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The Educational and Occupational Trajectories of Adolescents and Youth with Disabilities in India

Renu Singh, Uma Vennam, Jayanthi Narayan, Amita Tandon, and Gina Crivello







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Executive summary

The United Nation Convention on the Rights of the Child (CRC) obligates the state to meet the learning needs of all children,¹ while the Convention on the Rights of Persons with Disabilities (CRPD) specifically refers to persons with disabilities and aims to promote, protect and ensure their full and equal enjoyment of all human rights (United Nations n.d.).²

The CRPD specifies that 'States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children', and 'ensure an inclusive education system at all levels and lifelong learning' (Articles 7 and 24) (UNICEF n.d.). Furthermore, Article 27 states that 'States Parties recognize the right of persons with disabilities to work on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.'

Despite these conventions and national legislation being adopted by states, empirical evidence highlights that, globally, persons with disabilities experience comparatively lower educational attainment, lower employment, worse standards of living and poverty, than persons without disabilities (World Health Organization 2011; Department for International Development 2018). Evidence related to persons with disabilities living in low- and middle-income countries is scarce and to the best of our knowledge no longitudinal studies have captured their life-course trajectories related to education, occupation and family formation.

This study aims to address this gap in relation to adolescents and young people in India. The research brought together analysis of Young Lives longitudinal study data collected since 2001, with findings from an in-depth qualitative study conducted by Young Lives India in Andhra Pradesh and Telangana in November-December 2020, during the COVID-19 pandemic. The study findings were discussed with a research advisory group to address policy gaps and develop policy recommendations to enhance the quality of life of persons with disabilities.

This report draws upon panel data from five rounds of Young Lives longitudinal survey (2001-2016) to analyse the self-assessed educational and occupational outcomes of 100 young persons with disabilities (a Younger Cohort age 15 and an Older Cohort age 22 in 2016).³ It also draws on a subsequent qualitative sub-study conducted with a nested sample of 34 young persons with disabilities and their caregivers, when they were age 18 (Younger Cohort) and 25 (Older Cohort).

The study explores the facilitators and barriers that adolescents and youth with disabilities face in their educational trajectories, and their related transitions to the labour market, marriage and family formation. It also captures the effects of the COVID-19 lockdown on their lives and aspirations for the future.

Findings from five rounds of the longitudinal survey

Young Lives longitudinal research reveals that 11.4 per cent of persons with disabilities were denied any educational opportunity throughout their life course; 47.1 per cent of persons with disabilities had completed elementary education at age 15, compared to 77.5 per cent of persons

¹ Article 1 of the CRC defines a child as 'every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier'.

² Article 1 of the CRPD defines persons with disabilities to 'include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.

³ It is important not to generalise findings from this study, since the sample remains small.

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without disabilities.⁴ For secondary education and above, at age 22 only 53.3 per cent of persons with disabilities attained this level of education, compared to 76.9 per cent of persons without disabilities.⁵

These glaring inequalities have a cascading effect on employment opportunities. Only 63.3 per cent of persons with disabilities were engaged in employment at age 22, compared to 71 per cent of those without disabilities. Desegregated data reveal that 31.6 per cent of persons with disabilities were engaged in salaried jobs at age 22, with an average salary of INR 5,750 per month compared to 34.8 per cent of those without disabilities, with an average salary of INR 9,136 per month.⁶ Persons with disabilities therefore on average earned 37 per cent less than persons without a disability in salaried employment.

Desegregated data by gender show that among persons with disabilities, young men fared better than young women in terms of both education and transitions to the labour market. To elaborate, 54.5 per cent of boys with disabilities completed elementary education by age 15 compared to 51.7 per cent of girls with disabilities, while 66.7 per cent of men with disabilities at age 22 completed secondary education and above, compared to 50 per cent of women with disabilities. This in turn has a significant impact on transitions to labour market, with all the men with disabilities at age 22 being engaged in paid employment, compared to 54.2 per cent of women with disabilities.

Findings from the in-depth qualitative study

Building upon the quantitative data, the qualitative study explored the lived experiences of persons with disabilities using a life-course perspective and identified enablers and barriers to education and employment.

The majority of the young persons with disabilities appeared to have transitioned through school without being negatively labelled. Only three persons with disabilities (out of a sample of 34) had enrolled into special schools, while most with varying impairments (from mild physical impairment to sensory and cognitive impairments) attended government or low-fee charging private schools. Though 13 out of 34 (38.2 per cent) experienced bullying by their peers, the majority were largely accepted within the school community. In the absence of special educators and no accommodations put in place by mainstream teachers, these children had to make adjustments and often sought the help of peers to cope with school. Although all teachers need to be trained to address the diverse needs of children in their classrooms, the absence of stigmatisation attached to labels of disability for these children may have worked in their favour and helped with social, if not academic, inclusion.

The trajectories of persons with disabilities vary depending on the nature and severity of their disability. Persons with physical disabilities fared significantly better than those with other disabilities in terms of education opportunities, with five out of seven people interviewed having completed secondary education and at age 25, two of the five Older Cohort young people were working for pay. Fewer people with visual impairments attained similar educational levels (only two out of five completed secondary education)⁸ and similarly among those with hearing impairments (only seven out of 12 completed secondary education), and at age 25 only one of the two Older

⁴ Analysis based on the Younger Cohort data.

