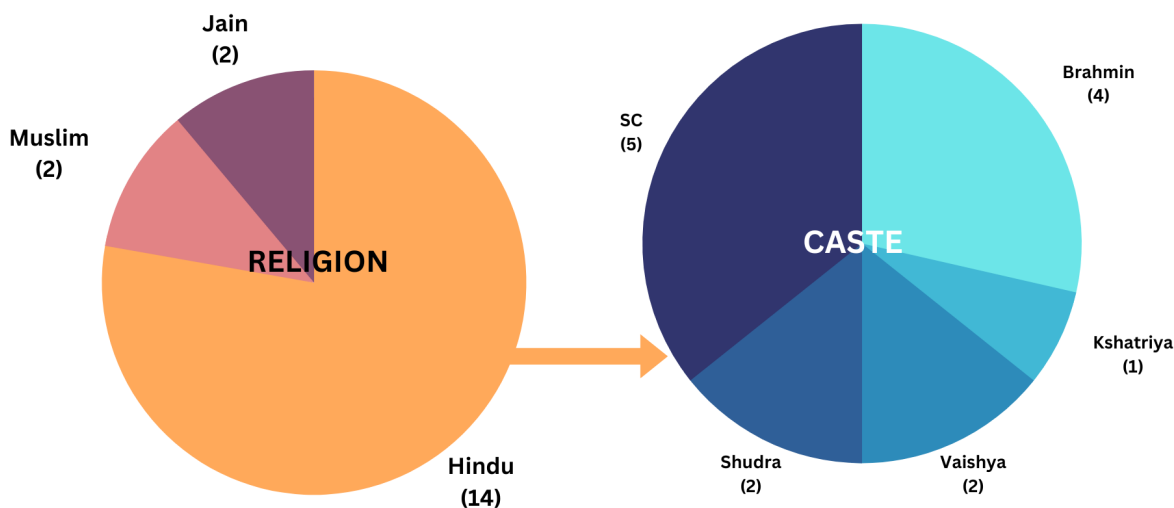
Finally, understanding cognitively disabled children's attitudes towards inclusion and gaining insight on what they value being and doing was fundamental to this research. The barriers to this were ascertaining each child's modes of communication and connecting with them sufficiently over the limited time period of an hour-long interview to elicit an understanding of what they value. Although visual cues and assistance from caregivers who were adept at mediating their social relationships with others were useful, there are other participatory methods of research that could have better demonstrated the experiences of children who were non-verbal or with limited language skills. This research hopes that the simplicity of questions posed to children to get to the root of what they value and enjoy, and in-depth interviews with caregivers on what capabilities were valuable in the child's life, supported by observation, are sufficient to accomplish the research objective. It hopes to serve as a methodological contribution to childhood disability research by presenting the experiences of cognitively disabled children in Bengaluru, India using a Capability Approach to ethnographic research.

### Chapter 3 – Demographic mapping of cognitively disabled children and their households

Out of the 18 participating children with cognitive disabilities, 11 presented with ASD and 8 presented with ID. One participant was diagnosed with comorbid ASD and ID. Some participants had other comorbidities including spina bifida, ADHD, Down Syndrome and OCD.

Although data was collected on participants’ religion and caste as shown in the figure below, no direct connections were established during ethnographic observations and interviews between the cognitively disabled child’s religion and caste, and their experience of inclusion and development of valued capabilities. However, I did observe that these factors played some role in the participants’ lives.

Figure 3.1: Religion and caste of the participants



I met with Rajesh, his parents and younger brother at the St. John’s OPD on a rainy afternoon towards the end of August. 10-year-old Rajesh is mostly non-verbal but he is able to use a few words or adaptation of words to communicate his basic needs with his mother, who is his primary caregiver. He is unable to write and doesn’t show interest in drawing or painting. He is however able to show care for his loved ones by being physically affectionate. He is close with his seven-year-old younger brother and enjoys listening to music, and singing filmy and devotional songs. During our interview, when I asked him about what he enjoys, he was urged by his little brother to sing. Rajesh demonstrated and sang an entire devotional song about Sai Baba. His parents were beaming with pride after his rendition. All their investment in speech therapy had not been as instrumental to improving Rajesh’s speech as his love for music had been. But as his father recalled, his enthusiasm for devotional songs was not always met with appreciation:

*“Recently, we went to a temple and suddenly out of nowhere he started shouting. The priest was so angry and started scolding him. I had to tell him that Rajesh is autistic. He doesn’t understand*

*that he shouldn't be shouting in a temple. But I can't always do that and there may be times when I'm not there to do that."*

In another instance, I asked Ritesh, whose case I already discussed in Chapter 2.4, when he felt most joyful, he replied:

*“ಹಿಂದಿನ ತಿಂಗಳು, ಮಾರಮ್ಮನ ದೇವಸ್ಥಾನದಲ್ಲಿ ಮೆರವಣಿಗೆಗೆ ನನ್ನ ಫ್ರೆಂಡ್ಸ್ ಜೊತೆ ಹೋದಾಗ.”*

Translated from Kannada: *“Last month, when I went to the procession at the Maramma temple with my friends.”*

His father added:

*“ಅದರಲ್ಲೂ ಅವನೇ ಮುಂದಾಳು. ಬೆಳಿಗ್ಗೆ ಇಂದ ಸಾಯಂಕಾಲ ೭ ಗಂಟೆ ತಂಕ ಓಡಾಡಿದ್ದ.”*

*“He is the one taking all the initiative there. From early in the morning till 7pm in the evening, he was involved in it.”*

Shivansh is a six-year-old boy from a Hindu Brahmin family. Everyone in his family is vegetarian and they care deeply about this. When I asked his parents whether Shivansh understands the difference between good and bad in an age-appropriate manner, his father replied:

*“हम पुरे वेजीटेरियन ह। उसको पता है, आँखे बंद कर देता ह। हम चाहते है की इस उमर में वह यह सब चीज़े ना देखें। ऐसी चीज़े देख के ट्रामा हो सकती ह। कोई इंसान जानवर को ऐसे कर सकता है तो इंसान को भी कर सकता ह।”*

Translated from Hindi: *“We are pure vegetarians. He knows, he closes his eyes (when he sees meat in stores). We don't want him to see these things at such a young age, it may cause psychological trauma. If a person can do this to another animal, then that person may be able to do the same to another human being.”*

The presence and influence of factors like caste and religion in the lives of participants is undoubted, but further research must be done on whether these conversion factors are capability increasing or decreasing. It did not fall within the purview of this research to inspect these factors further when the evidence on the factors did not lend themselves as relevant to the research objective.

### **3.1 Contextualising the households of cognitively disabled children**

Languages spoken or understood by participants included Kannada, Hindi, English, Tamil, Telugu, Malayalam, Bengali and Marathi. Most children were bilingual with the exception of four participants who only spoke their mother tongue. 11 participants resided in the same household as grandparents, uncles or aunts. In many cases, parents indicated that grandparents who resided in the same household were involved in caregiving for the child in question. Many children also expressed a strong affinity for grandparents. When asked what activities he enjoys doing at home, Shivansh answered:

*“घर में हमेशा दादू के साथ खेलता हू, उनके साथ चॉकलेट खाता हू।”*

Translated from Hindi: *“At home, I always play with my paternal grandfather. I eat chocolates with him.”*

Research on the siblings of children with Intellectual Disabilities shows that they experience more negative impact compared to siblings of typically developing children due to behaviour problems of their sibling (Neece et al., 2010). Mulroy et al., (2007, p.216) suggest that the disadvantages for the siblings of children with cognitive disabilities majorly centre around “parental and personal time constraints, relationships and socialising, restrictions, parental emotion and burden of helping.” While most parents in this study described that their child had a good relationship with their sibling(s), in cases where the disabled child presented with extreme behavioural problems, there was evidence of negative impact on siblings.

Prashant is a 15-year-old boy with both ASD and ID who exhibits major behavioural issues, speech deficiency and delayed development. He plays cricket with his 10-year-old brother and 14-year-old sister, but other children do not play with him because he hits them when he does not get his way. His mother says that he can be empathetic towards his siblings at times but he also mostly forces them to go along with what he wants:

“ಅವನ ತಮ್ಮ-ತಂಗಿರು ಅವನು ಹೇಳಿದ ಮಾತು ಆ ಉ ಅಂದೇ ಕೇಳಬೇಕು, ಇಲ್ಲದೆ ಇದ್ದರೆ ಹೊಡಿತಾನೆ. ಅವರಿಗಿಂತ ತುಂಬ ಚೆನ್ನಾಗಿ ತಿಂದು, ಗಟ್ಟಿ-ಮುಟ್ಟಿಯಾಗಿದ್ದಾನೆ. ಆ ಮಕ್ಕಳು ಚಿಕ್ಕದಾಗಿ, ವೀಕ್ ಆಗಿದ್ದಾರೆ.”

Translated from Kannada: *“With his siblings and cousins, he wants them to listen to whatever he says without question. Sometimes he will hit them if they don't give him what he needs. He is much healthier and stronger than them because he is older and well-built. The other children are younger and weaker.”*

In other cases, children had typical sibling relationships where they were affectionate towards their sibling but also displayed jealousy at times. If I were to return to the case of Jeet who I introduced at the beginning of this research, he is affectionate and caring towards his one-year-old brother and enjoys watching TV and playing with him. However, his father describes how he has recently started competing with his little brother:

*“If (his little brother) asks me to play a song in the car, Jeet will request a different song that he wants instead.”*

Nine-year-old Nihaar’s father describes his relationship with his sister as “non-existent”. Nihar is on the autism spectrum, and is mostly non-verbal except for when he repeats a few words. While describing why he struggles to interact with other children, his father said:

*“If there’s a crowd of kids, he wants to be a part of it. If some kids are playing football, they understand that it’s a team game, you have to kick the game and pass it on. He will pick up the ball and start running. He is just not able to contextualise it. I’m not blaming him, I’m saying that’s how he joins in. He thinks now that I’m running, everyone is running behind me and he becomes happy. That’s his way of enjoyment.”*

When I asked Nihar’s parents about whether they had made any efforts to make him feel more included or accepted amongst his peers, his father replied:



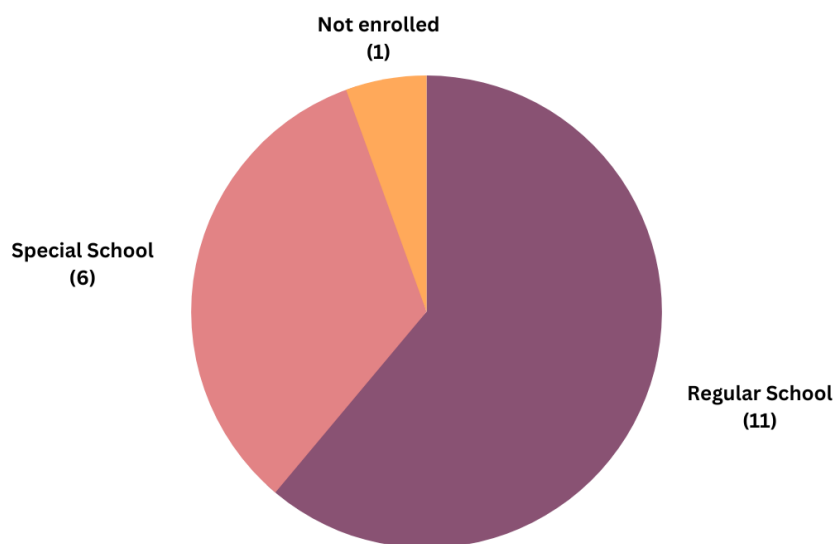
*“How can we expect other kids to understand him? We don't expect our daughter to understand him, and besides, we don't want to spoil her adolescence. So we can't expect others to. Most people don't understand. If there's a child watching something on the phone, he will go and take it. And then they will get offended. So we try to avoid these kinds of settings.”*

In cases like Nihaar and Prashant's where children displayed extreme behavioural problems and language limitations, sibling relationships were adversely affected. With every participant, an effort was made to contextualise their household to understand their relationship with siblings, grandparents and other family members residing in the same house. Members of the same household were the first opportunity for children to form interpersonal relationships, and they played an important part in the mediation of the disabled child's relationships with the outside world, and in inhibiting or encouraging the development of valued capabilities.