⁵ Analysis based on the Older Cohort data.

^{6 100} Indian rupees is approximately £1.

⁷ It is important not to generalise from the findings from this study, given the small sample size.

⁸ The Older Cohort qualitative study sample contained no people with visual impairments.

Cohort young people was working for pay. Of the four people with multiple impairments and three with intellectual impairments, only one had completed elementary education.

Young people with high support needs and their families remain the most vulnerable, with limited access to early intervention, education and care facilities. For these most marginalised young people with high support needs, exclusion begins at an early age, with a limited number being enrolled and the few who are being 'pushed out' and excluded on account of limited learning aids and teacher resources. This 'exclusion' process impacts both the person with the disability and the family as a whole, with limited opportunities available for labour market transitions and care facilities.

Numerous barriers emerged, including both school-related factors (infrastructure, lack of inclusive practices such as accommodations and adaptations, bullying, lack of devices and school transport, insensitive teachers, and corporal punishment) and out-of-school factors (poverty, death of a caregiver and marriage). Children complained about bullying and corporal punishment as well as absence of aids such as mobility training and braille books, and teachers who made no special provisions to address their individual needs. Many dropped out of school due to familial circumstances such as the death of a caregiver, care responsibilities and financial stress. Marriage also disrupted the educational trajectories of girls with disabilities.

Key facilitators to successful educational transitions included high parental aspirations, as well as encouraging teachers and supportive friends. Young persons with disabilities displayed immense determination and resilience, and despite difficulties in mobility and infrastructure, many managed to transition through secondary education, with a few moving on to higher education. Encouragement from sensitive teachers was a key factor in motivating students with disabilities. While no gender discrimination was observed in educational trajectories of the sample at the elementary level, gender inequity becomes prominent at the secondary level, with more boys than girls completing secondary education. It is encouraging to note that many young persons with disabilities from the bottom wealth tercile and rural areas completed secondary education.

The nature of employment of persons with disabilities varied, from daily wage earners on farms or factories, paid domestic work, running their own grocery shop, autorickshaw driver and mechanics, to entrepreneurs. Only one young woman with a disability (physical impairment) was working in a regular professional job as a staff nurse. Given that only two of the 34 young people had received vocational training, inadequate skill training and a lack of awareness about disability related schemes, such as funds for entrepreneurs under the National Handicapped Finance and Development Corporation (NHFDC), also significantly impacted labour market trajectories.

There was significant gender disparity in employment: only three of the eight 25-year-old women with disabilities were in paid employment and most married women, including those who had finished school, were undertaking unpaid housework and caregiving for their families, and not working outside the home.

The aspirations of persons with disabilities had changed over time and became aligned to the opportunities available to them. At age 25, only one young man with a disability was an entrepreneur (out of ten Older Cohort young people). **None of the young people had secured a government job, despite 4 per cent of all government jobs being reserved for persons with disabilities.** All the respondents had limited information about career choices, with knowledge mainly acquired from friends and family, again pointing to limited career avenues for young persons with disabilities.

The family formation of persons with disabilities was not impacted by their educational and employment trajectories. At age 25, an overwhelming majority of women with disabilities were married (seven out of eight women) regardless of their educational or employment trajectories,

and interestingly none of their partners have a disability. It appears the disability did not stand in the way of young women with disabilities getting married to able bodied individuals, although information on dowries was limited and there was no insight on any financial incentives being offered to the groom or his family.⁹ Encouragingly, at age 25, two women with physical disabilities noted having a 'love marriage' and without a dowry, pointing to the social inclusion of persons with disabilities.

Strong family bonds and support mechanisms existed for persons with disabilities. Unlike in other countries where persons with disabilities receive state institutional support and there is strong advocacy for independent living, in Indian society the model of interdependence within the family structure has helped significantly in the growth trajectory of persons with disabilities. An overwhelming majority (32 out of 34 people) acknowledged the ongoing help of family members, peers and supportive teachers. **The absence of supportive institutional mechanisms was replaced by parental siblings, friends and/or spousal (financial and emotional) support.**

Across both young men and young women with disabilities, **those with physical and sensory impairments were actively included within the family structure and integrated within the community**. These young people highlighted that their disabilities did not adversely impact their emotional or psychological well-being as they were growing up, and shared how they made adjustments to their life circumstances as they transitioned into adulthood. They appeared to be well-assimilated within their communities and only **those with severe behavioural difficulties faced stigmatisation**. Social exclusion was noted among those with severe intellectual impairments, with family members noting high levels of prejudice and ostracisation towards the individual and the family as a whole.

Impact of COVID-19 on the lives of persons with disabilities

The prolonged lockdown has had a huge impact on the livelihoods of the households of persons with disabilities, as these were largely engaged in the informal sector¹⁰ which faced disruption due to the pandemic. In total, 24 out of 34 households reported financial difficulties, 27 received free food rations during the lockdown, and eight households reported food insecurity. Families of young persons with intellectual and multiple disabilities were most significantly compromised as they were deprived of access to medical care during the lockdown. Five out of these seven people with disabilities and/or their family members reported that the pandemic had caused significant difficulties on a daily basis, and the lack of medical care resulted in additional stress and anxiety.

There was also a lack of institutional support and implementation of government schemes. Only 15 of the 34 people with disabilities had a disability certificate and were aware of government schemes applicable to them. Only one person was aware of affirmative action schemes, including reserved government jobs, and no respondents had secured a government job.

Policy implications

Persons with disabilities are not a homogeneous group; it is important to recognise that each individual has their own strengths and limitations, and policies need to be framed to address their individual needs. Nevertheless, based on the study's findings and feedback from policymakers and academics, the key policy implications are outlined below.

⁹ Three young women with disabilities spoke of dowry being given to the groom's family, and there was significant variation, ranging from INR 40,000 to INR 500,000.

¹⁰ This includes daily wage earners, auto drivers and construction workers.

 Build awareness among caregivers and persons with disabilities about government provisions: It is important to build awareness of disability rights as well as the provisions of various laws and government schemes. In the qualitative study, fewer than half of the young people (three Older Cohort and 12 Younger Cohort) had a disability certificate and many families and youth with disabilities were not aware of existing government schemes. Those who had a disability certificate received the monthly pension of INR 3,000, but many were either not able to get a certificate, had only done so with difficulty, or had received an erroneous certificate.

Since many respondents were not aware of their entitlements, it is important that all public officials (for example, Integrated Child Development Services and Accredited Social Health Activist (ASHA) workers, regular and resource teachers, District Early Intervention Centres (DEIC) and District Disability Rehabilitation Centre staff) are aware of the provisions of various laws and schemes, to be able to provide the requisite information to children with disabilities and their families.

Communication materials such as animated films, information brochures and both social media and national radio/television could be used to generate awareness of existing policies, programmes, and entitlements.

- Enhance inter-sectoral convergence: Better convergence of various schemes using a lifecourse approach is needed in order to provide seamless services for persons with disabilities. Under the leadership of district magistrates/district collectors, all departments (including *Panchayati Raj* institutions¹¹ and municipalities) should work towards greater convergence to ensure the smooth transitions of persons with disabilities from early intervention services, to school and into the labour market. It would be useful to prepare convergent action plans at the district level, clearly defining the roles and responsibilities of the line departments and specifying accountability mechanisms, so that nobody with a disability is left behind.
- Strengthen existing programme provisions: National and state governments must aim to strengthen existing programme facilities such as the district disability rehabilitation centres, with clearly defined roles and responsibilities to ensure greater accountability and effective implementation of services at district and sub-district levels. This would include augmenting the financial and human resources allocated to these provisions.
- Expand the RPWD to cover epilepsy: Epilepsy is a disabling condition that affects children's right to education and their capacity to lead a full life. Though chronic neurological conditions are a category in the RPWD Act 2016, epilepsy is not explicitly mentioned. It is important to expand the list of disabilities under this category to include epilepsy, to ensure that affected children and families receive the benefits they need.
- Provide inclusive learning environments: All learning environments should be equitable and provide a level playing field for persons with disabilities through the necessary accommodations and adaptations. Samagra Shiksha Abhiyaan and the National Education Policy 2020 make provision for special educators to support the learning of students with disabilities. The number of special educators in the system remains very small, and they also face the challenges of being specialised in only one disability, and lack knowledge of both content and whole class instruction. Hence, it is imperative to enhance their capacities and skills to be able to collaborate effectively with regular teachers and the parents of children with disabilities to promote inclusion. School development plans must therefore plan for inclusion and identify strategies for both the academic and social inclusion of students with disabilities.

¹¹ The system of local self-government in villages in rural India.

Ensuring the active participation of a parent of a student with disability in the school management committee may also provide impetus towards this effort. Curriculum developed under the new National Education Policy 2020 must also use a gender lens to ensure that true inclusion is adopted by learning environments.

Build frontline workers' capacity for inclusion: The success of inclusion lies with preschool and school teachers, who must plan for the success of diverse learners (Singh 2005). Given the importance of early years, it is crucial that families and young children have access to quality early intervention services. To meet the challenge of inclusion, teachers have to build a wider teaching repertoire that addresses and interrogates the pressures of exclusion that exist within the cultures of school, by working on the key aspects of the context, the content of learning, and pedagogy (Singh 2009).

To achieve this all pre-service and in-service teacher training courses need to be transformed and all regular teachers must be trained to modify the teaching and learning process to include each student. The National Council for Teacher Education could consider revamping the content of pre-service teacher education programmes, to enable teachers to make appropriate accommodations and adaptations. Modular courses on inclusive education need to be developed using a hybrid model, and teachers undertaking such courses granted accredited certificates to acknowledge their efforts. Focus on building capacities of staff in *Rashtriya Bal Suraksha Yojana* (RBSY) as well as Integrated Child Development Services (ICDS) such as *Anganwadi* workers is urgently required, so that there is effective early identification of developmental delays and early intervention services provided. The Disability Commissioner's Office in each state may also recognise and reward teachers and other officials who are considered role models in fostering inclusion, and spread awareness of best practices.