### 3.2 Education and school enrolment

10 of all participating children were enrolled in a regular school although only two had assigned shadow teachers. Six children were in special education programmes and two participants were not enrolled in a school or educational facility of any kind. Parents of all participating children expressed a strong preference for inclusive education and believed that children with cognitive disabilities should be accommodated in regular schools except in cases of extreme disability or behaviours. I will present the cases of 5 participants in this research to represent the variation in children's experiences of inclusion through schooling.

**Figure 3.2:** School enrollment in participating children



Krishna is a 12-year-old boy with Down Syndrome and Intellectual Delay. His speech and language abilities are very limited. His lower-middle class family also includes two older brothers who are 18 and 20 years old. When I asked about what he enjoys or values the most, he replied and kept repeating, “Bloomers School”. His mother came to his aid by explaining:

“ಕೋವಿಡ್ ಮುಂಚೆ ನಾರ್ಮಲ್ ಸ್ಕೂಲಿಗೆ ಹೋಗ್ತಾ ಇದ್ದೆ, ಆ ವಯಸ್ಸಲ್ಲಿ ಓದದು ಬರಿಯದು ಏನು ಇರ್ತಿರ್ಲಿಲ್ಲ. ಕುಳಿತುಕೊಟ್ಟಿದ್ದೆ, ಮಕ್ಕಳ ಜ್ಯೋತೆ ತುಂಬಾ ಮಿನ್ನೆ ಆಗ್ತಿದ್ದೆ. ಆದ್ರೆ ಈಗ ಸ್ಪೆಷಲ್ ಸ್ಕೂಲಿಗೆ ಹಾಕಿದ್ಯೆಲೆ, ಸ್ಕೂಲಿಗೆ ಹೋಗಕ್ಕೆ ಹಲ ಮಾಡ್ತಾನೆ.”

Translated from Kannada: *“Before the pandemic, he would attend a regular school. He was young and in a lower grade, so he didn't have to write or read. He would sit in class and mingle with all the other kids. Later, the teachers suggested that he goes to a special school because he wouldn't be able to keep up. Now he throws tantrums saying he doesn't want to go to school.”*

While describing him and the hopes she has for his life, his mother said:

“ಅವನು ನಾರ್ಮಲ್ ಮಕ್ಕಳ ಹಾಗೆ, ಏನು ವ್ಯತ್ಯಾಸ ಇಲ್ಲ. ಮಾತು ಒಂದೇ ಕಡಿಮೆ, ಹಟ ಜ್ಯಾಸ್ತಿ. ಎಲ್ಲಾ ಪೇರೆಂಟ್ಸ್ ತರಹ ಅವನು ಓದ ಬೇಕು, ಮಾತಾಡ್ಬೇಕು ಅಂತ ಆಸೆ. ನಾಳೆ ದಿವಸ ಅವನು ಯಾರಮೇಲೂ ಡಿಪೆಂಡೆಂಟ್ ಆಗಿ ಇರ್ಬಾರ್ದು, ಅವನ ಕೆಲಸ ಅವನೇ ಮಾಡ್ಕೊಬೇಕು.”

*“He is just like all normal children, there is no difference. The only difference is that he doesn't talk much and throws tantrums at times. Like all other parents, we want him to study well, to be able to talk. He should not be dependent on anyone. He should be able to do his own work.”*

Rohan is a 14-year-old boy who attends a special school. His mother is a counsellor at the same school. His father is an IT professional and they are a middle-class family. His maternal grandmother resides with them. During our interview, he told me that he likes answering questions in class and is most excited about a field trip to the post office next week. When I asked his mother about the facilities available at his school, she said:

*“The school is very supportive. They provide everything that children need socially, psychologically and emotionally. There are group tasks and activities with children across age groups, presentations and opportunities to express themselves. The teachers, they help and moderate. He is interacting with others in the school setting.”*

However, Rohan isn't always able to understand and navigate social cues. His parents received complaints from the regular school that he used to previously attend, that he tends to stare at other children, come too close and violate physical boundaries. There were instances when he sniffed or blew on the teacher's saree. He would imitate inappropriate behaviours, spit and throw things. When his classmates asked about what happened over the weekend, he would only speak about socially inappropriate subjects like hurting someone, getting scolded or releasing gas. He was guilty about his behaviour and apologised, but this would recur every so often. All of this made him unpopular with other children until he had to change schools,

Jai is the oldest participant of this study. He is 17-years-old and has spina bifida, intellectual disability and speech delay. He can write but it takes him a lot of time to do it, and he still cannot do maths. He says that if he could change one thing about his life, he wishes to be able to talk properly. If there is one thing he wishes he could learn to do, it would be to drive. When I asked Jai's mother about their family income, she replied:

“ಇನ್ನೂ ಏನು ಇಲ್ಲ. ನಾನು ದುಡ್ಡು ನಂಗ. ನಮ್ಮನೆಯವರು ಕೆಲಕ್ಕೆ ಹೋಗೋರು, ಬರತಾನೆ ಕುಡ್ಡೊಂಡು ಬಂದ್ತೋರು. ಟೈಲರಿಂಗ್ ಕೆಲಸ ಮಾಡ್ಕೊಂಡೆ ನನ್ನ ಮಕ್ಕಳನ್ನ ನೋಡ್ಕೊಂಡಿದ್ದೀನಿ. ಯಜಮಾನರು ಕೆಲಸ ಮಾಡ್ತಿದ್ದಲ್ಲ, ಆ ಓನರ್ ಬಂದು ಮಕ್ಕಳ ಸ್ಕೂಲ್ ಫೀಸ್ ಕತ್ತಿದ್ರು, ಅದ್ರಿಂದ ಸಹಾಯ ಆಗತಿತ್ತು. ಆಯಪ್ಪಾ ಕೆಲಸ ಬಿಟ್ಟ ಮೇಲೆ, ಅವರು ಫೀಸ್ ಕಟ್ಟಲಿಲ್ಲ ಅದಕ್ಕೆ ಸ್ಕೂಲಿನವರು ಅವನನ್ನು ಫೇಲ್ ಮಾಡಿಬಿಟ್ಟರು. ಎಕ್ಷಮ ಟೈಮ್ ಅಲ್ಲಿ ಅವನ ಚಿಕ್ಕಪ್ಪ ಅಜ್ಜಿ ಇಬ್ಬರೂ ತೀರಿಕೊಂಡರು, ಆ ಟೈಮ್ ಅಲ್ಲಿ ನನಗು ತುಂಬ ಕಷ್ಟ ಆಗಿತ್ತು.”

Translated from Kannada: *“I have almost no income. We can eat if I earn. My husband used to work as a car driver. He would come home drunk everyday and never supported me financially. I have raised my two children by doing tailoring work. The person my husband used to work for used to pay the children's school fee so we managed somehow. Once my husband quit his job, the owner stopped paying the school fees. Around that time, his grandmother and uncle also passed away. I was in a lot of difficulty and couldn't pay his fees. The school didn't allow him to write his exams and he failed 10th standard.”*

School teachers had alerted Jai's mother about the problems he was facing, but she had pleaded with them to keep him in school by telling them about their situation at home. She looked back regretfully and recalled:

“ನಮ್ಮ ಮನೆಯಲ್ಲಿ ತುಂಬ ಜನ ಇರೋರು, ಅವನನ್ನ ನೋಡ್ಕೊಳ್ಳಕ್ಕೆ ನನಗೆ ಆಗ್ಲಿಲ್ಲ. ಇವನ ಅಪ್ಪನ ಮನೆಯವರ ಕಡೆಯಿಂದ ನನಗೆ ಕಷ್ಟ ಇತ್ತು. ಅವರಿಗೆಲ್ಲ ಮಾಡ್ಕೊಂಡೇ ಇದ್ದೆ, ಏ ವರ್ಷದ ಹಿಂದೆ ಮನೆ ಶಿಫ್ಟ್ ಆಗಿದ್ದು. ಕೆಲಸ, ಮನೆಯವರನ್ನು ನೋಡ್ಕೊಳ್ಳೋದ್ರಲ್ಲಿ ನನ್ನ ಮಕ್ಕಳ ಕಡೆ ಗಮನ ಕೊಡಕ್ಕೆ ಆಗ್ಲಿಲ್ಲ.”

*“We lived with my husband's family, there were a lot of people and I had to do all the work. 5 years ago we moved away. I was so busy with work and looking after family that I wasn't able to give my children attention when they needed it.”*

Jai's household was the only one in this study that fell into the category of destitute households and was in dire economic trouble. Besides, Jai had breathing difficulties and asthma since birth. The doctors had said that these problems were probably a result of his parents' consanguineous marriage. Doctors had advised that Jai would soon need to start wearing a BiPap machine to aid him with breathing at night time, and his mother was desperate to find the funds to buy the expensive equipment. Not being enrolled in school could be directly linked to economic destitution or a disabling social institutions like gender in this research as discussed towards the end of this chapter. Some children like Rohan were enrolled in special schools as they had severe disabling conditions or behaviours that prevented them from joining regular schools. Others like Krishna were able to interact with their neurotypical peers but did not have age-appropriate cognitive and speech development which excluded them from accessing regular schools.

On the other hand altogether, among children attending regular school, experiences were varied. With respect to children in this research who were managing age-appropriate academic programmes alongside their neurotypical peers, it was still evident that their disability was coming in the way of their education. Six-year-old Shivansh loves going to school and especially enjoys learning maths. When asked about his favourite things, clay, slime, sand and his friends made the top of his list. His parents say that he is interested in numbers and has recently expressed an interest in learning to play chess after watching YouTube videos. However, he has spina bifida and mild intellectual disability due to which he is currently unable to walk without crutches and requires full-time care as his condition causes loss of bowel and

bladder control (also called neurogenic bowel/bladder). He has a good relationship with his grandparents and cousins. His parents describe him as affectionate and caring towards his younger cousins and towards his classmates.

“जब भी वह क्लास में आता है या जाता है, सारे बच्चे टीचर को छोड़ के इसको ही बाई बोलने आजाते ह। कम्युनिकेशन बच्चोंके साथ अच्छा ह।”

Translated from Hindi: *“Whenever he comes to class or leaves, all the children forget about the teacher and come to say hi or bye to him.”*

Although he attends regular school, he is not able to do everything that his peers do. This troubles him deeply according to his mother:

“क्लास के फर्स्ट बेंच से लास्ट बेंच तक चला जाता ह पर गेम्स तो नहीं खेल सकता है।”

*“He can go from the first bench to the last bench of the class (with his crutches), but he can't play games.”*

वह बोलता है मुझे मैं ये नहीं कर पा रहा हु, मुझे बुरा लग रहा है, मेरीसे उसने बात नहीं किय, मेरेको नहीं लेके गए, मेरे साथ ही ऐसे क्यों होता ह। मैं क्या बोलू उस्स।

*“He tells me that he can't do it anymore, that he feels bad when someone does not talk to him or others don't take him along. He asks me why this always happens to him and I don't know what to say to him.”*

Raunak is a 16-year-old boy from a middle-class Bengali family with ASD and OCD. His mother is also a counsellor and his father is an IT professional. He stutters, repeats words and speaks in a child-like manner. His perception of himself as vulnerable and dependent reflected the institutions shaping him from the outside. When I asked him about the ways in which he helps at home, he replied:

*“No no, I am always dependent on my mother. I never do anything by myself. In my old school, I used to do it, but now I don't.”*

He is currently studying commerce in 11th std. As per the Indian system of education he has completed 10th grade or schooling and is now enrolled in another educational institution where he will receive pre-university education. He has no friends in his new school but does have friends from the old school whom he occasionally keeps in touch with. He has been in an ICSE school throughout and now he is in a CBSE school, however, he has been able to manage academically according to his mother. On hearing Raunak's answer, his mother immediately piped in:

*“Is it because you can't or is it because you are just used to getting work done for you?”*

To which Raunak replied:

*“Sometimes I can't and sometimes I'm used to always getting help.”*

When I asked him what he likes or enjoys the most, he answered:

*“When I eat my favourite foods, when I hear the word party and hear my favourite songs, I feel very happy. When there is free time”*

When I asked him if there was anything new that he wanted to learn, he immediately said:

*“No no no.”*

His mother said to him:

*“By learning, she doesn’t mean studying.”*

I clarified further that it could be anything new he wanted to do or learn to do. Raunak replied:

*“I wanted to learn to be a chef and singer. I want to learn how to shave my beard once it starts to grow. I want to learn to do shopping and learn to make the food that I like.”*

His mother replied:

*“Okay, you want to have your beard. Is there any work that you want to learn to do, like a skill? These are things you can do as is.”*

Raunak replied:

*“No engineering. I want to be a chef-singer.”*

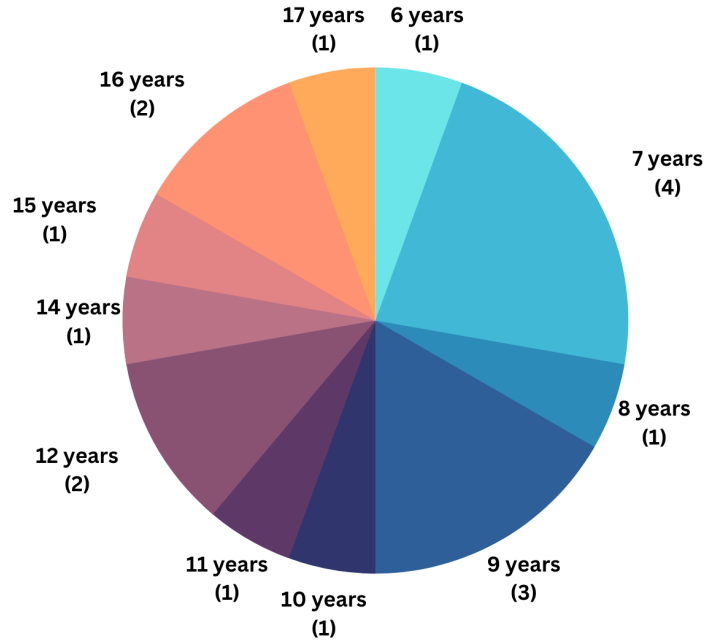
It was evident from my interview with him that he did not enjoy any aspect of the schooling he currently received, and felt constrained by his parent’s expectations and the system of education where he was not free to pursue being a chef or singer, or simply where he had no free time. Observation and data collection showed that the experiences of inclusion amongst children with cognitive disabilities enrolled in regular schools were also less than ideal, as schools did not cater to their specific needs.

### **3.3 Chronological and social age**

Continuing with the idea that childhood is a period of evolving agencies and capabilities, that is only one part of the entire human experience, in this research I seek to investigate the social age of children with cognitive disabilities. Borrowing from feminist theory, Clark-Kazak (2008, p.1313) proposed “social age analysis” as a means to include children and young people in broader developmental programming by studying the “social meanings ascribed to biological human development and/or chronological age.” An exploration of the physical realities of present-day development shows that the ideas of individualism and self-reliance are discriminatory towards the very young, very old, persons with disabilities, chronic illnesses and nursing mothers. Nonetheless, backed by research in childhood disability, the stance this research takes is that mutual interdependence is the key to collective growth and survival.

By analysing social age alongside chronological age, the capability-constraining institution of age is revealed. There are massive power imbalances in society that are the result of socially defined gender and age roles, and the effect they have on women and children. The double edge to these imbalances is the discrimination that is also faced by younger and older men (Groves, 2005). Grasping the nuisances of the power relations that marginalise children and young people requires challenging the assumptions of universal chronological experiences in the lives of young people that do not account for their multiple “subject positions” including class, race, religion, gender and impairment (Mouffe, 1993, p.77). In this research, an effort was made to observe the disabled child-caregiver relationship and bring to light the multiple power dynamics reflected within. The child by being young of age is considered immature and dependent on the adult and this dependence is heightened by impairment.

**Figure 3.3:** Chronological ages of participating children



15-year-old Prashant, whose case I already introduced in Chapter 3.1, has serious behavioural problems as a result of his comorbid ASD and ID that makes life challenging for his siblings and his mother. He is unable to perform most activities of daily living that his typically developing peers can. While describing the difficulties she has had in raising his, his mother said:

“ಅವರ ಅಪ್ಪ ಇದ್ದೆ ಸರಿ ಇರ್ತಾನೆ, ಇಲ್ಲ ಅಂದ್ರೆ ನಮ್ಮನ್ನ ಆಟಾಡುತ್ತಾನೆ. ನಾನು ಪುಸ್ತಕಿಗಿ, ಉರಿಗೆ ಎಲ್ಲಾ ಹೋಗಲ್ಲ. ಕರ್ಕೊಂಡ್ ಹೋದ್ರೆ ಕಷ್ಟ ಕೊಡ್ತಾನೆ, ಅದಿಕ್ಕೆ ನಾನು ಕರ್ಕೊಂಡೇ ಹೋಗಲ್ಲ.”

Translated from Kannada: “If his father is around he is okay, if not he will take us for a ride. I can't go to functions or go travelling. If I take him along, he'll just give me a lot of trouble, that's why I don't even take him.”

Despite the inconvenience her son's condition causes, she recognises his helplessness in all of it:

“ಅವನು ಮಗು ತರಹ. ಅವನದ್ದೇ ಲೋಕದಲ್ಲಿ ಇರ್ತಾನೆ. ನನಗಂತೂ ಅವನಿಗೆ ಬುದ್ಧಿಬಂದ್ರೆ ಸಾಕು. ಕಲೀದೆ ಇದ್ದು ಪರವಾಗಿಲ್ಲ, ಬೇರೆಯವರಿಗೆ ತೊಂದ್ರೆ ತೊಂದ್ರೆ ಕೊಡಬಾರದು.”

Translated from Kannada: “He's just like a child. He'll be in his own world. I just wish for him to gain some common sense. Even if he doesn't learn anything else, he shouldn't trouble others.”

As children mature through adolescence into adulthood, there are social rites of passage they must endure. Societal expectations attributed to the chronological age of 18 include finding employment or pursuing higher education. This is not the reality of many children with cognitive disabilities as they may never find employment or be literate. This research found that the disability-enhancing influence of age was more pronounced at pivotal points in the participating children's overall development, such as at the time of development of language skills, during adolescence and when entering adulthood. I will return to Jai's story from Chapter 3.2 to illustrate this further. As a 17-year-old, Jai is on the cusp of adulthood and

faced with the prospect of his future. Devastated by the recent loss of his father, bogged down by the physical realities of his disability and frustrated by the inability to speak when he so desperately wants to, Jai is unable to think of the future. His mother on the other hand wishes for him to find a reason and engage in his own life:

“ಅವನೇ ಅವನ ಲೈಫ್ ಲೀಡ್ ಮಾಡ್ತೀನಿ ಅಂತ ಅವನಿಗೆ ಶಕ್ತಿ ಬರಲಿ ಅಂತ ನನಗೆ.”

Translated from Kannada: “*I want him to find the strength to lead his life by himself.*”

“ಮುಂದೇನು ಮಾಡದು, ಮುಂದೆ ನೋಡ್ತೀನಿ ಅಂತಾನೆ.”

“*When I ask him what he wants to do in the future, he says we'll see when we get there.*”

The inability to achieve a valued functioning at the socially-appropriate time signifies the onset of ‘capability deprivation’ (Burchardt, 2004). Everytime a person with an impairment is unable to obtain a capability set at the social age when the capability is first expected to be obtained, they experience a greater sense of disability. On the basis of this, I would like to argue that not only do capabilities evolve over time, but what capabilities are valued or hold importance in one’s life also evolve with age. I will return to this argument in Chapter 4.