- Focus on skill development: For persons with disabilities to realise their full potential it is important to remove the barriers they face in accessing employment opportunities and skill training. The Skill Council for Persons with Disability, which was established to offer meaningful, industry relevant, skill-based training, must aim to reach persons with disabilities in rural and remote locations and provide them with meaningful vocational opportunities. Efforts toward creating awareness of the Prime Minister's skill development scheme, *Pradhan Mantri Kaushal Vikas Yojana* (PMKVY), particularly for persons with disabilities, and encouraging them to benefit from it will provide meaningful vocational opportunities. The government must allocate funds and run campaigns to ensure greater awareness of skills development schemes such as *Divangjan Svavalamban Yojana* (which provides concessional loans to young entrepreneurs with disabilities) and the ADIP Scheme (which provides aids and appliances).
- Smooth transitions to the job market: It is important to mainstream the practice of preparing comprehensive individual employment plans to facilitate the smooth transition of persons with disabilities to the job market. Career guidance and counselling, training on work ethics and soft skills, accessibility audits of the workplace, as well as sensitisation of employers should be integral to these plans. Furthermore, guidance and standards for making reasonable accommodations in workplaces need to be given priority. The National Career Service Centre for Disabled under the National Career Service Project and the Skill Council for Persons with Disability under the National Skill Development Corporation need to be strengthened and work with District Disability Rehabilitation Centres to provide career guidance services and employment opportunities to young persons with disabilities. Networks must also be established between schools/vocational training institutes and industries to facilitate the entry of persons with disabilities into the job market.

Provide support for caregivers and people with high support needs: The anxiety of caregivers on the future of their wards as to who would look after them cannot to be ignored. The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation (now intellectual disabilities), and Multiple Disabilities Act (1999) was enacted to provide guardianship support to those who are dependent due to their impairment. The RPWD Act also makes provisions for caregiver allowances for persons with disabilities with high support needs. Implementation of these Acts needs to be improved so as to reach all those who need this support.

The Department of Empowerment of Persons with Disabilities has introduced the Rights of Persons with Disabilities (Amendment) Rules, 2019. The amended rules entitle persons with benchmark disabilities to apply to the authorities for high-support services. State governments and union territory administrations need to notify the authority about people with high-support requirements. Adequate resource allocation is also needed to effectively implement this legislation.

A new scheme should be considered to provide specialised services to people with high support needs, which could include professional training/certification courses to create a cadre of trained caregivers to support such people.

Parent support groups could also be established at the sub-district level to help parents cope with their own feelings, and share information about available services and best practices.

- Create a database of persons with disabilities: The process of obtaining a Unique Disability ID certificate needs to be improved so that persons with disabilities can receive their entitlements. National and state governments should consider creating a comprehensive database that allows for the year-on-year tracking of persons with disabilities, with the data made accessible to practitioners so they can utilise it for effective planning, including through developing individual rehabilitation plans.
- Expand research on the experiences of persons with disabilities: Given the socio-cultural variations within India, it would be useful to conduct similar qualitative research in other parts of the country in order to get a broader picture of the lived realities of persons with disabilities. Funds should be specifically allocated to undertake research on the lived experiences of persons with disabilities to inform and educate policymakers of their experiences in different contexts. It is imperative that the voices of persons with disabilities remain centre stage and that their experiences guide the development of government policies and programmes, so as to ensure laws and policies address their needs, and their rights are realised

1. Introduction

Young Lives is a global mixed-methods study of childhood poverty that has collected data from 12,000 children across four countries (Ethiopia, India, Peru and Vietnam) since 2002. In India, 3,000 children and their families have been studied across 20 sentinel sites¹² in undivided Andhra Pradesh (Andhra Pradesh and Telangana, after 2014) through five quantitative survey rounds and four qualitative sub-studies.

One of the major strengths of Young Lives has been its innovative and comprehensive methodology, which has harnessed the power of longitudinal research to illuminate the patterns of change and causal processes affecting children as they move from infancy to adulthood. Using a bio-ecological perspective, its conceptual framework acknowledges interdependent processes and drivers of human development and highlights the saliency of contextual and environmental factors, focusing on protective and enabling aspects as well as risks.

The five survey rounds have gathered valuable information related to educational history and experiences of schooling, as well as data related to occupation, income, time use and so on. The longitudinal survey questionnaire (both household and child questionnaires) obtained information on whether the children had a permanent disability. Round 5 of the longitudinal study included the Washington Group questions for the first time (see Annex 1).

Putting together a team of international and national experts with expertise on mixed-methods disability research and child rights, Young Lives undertook mixed-methods research to explore the educational and occupational experiences, and the barriers that adolescents and youth with disabilities face during their transitions through school and into the labour market.

Young Lives identified a sample of 100 adolescents (the Younger Cohort at age 15) and youth (the Older Cohort at 22) with disabilities from the five rounds of longitudinal survey data (2001-2016), based on self-assessment of their disability. Subsequently, an in-depth qualitative study of a sub-sample of 34 young persons with disabilities aged 18 years old (Younger Cohort) or 25 (Older Cohort), as well as their caregivers, was undertaken in 2020. This study also captured data on the impact of the COVID-19 pandemic on their lives.