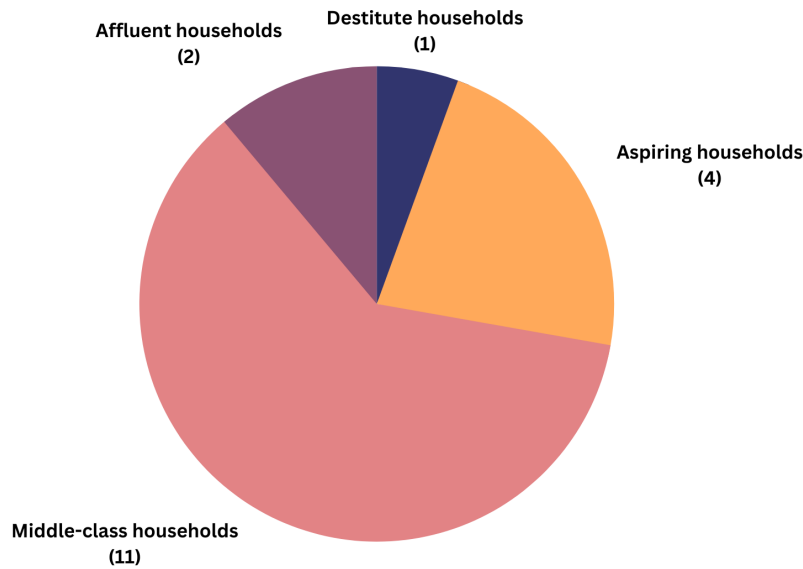
### **3.4 Household income and parental occupation**

Analysis based on pan-India surveys conducted in 2014, 2016 and 2021 by People Research on India’s Consumer Economy (Shukla, 2023) shows that India’s middle-class is booming, and provides a useful classification for the households of cognitively disabled children in this study. As per PRICE data surveying 200,000 households across the country, income can be used to classify households in India in this manner:

- a) Affluent households: earn more than ₹30,00,000 annually (over €33,700)
- b) Middle-class households: earn ₹5,00,000 to ₹30,00,000 annually (€5,616 - €33,700)
- c) Aspiring households: earn ₹1,25,000 to ₹5,00,000 annually (€1,404 - €5616)
- d) Destitute households: earn below ₹1,25,000 annually (below €1404)

The following figure represents the household income of the participants of the research. Nearly two-thirds of the households in this sample can be classified as middle-class households as per the classification adopted by this research.

**Figure 3.4:** Classification of household income of participants



Considering the high prices of special education, speech and occupational therapy, and consultations with doctors and psychologists, even the more affluent and middle-class households have a hard time finding good quality of care and services for their child. Aniket is a 9-year-old child with Intellectual Disability from a middle-class family enrolled in a regular school. His school has recently appointed a shadow teacher to help children like him. Despite investing a lot of money in his education, his parents are dissatisfied with the support he receives from his school. His mother says:

*“They say we cannot look after one kid, 30 kids are there in the class. Being a parent, I feel that when we are sending him to school and he is at the ability where he can attend a normal school, teachers should also take the initiative to help him. Therapists have said that he is able to attend regular school. But if he is sleeping in class, they just let him sleep because who will bother with one kid when 30 kids are there. They’ll just say, he was sleeping so he has not written. But if they put a little effort, like if they sat him down in the first bench and kept an eye on him, it would help. Last year, before there was a shadow teacher, only the class teacher would bother to keep a check on him. Other teachers would come, teach and leave without checking to see if he’s writing or what he’s doing.”*

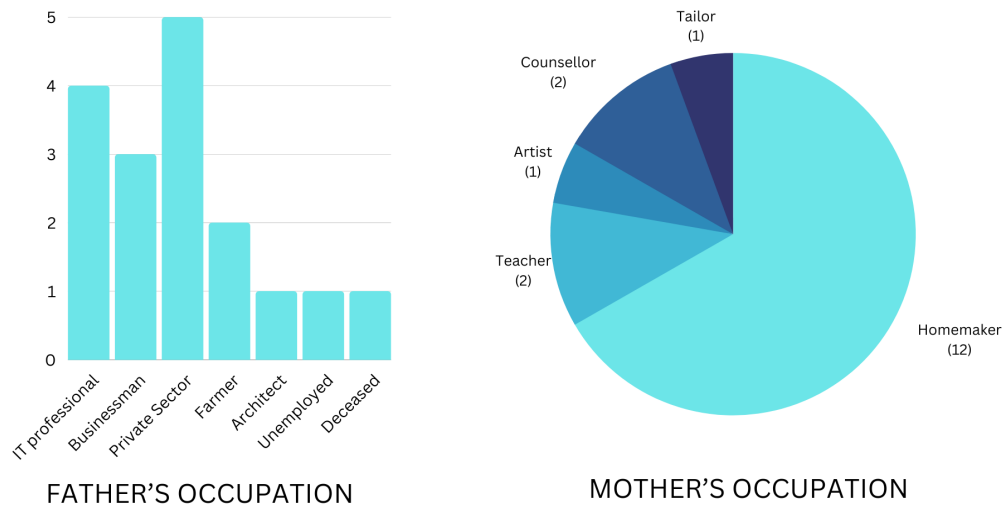
According to Aniket’s father, he is even worse off now that there is a shadow teacher:

*“They don’t give the special attention he needs. Now the shadow teacher has come, he is completely left out. Since the shadow teacher is there, the other teachers don’t even try anymore”.*

The data gathered in this research did validate Reichmann et al. 's claim (2008) that family situations can influence a disabled child’s life experience and the disability in turn can have significant impacts on the family’s careers, finances, health and time. Information on parental occupation is presented in the figure below.



**Figure 3.5:** Parental occupation of participating children



There has been research about the negative effect of a child's disability on the mental health of the mothers of children with ASD and ID, and their increased burden of care (Marcenko et al., 1991; Fairthorne et al., 2016). In this research, all 18 households identified the mother as the primary caregiver of the cognitively disabled child, which validated existing research. As a result of mothers being engaged in full-time caregiving, it is no surprise that the data on parental occupation shows that a large majority of mothers are homemakers (12) and the others are engaged in part-time or flexible jobs that could be managed alongside their full-time caregiving responsibilities. Only in 2 cases, the mother was the primary breadwinner of the household. In the former case (Jai's story discussed in Chapters 3.2 and 3.3), the father was deceased and the household was struggling to get by on the mother's tailoring income. In the latter, in an aspiring household, Srinath's mother worked at a private job and his father stayed at home ever since he lost his business during the pandemic. His mother gets him ready and drops him off to school before work in the mornings. His father picks him up and drops him off to his football classes. Both parents try to accompany him to his therapy sessions at the hospital, which is when I interviewed them. His mother helps him with his studies in the evenings and plans the activities they do together on the weekends. Srinath was extremely distracted during our interview. I was only able to gather from him that he likes to draw, wants to learn to play the tabla before he got distracted by colour pencils and would not answer. When asked about when he feels most loved or valued, he answered:

*"Mummy, don't go to work, to office. Saturday when she's at home I'm happy."*

Srinath faces trouble with concentration and doesn't receive a lot of support from the teachers in the regular school he attends. But despite his diagnosis of mild ASD, his mother is optimistic about the future:

*"I just want to be able to provide him with whatever he wants. Rather than pushing him to do what we want him to do, we want to encourage him in what he wants to do. He has very good capabilities. He can quickly read people. He will not approach everybody. With people who are*

*close to us, he will go to them and be very sweet. He's very caring and concerned for other children and people, even compared to my daughter. When someone is hurt or upset, he will be considerate. It's very easy to be with him. As a mother, I want him to be independent enough, to be doing what he wants to do, and excel in that. Whenever he is interested, I try to encourage him and give him opportunities to explore more in that. Going forward, I always think positively about him, his lifestyle and how he is going to be because he understands people, he reads their minds and faces so that will help him know how to react appropriately to people. Beyond all his basic needs and standing out on his own, I want him to do something good for society, for people in need.”*

Data collected on parental occupation showed that a child's diagnosis of ASD or ID could have far-reaching implications for the entire family. Specifically for mothers, caregiving became a full-time job and pushed career prospects into the background. Even when mothers had a full-time job or were the primary breadwinner, they were still majorly responsible for caregiving.

### **3.5 Gender disparity in diagnosis and care of children with cognitive disabilities**

I was relieved to meet Noor and her family at the beginning of the 3rd week of field work as she was the first female participant I enlisted for this research. However, she ended up being the only one. From an aspiring Muslim household, Noor is an 11-year-old girl with severe intellectual disability. Her language and cognitive abilities are very limited. When I asked her what she enjoys or what she wants to be when she grows up, Noor was silent and engrossed in observing my pen so her mother explained:

“ನೀವು ಹೇಳಿರೋದು ಅವಳಿಗೆ ಅರ್ಥ ಆಗಲ್ಲ.”

Translated from Kannada: “What you're trying to ask her is something she cannot comprehend.”

While I was interviewing her parents, Noor took a piece of paper and a pen from me and kept scribbling lines all over the paper or clicking the pen incessantly. Noor struggles with serious behavioural issues that make interacting with other children difficult. She has a troubled relationship with her younger brother and other children in general according to her mother who said:

“ತಮ್ಮಂಗೂ ಹೊಡೆದ್ದುಡ್ಡಾಳೆ, ಯುವಳದ್ದುಅವನು ಏನಾದ್ಯು ತೊಗೊಂಡೆ, ಸುಮ್ಮನಿರಲ್ಲ. ನನ್ನ ತಮ್ಮ ಅಂತ ಅವಳಿಗೆ ಏನು ಇಲ್ಲ, ಬೇರೆಯವರನ್ನೂ ಬಿಡಲ್ಲ. ಈಗ ಆಚೆ, ಯುವಳಿಗಿಂತ ದೊಡ್ಡ ಹುಡುಗಿಗೆ ಹೊಡೆದ್ದಿಟ್ಟು ಬಂದಿದ್ದಾಳೆ. ಅವರ ಅಮ್ಮ ಹೊಡಿಯಕ್ಕೆ ಬಂದು, ಬುದ್ಧಿ ಕಡಿಮೆ ಅಂತ ಹೇಳದೆ ಪಾಪ ಅವರು ಹೋಗಿಟ್ಟು.”

Translated from Kannada: “She'll hit her brother also, if he takes something that is hers, she won't let it be. She has no consideration that he is her brother, she doesn't show other people any consideration either. Just now, she hit another girl who is much bigger than her outside. That girl's mother came to hit her, but I told her that she's mentally disabled so she let her go.”

Her father added that there was another side to this issue:

“ಎಲ್ಲಾರಿಗೂ ಚೆನ್ನಾಗಿ ಇರ್ತಾಳೆ. ಅವಳಿಗೆ ಕ್ರಾಸ್ ಮಾತಾಡಿದ್ಯೆ ಹೊಡಿತಾಳೆ. ಯಾರದರರೋ ಅವಳಿಗೆ ಹೊಡೆದು ಬಂದು ಹೇಳಲ್ಲ.”

“She'll be nice with everyone but if they say something she is not okay with, she will hit them. Even if someone else hits her, she won't come and tell us.”