This study's findings fill a critical evidence gap by shedding light on the lived realities of persons with disabilities, and highlight the challenges faced by them during the COVID-19 pandemic.

1.1. Global overview of persons with disabilities

Over a billion people, 15 per cent of the global population, are estimated to be living with a disability (World Health Organization 2011),¹³ while a study across 54 countries in 2013 estimated the global prevalence of disability to be 14 per cent (Mitra and Sambamoorthi 2013). According to O'Reilly (2007), approximately 426 million persons with disabilities in developing countries live below the poverty line, and often represent the 15–20 per cent most vulnerable and marginalised poor people in such countries (O'Reilly 2007). Persons with disabilities thus face barriers to health, education, employment and other public services, and lack opportunities that would allow them to escape poverty (World Health Organization 2011). A World Bank report (2009) concluded that it would take a multi-faceted approach for persons with disabilities to realise their full potential and to maximise their social and economic contribution to society.

¹² Mandals or blocks.

¹³ This is based on country reported estimates as well as prevalence estimates based on two large data sources, WHO World Health Survey of 2002–2004, from 59 countries, and WHO 25 Chapter 2 Disability – a global picture Global Burden of Disease study, 2004 update.

Numerous global efforts have been made to address this situation, particularly since the UN Convention on the Rights of Persons with Disabilities (CRPD) came into force (United Nations n.d.). The CRPD states that disability is an evolving concept and that it 'results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others'. It also states that persons with disabilities 'include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society and Health, which elucidates functioning and disability as a dynamic interaction between health conditions and contextual factors, both personal and environmental. A recent United Nations (2018) report on disability and development also states that 'disability is defined as a limitation in a functional domain that arises from the interaction between a person's intrinsic capacity, and environmental and personal factors'. This study follows these definitions in adopting a bio-psychosocial model of disability.

Since the adoption of the Convention, the importance of mainstreaming disability for realising the rights, well-being and perspectives of persons with disabilities has garnered growing political commitments. This is evident in the 2030 Agenda for Sustainable Development, which recognises disability as a cross-cutting issue, including explicitly in five Sustainable Development Goals (SDGs).¹⁴

However, a UN report on the realisation of the SDGs reported that despite progress made in recent years, persons with disabilities continue to face numerous barriers to their full inclusion and participation in the life of their communities. It highlighted the continued lack of access to basic rights such as education, health, and employment, the overrepresentation of persons with disabilities in poverty and their underrepresentation in political processes. Women and girls with disabilities are reported to fare even worse, with attitudinal and environmental barriers hampering their participation and inclusion in society (UN Women 2018). Peairson et al. (2014: 10) highlighted the vulnerability of women and girls with disabilities, stating that 'families restrict the movement of their daughters with disabilities in particular because of concerns about their safety, fears that people will harm, sexually coerce or otherwise take advantage of them'. An UNESCO report (2019) also pointed out that girls with disabilities are more likely to face exclusion from educational systems, often subjected to double discrimination due to their gender and disability status, and are reported to be three times more likely to be illiterate and two times less likely to be employed as men with disabilities.

Global data indicate the education status of persons with disabilities, although global data are relatively limited. Estimates highlight that globally, there are about 62 million children with disabilities at primary school age, and there are many more children with disabilities (186 million) who have not completed primary education (UNESCO 2009). Persons with disabilities experience inequalities in their daily lives and have fewer opportunities to access a quality education that takes place in a truly inclusive environment (UNESCO 2015). Research points to physical, attitudinal and socio-cultural barriers that students with disabilities face across the globe. These include infrastructural barriers such as inaccessible buildings and attitudinal barriers such as negative attitudes of teachers, including low expectations and discriminatory behaviour towards students with disabilities, and lack of awareness among parents.

Exclusion from education has a ripple effect on the labour market transitions of persons with disabilities. A Campbell evidence gap map on assessing the effectiveness of interventions for persons with disabilities in low-and middle-income countries (LMICs) found that there were

¹⁴ SDG4 (education), SDG8 (employment), SDG10 (reducing inequalities), SDG11 (inclusive cities) and SDG17 (means of implementation).

relatively few studies addressing livelihoods and these were not of a very high quality (Saran, White and Kuper 2020). Fritz (2019) reports that in LMICs, companies often do not fulfil their role in ensuring inclusive business and work environments, and exclusion is often explained by institutional and social barriers concerning accessibility and capability for inclusion in workplaces. The World Bank highlighted that around 80 per cent of persons with disabilities live in LMICs, and worldwide a 50-75 per cent lower employment rate of persons with disabilities than persons without disabilities (Mitra, Posarac and Vick 2011). In Northern Africa and Western Asia, women with disabilities are five times less likely to be employed than men without disabilities (United Nations 2018). A separate study found that the employment rates of persons with disabilities were significantly lower than those of persons without disabilities in nine out of 15 LMICs¹⁵ (Mizunoya and Mitra 2013). These rates are even lower for persons with multiple disabilities, with 14 out of 15 nations also reporting a higher rate of persons with disabilities working in the informal sector compared to persons without disabilities.

1.2. Education of children with disabilities

It is well recognised that children with disabilities continue to be excluded from education around the world, and those that do attend school are more likely to be excluded from the classroom and to drop out (UNICEF and Education Development Trust 2016). Numerous studies highlight that along with gender, poverty and impairment-related factors compound exclusion from education (Banks et al. 2019; Simui et al. 2018). A recent UNESCO study 'confirms that persons with disabilities are nearly always worse off than persons without disabilities: on average, the former are less likely to ever attend school, they are more likely to be out of school, they are less likely to complete primary or secondary education, they have fewer years of schooling, and they are less likely to possess basic literacy skills' (UNESCO 2018). Barriers highlighted in another study are 'poor accessibility of facilities, lack of transport, lack of capacity of schools and teachers, limited resources, attitudes and low level of awareness amongst guardians about the educational opportunities for their children' (Banks et al. 2019).

To address this situation, there has increasingly been a move from the 'segregation' of students with disabilities in special schools towards 'integration' and 'inclusion' within mainstream schools, representing a shift from the 'deficit model' to the 'human rights model'. The latter signified a shift from focusing on the limitations of the individual, to the barriers imposed by attitudinal, curricular and physical challenges posed by the environment (Singh 2017). Though inclusive education was not explicitly mentioned in the Millenium Development Goals, it was put firmly on the map with SDG4, which calls for inclusive and quality education for all (Kamenopoulou 2018).

1.3. Overview of persons with disabilities in India

In an attempt to ensure the realisation of the rights of persons with disabilities, India has ratified the CRPD and recently replaced an earlier law for persons with disabilities with the Rights for Persons with Disabilities Act 2016 (RPWD) (Ministry of Law and Justice 2016). This states that the 'appropriate Government shall ensure that the persons with disabilities enjoy the right to equality, life with dignity and respect for his or her integrity equally with others'. Section IV related to skill development and employment states that 'the appropriate Government shall formulate schemes and programmes including provision of loans at concessional rates to facilitate and support employment of persons with disabilities especially for their vocational training and self-employment'.

¹⁵ Bangladesh, Pakistan, Laos, the Philippines, Brazil, Mexico, Paraguay, Burkina Faso, and Mauritius.

The Right to Free and Compulsory Education Act 2009 was amended in 2012 to specifically include children with disabilities, and the National Education Policy of 2020 highlights the need for children with disabilities to receive a safe, inclusive, and effective learning environment. Yet, the situation and understanding of disabilities remains very poor. Children and adults with disabilities are viewed as a homogenous group or at best seen as belonging to specific disability groups with common characteristics. No attention is given to the fact that persons with disabilities are first and foremost children, young people, and are influenced by various factors such as caste, ethnicity, poverty, gender, birth order, or geographical location, rather than solely by their impairment.

The Samagra Shiksha Abhiyan scheme ensures inclusive and equitable education from preschool to higher secondary levels (Ministry of Human Resources Development 2018). It includes various provisions for children with special needs, such as identification of children with disabilities and assessment of their educational needs, the removal of architectural barriers in schools, provision for aids and appliances, braille books, scholarships and assistive devices, and home-based education, and the organisation of awareness camps to increase the enrolment and retention of children with disabilities. As enrolment of girls with disabilities is low (NIEPA 2018), education of these girls is a major focus in *Samagra Shiksha Abhiyan*. In order to encourage their participation across all levels of education, the scheme provides a monthly stipend of INR 200 for ten months.

While the scheme focuses on enhancing access to education for children with disabilities, it also includes important measures to effectively include children with disabilities. These include capacity building programmes for teachers and other school staff; making adaptations and modifications in the curriculum, teaching-learning process and evaluation process; designing the curriculum in more accessible formats; and implementing individualised plans. Moreover, the recent National Education Policy 2020 stresses 'ensuring the inclusion and equal participation of children with disabilities in ECCE and the schooling system will also be accorded the highest priority' (Ministry of Human Resource Development 2020). This policy is in line with the RPWD provisions for ensuring inclusive education for children with disabilities, but it is too early to judge if it has brought about any systemic changes.

Data on the prevalence of disability in India have been collected through the 2001 and 2011 Censuses. The 2001 Census only collected data on five types of disabilities, while the 2011 Census included data on eight types: seeing, hearing, speech, movement, mental retardation, mental illness, multiple disabilities and any other disability. According to Census 2011, there are 26.8 million persons with disabilities in India, 2.21 per cent of the population.¹⁶

Persons with disabilities in India are still among the poorest in the country, are mostly uneducated and are widely unemployed. Menon, Parish, and Rose (2013) also highlight that households with individuals with disabilities have up to 14 per cent lower average monthly per person spending, compared to families with able members. The link between poverty and disability continues due to prevailing discrimination, social exclusion and the denial of equal opportunities to access basic rights such as education.

1.3.1. Education status of students with disabilities

India has committed to attaining SDG4,¹⁷ which requires improving access to and quality of education, and addressing obstacles faced by the most vulnerable students, including those with

¹⁶ Various reasons have been attributed to India's census data on disability being lower than averages reported globally, including questions pertaining to disability not being asked by enumerators during the census survey, or families being reluctant to share information. See Dandona et al. (2019).