The day I met them was the family's first visit to St. John's hospital. Her mother spoke of their hopes in coming there:

“ಅವಳು ಚೆನ್ನಾಗಿ ಆಗ್ಬೇಕು ಅಂತ ನಮಗೆ ಆಸೆ. ಎಲ್ಲಿ ಯಾವ ಡಾಕ್ಟರ್ ಹತ್ರ ಕರ್ಕೊಂಡು ಹೋದ್ರೆ, ಚೆನ್ನಾಗಿ ಆಗ್ತಾಯೊ ಅಂತ ನಮಗೆ ಮನ್ನಸಿನಲ್ಲೆ. ಇಲ್ಲಿ ಡಾಕ್ಟರ್ ಬಗ್ಗೆ ತುಂಬ ಕೇಳಿದೀವಿ, ಯಾವದೋ ಟ್ಯಾಬ್ಲೆಟ್ ಕೊಡಬಹುದೇನೋ ಅಂತ ನಂಬಿಕೆ ಇಟ್ಟೊಂಡು ಬಂದಿದಿವಿ.”

*“We just want her to be okay. We are hoping that somewhere, if we take her to some doctor she might become alright. We have heard the doctors here are very good, we have come here with the belief that the doctor might prescribe some medicine that will make her issues better.”*

Noor's safety and bodily integrity was a rightfully a major point of concern for her parents:

“ನಾವು ಜಾಸ್ತಿ ಆಚೆ ಬಿಡಲ್ಲ, ಬಿಟ್ಟೆ ಆಚೆಯವರ ತರಹನೇ ಆಗ್ಬಿಡ್ತಾಳೆ. ಓಡಾಡ್ಕೊಂಡು ಸುತ್ತಾಡಿಕೊಂಡು. ನಮ್ಮವರು ಬೇರೆಯವರು ಅನುವುದು ಗೊತ್ತಾಗಲ್ಲ. ಯಾರಾದ್ರೂ ಕರ್ಕೊಂಡು ಹೋದ್ರೆ ಹೋಗ್ಬಿಡ್ತಾಳೆ.”

*“We don't allow her outside by herself. If we do, she just stays outside. She will be loitering and roaming around. She doesn't understand the difference between near ones and strangers. If somebody tries to take her, she'll go along with them.”*

Although she was unable to comprehend danger and constantly threw tantrums, her father wanted to emphasise her innocence:

“ಅವಳಿಗೆ ಮಗು ಮನಸು. ಚಿಕ್ಕ ಮಗು ತರಹ ಹರ ಮಾಡ್ತಾಳೆ. ತಮ್ಮಂಗಿ ಹೊಡದ್ದಿಟ್ಟು ಅವನು ಅಳತಿದ್ರೆ ಮುಖ ವಂತರಹ ಮಾಡ್ಕೊಳ್ತಾಳೆ.”

*“She has a child-like mind. She throws tantrums like a little kid. When she hits her brother, if he cries, her face becomes small and downcast.”*

Noor was enrolled in school only until UKG, when she was six years old. Regarding her schooling, her mother explained:

“ಅವಳಿಗೆ ಓದಕ್ಕೆ ಬರಿಯಕ್ಕೆ ತುಂಬ ಇಷ್ಟ. ಆದ್ರೆ ಎ ಬಿ ಸಿ ಡಿ ಒಂದ ಅಕ್ಷತ್ರ ಅವಳಿಗೆ ಬರಲ್ಲ. ಉ.ಕೆ.ಜಿ ತನಕ ಕಳಿಸಿದ್ದಿ, ಆದ್ರೆ ಬರೀ ಗಿರ್ ಹಾಕೊಂಡು, ಇಷ್ಟು ಪೇಪರ್ ಹರಡಿಕೊಂಡು ಬರೋಳು. ಸ್ಕೂಲ್ ನವರು ಸುಮ್ಮನೆ ಯಾಕೆ ಕಳಿಸ್ತೀರಾ, ಮನೆನಲ್ಲಿ ಇಟ್ಟೊಳಿ ಅಂತ ಹೇಳ್ತೀರು. ಸುಮ್ಮೆ ಕಾಸ್ ಕೊಟ್ಟು ಯಾಕೆ ಕಳಿಸ್ತಿರ, ಸುಮ್ಮೆ ಗಿಚ್ಚೊಂಡು ಇರ್ತಾಳೆ ಅಂತ.”

*“She actually really likes to read and write, but she does not actually understand any of the alphabets. We sent her to school until she was in UKG, but she would just scribble and draw lines endlessly and tear lots of paper and bring it home. The school told us to keep her at home as it was no use. They say why spend money when all she'll do is draw lines on paper?”*

When I asked her parents about special education to help her with activities of daily living, they were unaware of any such thing. Although, they had sent her to tuitions and nothing had been of any use in getting her to even learn numbers and alphabets. Noor was thoroughly excluded from her peers and also from any opportunities to pursue activities she valued or found interesting. Noor's impairment made it extremely difficult to deduce what she indeed valued or enjoyed. Although her parents cared for her and wanted her to be like other typically developing children, there is no such simple solution. Based on the experiences of other children with cognitive disabilities who have participated in this research, it seems that special education, speech and occupational therapy, and a realignment of her parents' expectations can help Noor in learning to perform activities of daily living, exercising her agency and figuring out what she values being and doing.

Since autism spectrum disorders were first described, a significantly larger number of males have been diagnosed than females, as can be seen across prevalence studies (Halladay et al., 2015). Autistic girls and women also tend to receive a diagnosis later in life although both children of both genders show similar ages of first concern (Rutherford et al., 2016). Even among children with the same levels of autistic traits, girls are less likely to be diagnosed. Furthermore, girls who do receive an autism diagnosis usually display more behavioural problems and autistic traits than boys who get diagnosed, suggesting that girls need to have greater difficulties due to their autism or other co-occurring issues in order to receive an autism diagnosis (Russel et al., 2011; Lundström et al., 2019).

Whitlock et al. (2020, p.1359) has suggested that autism goes unrecognised in girls because there is a “female autism phenotype” or a specific manner in which autism presents itself in females. There are four features that are characteristic of autism in females: Girls with autism show higher social motivation and interest in cultivating friendships and relationships than their male counterparts. They attempt to camouflage their autism or mask its characteristics by practising facial expressions and gestures, and forcing themselves to make eye contact. Since autistic people show co-occurring emotional and behavioural difficulties, research indicates that boys and men may externalise the difficulties while women and girls internalise them through anxiety or eating disorders (Westwood et al., 2016). The repetitive and restrictive behaviours and interests that autistic people typically show can also be influenced by gender. While boys focus on maths and mechanics, girls can have more socially-focused or normative interests like novels or pop stars, thereby not drawing attention to the behaviours (Bargiela et al., 2016). It has also been found that family doctors and primary school teachers who are usually gatekeepers for autism assessment and alerting parents of children’s learning difficulties show bias against girls and the female autism phenotype by relying on their own personal experience of autism to guide their work and practice (Unigwe et al., 2017).

In addition to the underdiagnosis of neurodevelopmental disorders in girls, there is a parental gender bias in intra-household resource allocation that has been observed when it comes to India, Bangladesh and other South Asian countries (Barcellos et al., 2014; Begum et al., 2022). There is a systematic bias in parent’s investment in the health and education of their male and female children, which has been attributed to sociocultural and religious norms. This includes spending more on boys’ education and being less likely to seek formal medical treatment when a girl child is ill. Although this research had only one female participant, the absence of girls with cognitive disabilities seeking care at the site of this research provided insight on how health and educational institutions, and social attitudes towards different genders can make an impairment even more disabling.

## Chapter 4 – The evolving nature of valued capabilities

The central human capabilities (see Appendix 1 - 10 Central Capabilities) of being able to live to the end of a life worth living; to have good bodily health, nourishment and shelter; and to have bodily integrity to move freely and be secure against assault were all capabilities valued by the caregivers of children with cognitive disabilities as expected, especially in cases where these capabilities were threatened. Every parent expressed fears and hopes around their child's ability to support themselves and live independently, to be safe and well-nourished. The capability to have bodily integrity was particularly valued by Noor's parents because she did not possess this internal and combined capability. As a young girl on the brink of puberty with highly limited cognitive abilities who is not able to communicate with her caregivers when other people hit her or trouble her in any way, she is particularly vulnerable and cannot move freely at the risk of physical or sexual assault.

The capability of children with cognitive disabilities to have emotions and form attachments outside of oneself to other things and people, along with the capability to form affiliations, live with and show concern for other human beings were both highly valued by caregivers. Children with fewer behavioural problems who were able to empathise with other people had better relationships with their peers, siblings and caregivers, which led to more favourable outcomes. The capability to express emotions and form affiliations were limited by language skills and non-verbal forms of communication in many cases. Children who struggled with these capabilities were perceived less favourably by their caregivers and experienced greater misalignment with caregivers on what was valuable in their lives. Another aspect of the capability to have affiliations is the capability to have the social bases of self-respect and non-humiliation. Zaid is a seven-year-old boy on the autism spectrum who is non-verbal and displays autistic wandering and hand-flapping. He can perform activities of daily living, can imitate sounds, and can understand and reciprocate emotions, especially with his mother. However he struggles with concentration, maintaining eye contact with strangers and socialising with other children. As his mother explains, other people's perception of him leaves much to be wanted:

*"People are usually supportive, but sometimes when we go to the park, I see other parents making faces when they see how he is behaving. That really hurts. I take him away from there usually. But nowadays, I confront them and ask 'Do you want something from my son?' when they are staring at him like he is a zoo animal."*

Fortunately, his mother thinks that Zaid himself is mostly unaffected by how other people perceive him and he is happy in his own world. However, as I discussed in the case of Shivansh in Chapter 3.2, there are many children with cognitive disabilities who understand and experience a keen sense of exclusion on a daily basis that can be even more disabling. Chandrakant is a nine-year-old boy with mild to moderate ASD from a middle-class Bengali Brahmin family. His mother recollects when a psychologist recently asked him what he wants to be during an assessment and he replied:

*"I want to be a normal human being"*

His mother went on to add:

*"That really shocked me. Who told him he's not a normal human being? Where did he learn that? When he is playing in front of the apartment, some parents will advise their children to not play"*

*with him. Adults should not interfere, kids can solve their own problems. Not only for Chandrakant, but for all neurodivergent kids, I want inclusion. Everyone deserves that. People should not judge them. If a neurodivergent child throws a tantrum, people approach you to offer parenting advice because they think this reflects bad parenting. That just needs to stop."*

Children like Shivansh and Chandrakant have the internal but not the combined capability to form affiliations. The capability to live with concern for plants, animals and the world of nature was not specially valued by caregivers. However, when children expressed a personal preference for pets or plants, these interests were encouraged by caregivers. Valuing this capability depended upon individual preference in each case. The one thing that all children appeared to value was the capability to play, laugh and enjoy recreational activities. Shraavan is a seven-year-old boy with ASD from a highly-affluent Kannada Brahmin household. His mother is a housewife, his father is an IT professional and he lives in a joint family with his four-year-old brother, grandparents, aunt and uncle. His parents express that what he enjoys most is being free and unconstrained in nature. His mother said:

*"When we go on vacations, he wants to wake up early, go out and go on a nature walk. If we plan something like that, he will insist that we wake up and follow the plan"*

Shraavan was drawing a giraffe while I interviewed him and his parents. When I asked him what he enjoys doing the most, he said:

*"Playing with trains. Building blocks. Cycling. I like music, melodious songs."*

When I asked him what he wanted to be when he grew up, he said:

*"Artist."*

I asked him where he had seen a giraffe and whether he had seen one in a zoo, he replied:

*"I saw it in Lion King"*

His father talks about how he enjoys freedom and play over activities that become repetitive and boring:

*"He starts a lot of activities with interest but as soon as rules and constraints start to pour in, he doesn't want to do it anymore."*

Not every child displayed the internal capability to use their senses, imagination and thought, however when children did possess this internal capability, caregivers were invested in developing their combined capabilities so that children could use their senses and imagination to think, reason and do things in a 'truly human' way. With respect to Zaid who I discussed earlier in this chapter, his father had the following to say about him:

*"He will succeed in something that he picks up. He is very good at sports, especially swimming. It is a matter of time before he finds his rhythm. Einstein was also autistic. We are not too worried about his future, but we also don't want to simply let it be. We have to keep putting in some effort."*

Resuming with the conversation from Chapter 3.3, based on the evidence gathered in this research, I would like to argue that the capabilities that are valued in the lives of children with cognitive disabilities evolve over time. Childhood is a period of critical development because some capability sets are obtained for the first time in childhood during milestones like when basic cognitive, language and

motor skills develop, during adolescence and as children mature into adulthood. Now, although there are socially-defined chronological ages for these developments, the actual age at which each child first develops each new capability set can widely differ. In this research, I did not expect to find children with cognitive disabilities to have the capability to control their own political and material environments. Since capabilities evolve in a gradual process, in response to the social, economic and political conversion factors in each individual child's life, these capabilities had already begun to develop in the lives of some children.

Coming back to the story of 12-year-old Krishna from Chapter 3.2, when I asked his mother if he is able to engage in decision-making about his own life, she said:

“ನಾವು ಅವನಿಗೆ ಸುಮ್ಮನೆ ಹೇಳಿದ್ದು ಅಣ್ಣಂದಿರಿಗೆ ಜ್ಯಾಸ್ತಿ ಆಸ್ತಿ ಕೊಡ್ತೀವಿ, ನಿನಗೆ ಕಡಿಮೆ ಕೊಡ್ತೀವಿ ಅಂತ. ಆದ್ರೆ ಅವನು ಇಲ್ಲ ನನಗು ಅಷ್ಟೇ ಬೇಕು ಅಂತ ಹೇಳಾನೆ. ಹೀಗೆ ಅವನ ಬುದ್ಧಿ ಬೆಳೆಬೇಕು, ಆಸ್ತಿ ಇದೆ, ಅದು ನನ್ನದು ಅಂತ ಗೊತ್ತಾಗಬೇಕು.”  
Translated from Kannada: *“We jokingly told him the other day that we will give more of our property to his older brothers, but he said that he wants the same amount of inheritance we give his older brothers. We want him to be able to understand these things, that some property belongs to him and he is responsible for it.”*

It was a positive surprise to find that Krishna had both the internal and combined capability to control his own material environment, by being able to have property rights on an equal basis with his siblings by wanting, asking and having parents who valued this capability. Returning to the story of Ritesh, he had some capability to control his own political environment. During the interview, his father explained:

“ಮೊನ್ನೆ ಎಂ. ಎಲ್. ಏ. ಎಲೆಕ್ಷನ್ ಟೈಮ್ ಬಂದಾಗ, ಊರು ಹುಡುಗರ ಜ್ಯೋತೆ ಸೇರಿಕೊಂಡು, ಮನೆ-ಮನೆಗೂ ಹೋಗಿ, ಕಾಂಗ್ರೆಸ್ ಗೆ ವೋಟ್ ಹಾಕಿ ಅಂತ ಹೇಳಿ ಹೋಗಿದ್ದ.”  
Translated from Kannada: *“In the MLA elections that took place recently, he went around door-to-door with the neighbourhood boys, telling people to vote for Congress.”*

When I asked his father if Ritesh understood the meaning of elections and what he was doing, he said:

“ಅವನ ಮಾವ ಕಾಂಗ್ರೆಸ್ ಪಾರ್ಟಿ ಮೆಂಬರು. ದೊಡ್ಡ ಹುಡುಗರ ಜ್ಯೋತೆ ಸೇರಿಕೊಂಡು, ಯುವನು ಇದೆಲ್ಲ ಮಾಡ್ತಾನೆ.”  
*“His uncle is a member of the Congress party. The older boys influence him to join them in campaigning.”*

While Ritesh is exercising his right to political participation, free speech and association, it is unlikely that he has the internal capability to participate politically in matters that govern his life or the combined capability to exercise the right to vote and control his political environment. This capability of his is in flux. It was also evident that as children mature into adulthood, the capability to have practical reason, to form conceptions of good and bad and critically engage in planning one's own life becomes vitally important. As I described in the cases of 16 and 17 year olds like Raunak and Jai, parents begin to value the capability to possess practical reason towards the end of childhood so that children can engage in the planning of their own lives. When children are unable to obtain this capability set, they experience

a greater sense of disability. Just as capabilities evolve, what capabilities are valued by caregivers also evolve through different points in childhood.

#### **4.1 Politics of the Household**

The single most important conversion factor that either aided or inhibited children with cognitive disabilities in transforming the vector of commodities into functionings to achieve valued capabilities was found to be the household's perception of their impairment. Research on the social inclusion of children with cognitive disabilities in Uganda has shown that depending on the characteristics of the child, caregiver and household, disability either causes an upward spiral towards visibility or downward spiral towards concealment or reinforcement of stigma (Masquillier et al., 2021). In this research, there was evidence to support this claim. An alignment between what children enjoyed, and the capabilities their caregivers valued meant better outcomes for children with cognitive disabilities. Alignment between children and caregivers on what was valuable in the child's life also was related to fewer behavioural problems and better relationships with siblings, grandparents and peers.

The complex stories of children with ASD and ID gathered in this study confirmed the importance of the domestic sphere and influence of the household in mediating disabled children's relationships with the outside world. The household was children's first point of reference of the social world, and the caregivers and other members of the child's household played a significant role in enhancing or constraining their capabilities. The caregivers' attitudes towards the child's impairment and how they were navigating the various discourses they encountered through schools, medical establishments, and religious and cultural institutions had a direct impact on the child's experiences of inclusion and development of valued capabilities.

#### **4.2 Influences of social institutions**

The ideas of culture and structure, which interact to define the habitus and create the social world, in post-structural thinking can be equated to the capability-constraining or capability-enhancing institutions in CA. Healthcare, education, gender, age and social attitude towards disability were the important social institutions guiding the development of valued capabilities of children with cognitive disabilities. As explored in the case of Noor, gender can be a highly disability-enhancing, capability-constraining social institution by preventing girls from being diagnosed with cognitive disabilities and inhibiting them from accessing educational and healthcare opportunities. The social construct of chronological age also directs the evolution of capabilities and the evolving value placed on capabilities at different social ages. Beyond the household's perception/navigation of impairment, there is an external societal perception of impairment that shapes all the opportunities that are available to children with cognitive disabilities. This defines their experience of inclusion, and whether they are able to achieve valued capabilities.

Educational institutions and the system of schooling that a child is exposed to has a strong influence on the child's sense of inclusion. Inclusive education is the focus of most legislation on children with disabilities in India, and rightly so, as it is something that most caregivers of children with cognitive disabilities seem to value. Special education is extremely essential for children with severe disabilities or extreme behavioural issues that prevent them from accessing regular schools. It helps children develop



good habits and routines, perform activities of daily living, and improve language and cognitive abilities. Cognitively disabled children enrolled in regular schools can experience physical exclusion when they are unable to engage in activities with their neurotypical peers or social exclusion through bullying and isolation from peers and educators. The high cost of education and disability-enhancing social institutions like gender can prevent children with cognitive disabilities from enrolling in school altogether. Healthcare institutions can also be gender-biased in their diagnosis and care of children with cognitive disabilities. However, medical professionals and healthcare institutions can also be a vital support to children with cognitive disabilities and their caregivers in navigating inclusion and developing valued capabilities.

### **4.3 The double economic burden of disability**

Every participating household that was interviewed and observed for this research cited the increased financial expenditure from obtaining healthcare, education and rehabilitation facilities for their cognitively disabled child. Data on household income showed that even affluent and relatively upper middle-class households were struggling to access the best healthcare facilities and education that was truly inclusive. Sen (1992, p.113) has noted how the same handicap such as age, impairment or illness that reduces one's income-earning ability also makes it more difficult to in-turn convert the income into additional capabilities. This is especially true for children with cognitive disabilities. Not only does cognitive impairment reduce the child's ability to become literate, find employment and earn income, it is also a massive drain on the household's financial resources. Sen has suggested that the extent of poverty amidst people who have such handicaps is underestimated because it does not take into consideration the "coupling" effect of the income-using handicap and the income-generating handicap that prevents the development of valued capabilities. Income-draining disadvantages can exponentially increase the feature of low-earning power in individuals with cognitive disabilities.

### **4.4 Scope for further research**

This research is limited in its representation of the multiplicity of cognitively disabled girls' experience of inclusion and the conversion factors that guide the development of their valued capabilities. There is scope for further research with a larger sample of girl children with ASD and ID, or young adult women with the same conditions to understand how they interact with disability-enhancing social, political and economic institutions. There is also a possibility for investigating whether religion and caste play a disability-enhancing or constraining role by asking cognitively disabled children and their caregivers questions about these factors in relation to their experience of inclusion or the development of valued capabilities.

### **4.5 Reflexivity and concluding statements**

The site of this research was a bustling general hospital visited by hundreds, if not thousands of people everyday in the densely populated centre of urban Bengaluru, India. The Department of Psychiatry and Centre for Special Needs at John's hospital is widely known as the place to seek healthcare for children with ASD, ID and other neurodevelopmental disorders in the city. In choosing this site, I hoped to access a wide sample of children with cognitive disabilities from across the city, from varied socioeconomic

classes, religions, and parental backgrounds. Nevertheless, this research seeks to assess the influence of institutions including those providing healthcare in the lives of cognitively disabled children. The biomedical establishment and its influence on the sample must be noted, as a hospital is the site of the research. Every participant I encountered and recruited for this study was at the site to consult with a psychologist or a doctor, who would also inform them of their capabilities and aid in its development in some manner. Being conscious of the various interacting power dynamics at play was essential to this research, which led me to my own positionality. I strived to balance promoting children's agency and an ethic of care by interpreting each child's modes of communication, ensuring the ongoing assent of all participants, and using the CA analytical framework to assess each child's experience of inclusion, what capabilities they valued and how the household contributed to development of valued capabilities.