¹⁷ SDG4 aims to 'ensure inclusive and equitable quality education and promote lifelong learning opportunities for all.'

disabilities. It is also a signatory to the CRPD, which commits to the principle of inclusion of all students with disabilities by adopting appropriate materials and techniques to address their specific needs, such as braille or sign language.

In India, children with disability constitute 1.54 per cent of 5-9 year olds and 1.82 per cent of 10-19 year olds (Census 2011). Among these, only 1.17 per cent or 25.6 million children, are enrolled in Grades 1 to 12 (Mehta 2015). The 76th NSS Round in 2018 (Ministry of Statistics and Programme Implementation 2019) showed that only 62.9 per cent of persons with disabilities¹⁸ had ever enrolled in a standard school. It also highlighted that only 14.9 per cent of persons with disabilities (19.8 per cent men and 8.2 per cent women) over 15 years old had completed secondary education and above. There was a clear decline in enrolment of children with disabilities by the end of elementary school (Grade 8), highlighting the fact that retention of students with disabilities remains a challenge as children move to higher grades. This was despite the 'no detention' policy that was adopted under the Right to Education Act 2010, which allowed all students to progress to the next grade automatically, until 2018. Another analysis of UDISE data revealed that the dropout of children with disabilities started from Grade 5 onwards, and in 2014-15 only 12.02 per cent of children with disabilities who were enrolled in Grade 1, were retained in Grade 12 (Gupta 2016). The dropout rate for children with disabilities was 93.22 per cent in 2012-13, which declined to 87.97 per cent by 2014-15. A report on out-of-school children highlighted that more than 600,000 (28.07 per cent) children with disabilities between 6-13 years old were not attending school, with the proportion higher among children with multiple disabilities (44.13 per cent), followed by children with mental (35.97 per cent) and speech disabilities (34.82 per cent) (SRI and EdCIL 2014). It is important to note the lack of institutional data on the dropout rates of students with disabilities; even the data maintained by UDISE does not provide information on dropout based on disability (UNESCO 2019).

An analysis of the enrolment data of children with disabilities as a percentage of total enrolment shows either a decline or no change over recent years (Table 1).

Level	2013-14	2014-15	2015-16	2016-17
Primary (1-5)	1.30	1.20	1.18	1.09
Upper primary (6-8)	1.18	1.12	1.13	1.13
Secondary (9-10)	0.61	0.57	0.56	0.56
Higher secondary (11-12)	0.27	0.26	0.25	0.26

Table 1: Percentage share of enrolment of children with disabilities (2013-2016)

Notes: Authors' calculations, using UDISE data.

Another report on the overall education status of children with disabilities states that 'despite increases in enrolment rates for children with disabilities, our review suggests that schools remain ill-prepared to accommodate these children and struggle to offer them quality education' (Singal, Ware and Bhutani 2017). A study by Grills et al. (2019), using data from across 17 states in India, confirms the negative relationship between disability and educational exposure among children. Limaye (2016) identifies a number of factors that influence the accessibility of education for children with disabilities; the lack of awareness and social stigma in civil society; gender discrimination; poverty and physical accessibility issues; negative attitudes of schools; lack of trained teachers; and gaps in government policies.

While research points to some initiatives undertaken by schools with respect to the physical and social inclusion of students with disabilities, it also highlights the lack of initiatives around pedagogical aspects, with very limited modifications having been made in the curriculum and curricular practices (Dhingra and Madaan 2020). Education systems are commonly designed based on homogenous delivery rather than diversity, resulting in exclusion and marginalisation.

The transition from school to higher education is even more complex. However, little research has been conducted to map out this transition for students with disabilities (Kunnath and Mathew 2019). According to the All-India Survey on Higher Education, 2018-19, only 0.22 per cent of students with disabilities were enrolled in higher education institutions (Ministry of Human Resource Development 2019). Kunnath and Mathew (2019) state that curricular practices discourage students with disabilities from actively engaging in higher education, by not allowing them to do the subjects of their choice, especially discouraging them from taking up courses which involve fieldwork, making the assessment process and rules related to providing scribes more difficult. Challenges witnessed in school also persist in higher education, and the inability of educational institutes to cater to the needs of the students with disabilities limits their opportunities for quality inclusive education (Morina and Perera 2020). Khan et al. (2020) argue that students with disabilities enter higher education with the hope that they will be provided with modern facilities in university spaces; however, a lack of supportive spaces continues to push them out of higher educational institutions. Research reiterates the need to address the wider issues of curriculum transaction, and teaching-learning and assessment processes, beyond access to physical infrastructure, at all stages of education (Ahmad 2016).

Given this situation, it is vital to understand the barriers and facilitators that young persons with disabilities face as they traverse the various stages of education.