This research chooses an ethnographic approach to fieldwork and data collection. The interviews and observations with participants were highly challenging and emotionally taxing. Since many children were non-verbal or had limited language abilities, it was an enormous undertaking to interpret each child's modes of communication in the short period of time that I spent with them. Looking back, I could have also used different participatory methodology to better accommodate the needs of non-verbal children. Wanting to collect photographs was an effort in this direction. Nonetheless, this research process of thinking deeply about what inclusion means to cognitively disabled children, understanding their uncommon modes of communication, and evaluating the internal and combined capabilities they possess was what led me to consider alternate methodology, so I am grateful for this process. Besides, ethnographic observations and qualitative interviews with participants were successful in revealing what inclusion means to cognitively disabled children, what they value and enjoy, and what capabilities caregivers value in the child's life, which was the objective of this research.

Throughout this research process, I was consciously aware of the ethical and moral responsibility placed on my shoulders by the caregivers of participating children to put forward true representations of the experiences of children with ASD and ID. As Nihaar's father stated towards the end of our interview:

*"We want you to raise our voice. One thing I want to emphasise is the sensitisation of people, especially service providers, towards children like Nihaar. When we have to get into queues and wait for our turn, these children can't wait quietly like others. The staff at such places should be trained and made aware. If you look at a person, you know they are a senior citizen so you go and treat them differently. But with these kids, you can't always tell by just looking at their faces. If I go to them and say he's a special kid who needs immediate attention, people ask me 'what do you mean by special kid?' Thankfully he doesn't have physical challenges, but because he doesn't look disabled, if people see him behaving badly, they just assume he is naughty.*

Children with ASD and ID are ostracised by society and experience exclusion purely as a result of their differences, and the manner in which their impairment reacts with social and environmental conditions around them. In appraising their central human capabilities and conversance with inclusion, this research hopes to disseminate a basic understanding of the capabilities cognitively disabled children have, and the social, economic and political institutions around them that encourage or constrain the development of valued capabilities.

## Appendices

### Appendix 1: 10 Central Capabilities

The 10 fundamental human capabilities defined by Martha Nussbaum (2011, p.42-43):

1. Life: Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
2. Bodily Health: Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
3. Bodily Integrity: Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
4. Senses, Imagination, and Thought: Being able to use the senses, to imagine, think, and reason-and to do these things in a "truly human" way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non beneficial pain.
5. Emotions: Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)
6. Practical reason: Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.)
7. Affiliation:
  - (A) Being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.)
  - (B) Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of nondiscrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin.
8. Other Species: Being able to live with concern for and in relation to animals, plants, and the world of nature.

9. Play: Being able to laugh, to play, to enjoy recreational activities.

10. Control Over One's Environment:

(A) Political. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association.

(B) Material. Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason, and entering into meaningful relationships.

**Appendix 2: Participant Information Form**

Child's Name	
Gender	
Age	
Date of Birth	
Mother's name	
Mother's occupation	
Father's name	
Father's occupation	
Contact number	
Email ID	
Number of siblings	
Other family members residing in the same house	
Other caregivers	
Religion	
Caste (if applicable)	
Total family income	
Current or highest grade completed	
School or other facility	
Mother tongue	
Other languages spoken	
Disabling condition/diagnosis	

Appendix 3: Questions with visual cues for children



**What do you enjoy doing?**



**When do you feel loved and supported by others?**



**What is something that you are proud of?**



**How do you like to help others?**



**How do you like to learn new things?**



**When do you feel the most respected and valued by those around you?**



**Is there anything you would like to change or improve in your daily life?**



**Can you describe a time when you felt included in a group or activity?**



**How do you like to communicate with others?**



**What do you think would make your life better and more enjoyable?**

#### **Appendix 4: Questions for the child's caregiver or responsible adult**

1. What is the kind of life you want for your child in terms of basic living, education, health and relationships?
2. What is your idea of your child being happy? What would this include?
3. What are the difficulties you face in supporting your child?
4. What do you think is society's view of your child? How does this affect you and your child?
5. Do you think your child will be able to eventually live a full and meaningful life independently, given her/his present condition?
6. What are your child's ambitions? What are your ambitions for your child?
7. What are the supports and services currently available to your child? How do you feel about it? What improvements do you think are needed?
8. What changes do you think are needed in your child's immediate surroundings to improve their life?
9. How is your child's relationship with their siblings/ friends/ neighbours/ relatives? How do you think this can be improved?
10. What have you done to make your child feel more accepted and included in society?
11. Do you involve your child in decision-making related to their life? If yes, how? If not, how can you involve them?
12. How are you teaching your child to be safe and secure when they are by themselves?
13. Is your child able to participate in creative activities like playing with children imaginatively, writing, drawing, singing, dancing, sport.
14. Does your child feel and show emotions like love, hate, anger, sadness, happiness?
15. Is your child able to form attachments with other people and express love, care, gratitude? Do they become sad when the people they love are not around?
16. Do you think your child understands the difference between good and bad? Are they able to make decisions for themselves on the basis of this?
17. Is your child able to show concern, empathy, care for other human beings? Can they recognise other's emotions?
18. Do you think your child receives the same respect and treatment as other children, without discrimination on the basis of their disability, gender, caste...?
19. Does your child care about animals (pets), plants, nature?
20. Does your child show happiness when engaging in play and recreation on their own?

## References

- Alkire, S. (2005) 'Valuing freedoms: Sen's capability approach and poverty reduction.' *Oxford University Press*, USA.
- Amado, A. N., Stancliffe, R.J., McCallion, M. M. P. (2013) 'Social Inclusion and Community Participation of Individuals with Intellectual/Developmental Disabilities' *Intellectual and Developmental Disabilities*, 51 (5): 360–375. <https://doi.org/10.1352/1934-9556-51.5.360>
- American Psychiatric Association (2013) 'Diagnostic and statistical manual of mental disorders' (5th ed.). Available at: <https://doi.org/10.1176/appi.books.9780890425596> (Accessed: 11 October 2023)
- Arneil, B. (2002) 'Becoming versus being: A critical analysis of the child in liberal theory.' In David Archard & Colin M. Macleod (eds.), *The Moral and Political Status of Children*. Oxford University Press. pp. 70--96.
- Asad, T. (1986) 'The Concept of Cultural Translation in British Social Anthropology'. *Writing Culture*, edited by James Clifford and George E. Marcus, Berkeley: University of California Press, 1986, pp. 141-164. <https://doi.org/10.1525/9780520946286-009>
- Barcellos, S. H., Carvalho, L. S., and Lleras-Muney, A. (2014) 'Child gender and parental investments in India: Are boys and girls treated differently?', *American Economic Journal of Applied Economics*, 6, 157–89.
- Bargiela, S., Steward, R., & Mandy, W. (2016) 'The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype.' *Journal of Autism and Developmental Disorders*, 46(10), 3281–3294.
- Begum, L., Grossman, P. J., Islam, A. (2022) 'Parental gender bias and investment in children's health and education: evidence from Bangladesh'. *Oxford Economic Papers*, 2022, 1045–1062. <https://doi.org/10.1093/oep/gpac006>.
- Bourdieu, P. (1986) 'Distinction: A Social Critique of the Judgement of Taste' Cambridge, Massachusetts.
- Burchardt, T. (2004) 'Capabilities and Disability: The Capabilities Framework and the Social Model of Disability.' *Disability & Society* 19 (7): 735–751. doi: 10.1080/0968759042000284213
- Cerwonka, A. (2007) 'Nervous Conditions: The stakes in interdisciplinary research.' *Improvising Theory: Process and temporality in ethnographic fieldwork*, pp. 1–25.
- Clark, M.L.E., Vinen, Z., Barbaro, J. (2018) 'School Age Outcomes of Children Diagnosed Early and Later with Autism Spectrum Disorder.' *Journal of Autism and Developmental Disorders*, 48, 92–102. <https://doi.org/10.1007/s10803-017-3279-x>



Corker, M. (1999) 'New disability discourse, the principle of optimisation and social change', in M. CORKER & S. FRENCH (Eds) *Disability Discourse*, pp. 192-209 (Buckingham, Open University Press).

Das, V., Addlakha, R. (2001) 'Disability and Domestic Citizenship: Voice, Gender, and the Making of the Subject.' *Public Culture* 13(3), 511-531. Available at: <https://www.muse.jhu.edu/article/26253>. (Accessed: 3 July 2023)

Davis J.M. (2000) 'Disability studies as ethnographic research and text: Research strategies and roles for promoting social change?' *Disability & Society*;15(2):191. <https://www.proquest.com/scholarly-journals/disability-studies-as-ethnographic-research-text/docview/195758743/se-2>.

Dawson, G., Burner, K. (2011) 'Behavioural interventions in children and adolescents with autism spectrum disorder.' *Current Opinion in Pediatrics*, 23(6), 616–620. <https://doi.org/10.1097/MOP.0b013e32834cf082>

Fairthorne, J., de Klerk, N. and Leonard, H. (2016) 'Brief report: burden of care in mothers of children with autism spectrum disorder or intellectual disability.' *Journal of Autism and Developmental Disorders*, 46(3), pp.1103-1109.

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., Hallam, A., Knapp, M., Wooff, D. (2006) 'The social networks of people living in the community 12 years after resettlement from long-stay hospitals.' *Journal of Applied Research in Intellectual Disabilities*, 19, 285–295.

Frega, M., Selten, M., Mossink, B., Keller, J. M., Linda, K., Moerschen, R., Qu, J., Koerner, P., Jansen, S., Oudakker, A., Kleefstra, T., van Bokhoven, H., Zhou, H., Schubert, D., Nadif Kasri, N. (2020) 'Distinct Pathogenic Genes Causing Intellectual Disability and Autism Exhibit a Common Neuronal Network Hyperactivity Phenotype.' *Cell reports*, 30(1), 173–186.e6. <https://doi.org/10.1016/j.celrep.2019.12.002>

Goldson, B. (1997) 'Childhood An Introduction to Historical and Theoretical Analysis'. In *Childhood in Crisis?* Scraton P. (ed). UCL Press: London; 1-27.

Government of India (2016) 'The Rights of Persons with Disabilities Act, 2016'. Available at: [https://www.indiacode.nic.in/bitstream/123456789/15939/1/the\\_rights\\_of\\_persons\\_with\\_disabilities\\_act%2C\\_2016.pdf](https://www.indiacode.nic.in/bitstream/123456789/15939/1/the_rights_of_persons_with_disabilities_act%2C_2016.pdf) (Accessed: 1 September 2023)

Halladay, A. K., Bishop, S., Constantino, J. N., Daniels, A. M., Koenig, K., Palmer, K., Taylor, J. L. (2015) 'Sex and gender differences in autism spectrum disorder: Summarizing evidence gaps and identifying emerging areas of priority.' *Molecular Autism*, 6(1), 36.

Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., Rodriguez, E. (2008) 'What does participation mean? An insider perspective from people with disabilities.' *Disability and Rehabilitation* 30: 1445– 1460. doi:10.1080/09638280701625534.

Hill, M., Davis, J., Prout, A., Tisdall, K. (2004) 'Moving the participation agenda forward.' *Children & Society* 18: 77– 96.

Hrdlicka, M., Urbanek, T., Rotreklova, A. (2023) 'Predictors of age at diagnosis in autism spectrum disorders: the use of multiple regression analyses and a classification tree on a clinical sample.' *European Child & Adolescent Psychiatry*. <https://doi.org/10.1007/s00787-023-02189-6>

Jenkin E., Wilson E., Clarke M., Campain R. (2019) 'The Principles and Ethics of Including Children with Disability in Child Research' Deakin University: Melbourne. 34(1), January 2020, p.1-16. <https://doi.org/10.1111/chso.12356>

Landsman G. (2005) 'Mothers and models of disability.' *The Journal of medical humanities*, 26(2-3), 121–139. <https://doi.org/10.1007/s10912-005-2914-2>

Le Boutillier C., Croucher A. (2010) 'Social inclusion and mental health.' *British Journal of Occupational Therapy* 73: 136– 139.

Lewis, J. (2003) 'Feminist Perspectives.' *The Student's Companion to Social Policy*. Alcock P, Erskine A, May, M. (eds). Blackwell Publishing: Oxford; 107-112.

Lundström, S., Mårland, C., Kuja-Halkola, R., Anckarsäter, H., Lichtenstein, P., Gillberg, C., Nilsson, T. (2019) 'Assessing autism in females: The importance of a sex-specific comparison.' *Psychiatry Research*, 282, 112566. <https://doi.org/10.1016/j.psychres.2019.112566>.

Marcenko, M.O., Meyers, J.C. (1991) 'Mothers of children with developmental disabilities: Who shares the burden?' *Family Relations*, pp.186-190.

Masquillier, C., De Bruyn, S., Musoke, D. (2021) 'The role of the household in the social inclusion of children with special needs in Uganda – a photo-voice study.' *BMC Pediatr* 21, 386 <https://doi.org/10.1186/s12887-021-02805-x>

Mehrotra, N. (2012) 'Methodological Issues in Disability Research: An Introduction' *Indian Anthropologist*, Vol. 42, No. 1, pp. 1-10. <https://www.jstor.org/stable/41922004>

Mitra, S. (2006) 'The Capability Approach and Disability', *Journal of Disability Policy Studies*, 16:4, 236-247. <https://doi-org.eur.idm.oclc.org/10.1177/10442073060160040501>

Mpaka, D. M., Okitundu, D. L., Ndjukendi, A. O., N'situ, A. M., Kinsala, S. Y., Mukau, J. E., Ngoma, V. M., Kashala-Abotnes E., Ma-Miezi-Mampunza, S., Vogels, ASteyaert, J. (2016) 'Prevalence

and comorbidities of autism among children referred to the outpatient clinics for neurodevelopmental disorders.’ *The Pan African medical journal*, 25, 82. <https://doi.org/10.11604/pamj.2016.25.82.4151>

Mulroy, S., Robertson, L., Aiberti K., Leonard H., Bower C. (2008) ‘The impact of having a sibling with an intellectual disability: parental perspectives in two disorders’, *Journal of Intellectual Disability*. Volume 52 part 3 pp 216–229. doi: 10.1111/j.1365-2788.2007.01005.x

Nambiar, S. (2013) ‘Capabilities, conversion factors and institutions’, *Progress in Development Studies*. Volume 13, Issue 3, pp.177-254. <https://doi-org.eur.idm.oclc.org/10.1177/1464993413486547>

National Human Rights Commission (2022) ‘Disability Rights (Rights of Persons with Disabilities Act & National Trust Act) and Mental Healthcare Act’. Available at: <https://nhrc.nic.in/sites/default/files/DisabilityRights.pdf> (Accessed: 21 October 2023)

Neece, C.L., Blacher, J., Baker, B.L. (2010) ‘Impact on Siblings of Children With Intellectual Disability: The Role of Child Behavior Problems.’ *American Journal of Intellectual and Developmental Disability*, 115 (4): 291–306. doi: <https://doi.org/10.1352/1944-7558-115.4.291>

Nussbaum, M. (2003) ‘Capabilities as Fundamental Entitlements: Sen and Social Justice.’ *Feminist Economics* (9): 33-59. <https://doi.org/10.1080/1354570022000077926>

Priestley, M. (1998) ‘Childhood Disability and Disabled Childhoods’. *A journal of global child research*. 5:2, 207-223. [https://doi-org.eur.idm.oclc.org/10.1177/0907568298005002007open\\_in\\_new](https://doi-org.eur.idm.oclc.org/10.1177/0907568298005002007open_in_new)

Prout, A., James, A. (1990) ‘A new paradigm for the sociology of childhood? Provenance, promise and problems.’ In A. James & A. Prout (Eds.), *Constructing and reconstructing childhood: New directions in the sociological study of childhood*. London: Routledge.

Qvortrup J., Bardy M., Sgritta G. (1994) ‘Childhood Matters: An Introduction.’ *In Childhood Matters. Social Theory, Practice and Politics*. Qvortrup J, Wintersberger H. (eds). Avebury: Aldershot; 1-24.

Rabinow, P. (1986) ‘Representations as social facts: modernity & postmodernity in anthropology’, in: G.E. MARCUS & I. CLIFFORD (Eds) *Writing Culture: the poetics and politics of ethnography*, pp. 234-261 (Berkeley, University of California Press).

Reichman, N. E., Corman, H., Noonan, K. (2008) ‘Impact of child disability on the family.’ *Maternal and child health journal*, 12(6), 679–683. <https://doi.org/10.1007/s10995-007-0307-z>

Richard, B. O. (2014) ‘Families, well-being, and inclusion: Rethinking priorities for children with cognitive disabilities in Ladakh, India.’ *Childhood* 21(3):308. DOI: 10.1177/0907568214526264

Russell, G., Steer, C., & Golding, J. (2011) 'Social and demographic factors that influence the diagnosis of autistic spectrum disorders.' *Social Psychiatry and Psychiatric Epidemiology*, 46(12), 1283–1293.

Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., Murray, A. (2016) 'Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder.' *Autism*, 20(5), 628–634.

Seidman, S. (1998) 'Are we all in the closet? Notes towards a sociological and cultural turn in queer theory', *European journal of Cultural Studies*, 1, pp. 177-192.

Sen, A. (1992) 'Inequality Re-Examined.' Cambridge, MA: Harvard University Press

Shukla, R. (2023) 'Gearing Up For a Billion-Plus Middle Class by 2047', *People Research on India's Consumer Economy*. Available from: [https://price360.in/Executive\\_Summary\\_Middle\\_Class.pdf](https://price360.in/Executive_Summary_Middle_Class.pdf) (Accessed: 15 October 2023)

Simplican, S.C., Leader, G., Kosciulek, J., Leahy, M. (2015) 'Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation', *Re-search in developmental disabilities*, vol. 38, pp. 18-29. <https://doi.org/10.1016/j.ridd.2014.10.008>

Skinner, D., Weisner, T. S. (2007) 'Sociocultural studies of families of children with intellectual disabilities'. *Mental retardation and developmental disabilities research reviews*, 13(4), 302–312. <https://doi.org/10.1002/mrdd.20170>

Terzi, L. (2005) 'Beyond the Dilemma of Difference: The Capability Approach to Disability and Special Educational Needs', *Journal of Philosophy of Education*, 39(3), August 2005, p. 443-459. <https://doi.org/10.1111/j.1467-9752.2005.00447.x>

Thomas N.P., O'Kane C. (1998) 'The Ethics of Participatory Research with Children'. *Children & Society* 12(5):336 - 348. DOI:10.1111/j.1099-0860.1998.tb00090.x

Tisdall E.K.M, Davis J.M, Gallagher M. (2009) 'Research with Children and Young People: Research design, methods and analysis.' Sage: London.

Tisdall, E.K.M. (2012) 'The Challenge and Challenging of Childhood Studies? Learning from Disability Studies and Research with Disabled Children', *Children & Society*, vol. 26, no. 3, pp. 181-191. <https://doi.org/10.1111/j.1099-0860.2012.00431.x>

UN General Assembly (1989) 'Convention on the Rights of the Child' Treaty Series, vol. 1577, p. 3, Available at: <https://www.refworld.org/docid/3ae6b38f0.html> (Accessed: 4 October 2023)

UN (2006) 'Convention on the Rights of Persons with Disabilities (CRPD)' Available at: <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd> (Accessed: 23 September 2023)

Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., Pellicano, E. (2017) 'GPs' perceived self-efficacy in the recognition and management of their autistic patients: An observational study.' *British Journal of General Practice*, 67, p445-452.

Unit of Hope (2022) 'St. John's National Academy of Health Sciences.' Available at: [https://www.stjohns.in/Bringing\\_Hope.php](https://www.stjohns.in/Bringing_Hope.php) (Accessed: 12 October 2023)

van 't Hof, M., Tisseur, C., van Berckeleer-Onnes, I., van Nieuwenhuyzen, A., Daniels, A. M., Deen, M., Hoek, H. W., Ester, W. A. (2021) 'Age at autism spectrum disorder diagnosis: A systematic review and meta-analysis from 2012 to 2019.' *Autism*, 25(4), 862-873. <https://doi.org/10.1177/1362361320971107>

Watson N., McKie L., Hughes B., Hopkins D., Gregory S. (2004) 'An Emancipatory Model of Care? The Potential for Disability and Feminist Theorists to Develop an Ethics of Care.' *Sociology* 38: 331-350.

Westwood, H., Eisler, I., Mandy, W., Leppanen, J., Treasure, J., Tchanturia, K. (2016) 'Using the autism-spectrum quotient to measure autistic traits in anorexia nervosa: a systematic review and meta-analysis.' *Journal of Autism and Developmental Disorders*, 46(3), 964–977.

Whitlock, A., Fulton, K., Lai, M., Pellicano, E., Mandy, W. (2020) 'Recognition of Girls on the Autism Spectrum by Primary School Educators: An Experimental Study'. *International Society for Autism Research*, 13: 1358–1372.

World Health Organisation (2011) 'World Report on Disability'. Available at: <https://documents1.worldbank.org/curated/en/665131468331271288/pdf/627830WP0World00PUBLIC00BOX361491B0.pdf> (Accessed: 14 October 2023)