1.3.2. Employment status of persons with disabilities

The RPWD explicitly provides for the employment of persons with disabilities through the implementation of schemes and programmes (including those to facilitate their vocational training and self-employment). The RPWD also includes measures for vocational and skills training, and calls for skill training programmes designed for persons with disabilities, especially for those with autism, developmental, intellectual and multiple disabilities, to have direct links to the job market. The Act advocates that persons with disabilities shall not be discriminated against by government bodies in employment matters. For instance, employees with disabilities shall not be denied promotion on the basis of disability, and should be provided with reasonable accommodations and a barrier-free working environment.

It is important to highlight that RPWD 2016 specifies that 4 per cent of vacancies in government jobs should be reserved for persons with disabilities: 1 per cent for differently abled persons with low vision and blindness; 1 per cent for the deaf and hard of hearing; 1 per cent for those with locomotor disability, including cerebral palsy, leprosy (cured), dwarfism, acid attack survivors and muscular dystrophy; and 1 per cent for those with autism, intellectual disability, specific learning disabilities and mental illness. However, while persons with disabilities constitute a huge population in India, they are rarely seen as productive human capital, and a lack of supportive structures in workplaces often does not allow them to engage in employment (Kunnath and Mathew 2019).

In spite of this legislation, according to Census 2011, only 26 per cent of persons with disabilities are part of the working population. Of these, 78 per cent are men, highlighting that unemployment among women with disabilities is higher. Census 2011 also shows that 36 per cent of the total population of persons with disabilities work (Ministry of Statistics and Programme Implementation 2018), and are largely engaged as agricultural labourers (31 per cent) and cultivators (23 per cent), in household industries (4 per cent) and in other activities (42 per cent).

In the public sector, there is a huge gap between the number of posts identified for persons with disabilities and the number of people employed. Out of the total posts reserved for persons with disabilities in early 2000s within government ministries/departments and the public sector, only 0.37 per cent and 0.44 per cent were filled by persons with disabilities, respectively (Table 2) (World Bank 2009). 'Inadequate job identification process' and 'limited coverage of disability categories' are posited as the two main reasons for the low representation of persons with disabilities in employment (Shenoy 2011).

Table 2: Number of posts reserved in ministries/departments and the public sector

Particulars	Ministries and departments	Public sector
Total number of posts	2,698,762	4,527,293
Identified posts for persons with disabilities	281,398 (3.54 per cent)	460,396 (4.46 per cent)
Employed persons with disabilities	9,975 (0.37 per cent)	20,053 (0.44 per cent)

Source: World Bank (2009).

A report from 2019 (Institute of Human Development 2019) paints a dismal picture of the economic participation of persons with intellectual and developmental disabilities and states that fewer than one in five people with any disability find their way into the workforce. It highlights that most reserved jobs in the government are given to people with physical, auditory or visual impairments. There is limited scope of employment for persons with intellectual and developmental disabilities (Institute of Human Development 2019). There has been no significant improvement in employment rates, as shown by NSSO 76th Round (2018), where the labour force participation rate in usual status¹⁹ was 23.8 per cent and worker population ratio was 22.8 per cent among persons with disabilities age 15 and above (Ministry of Statistics and Programme Implementation 2019). Even when persons with disabilities find employment, they are often underpaid and assessed on the grounds of their disability rather than on their skills (Kunnath and Mathew 2019).

Major barriers that persons with disabilities face in accessing employment opportunities include a lack of recognition of the capacities of persons with disabilities, unequal access to training programmes, lack of vocational skills, limited awareness about job opportunities, particularly in rural areas, along with social barriers such as stigma, prejudice and stereotyping (Shenoy 2011). Mehta et al. (2019) point to the myths around the recruitment of persons with disabilities, for instance, that persons with disabilities may not be able to cope with the pressure of having a job, that it is expensive for organisations to hire them, and so on. A study by the Indian Institute of Public Health (2014) of 147 employees with disabilities working in the IT and IT-enabled services sector in Hyderabad City reveals their perceptions of the serious barriers faced by them, which included physical access to and within the workplace, and the negative attitudes of their peers in the workplace.

There are also policy and programmatic measures that facilitate self-employment opportunities for persons with disabilities, for example, the provision of loans at concessional rates and skills training. The National Action Plan for Skill Training of Persons with Disabilities (Department of Empowerment of Persons with Disabilities n.d., a) was launched in 2015 by the Department of Empowerment of Persons with Disabilities in collaboration with the Ministry of Skill Development and Entrepreneurship to facilitate the skill training and vocational education of persons with disabilities by 2022, involving partners such as government and voluntary organisations in training programmes.

¹⁹ Number of persons in the labour force according to the usual status (ps+ss), that is, considering usual principal and subsidiary economic activity together.

The Department of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment also runs some additional schemes for persons with disabilities (Annex 8).

However, lack of awareness about government schemes, high interest rates and a complex process for securing loans make it difficult for persons with disabilities to access the benefits of relevant government schemes (Gulati 2020). Persons with benchmark disabilities (those with at least 40 per cent of the disabilities listed in the RPWD) are issued a Unique Disability ID certificate by the Department of Empowerment of Persons with Disabilities (2021). This card helps people to receive all the benefits they are entitled to. However, persons with benchmark disabilities are often unable to procure the certificate due to a lack of specialists, such as neurologists and psychiatrists, and the testing facilities at district-level hospitals (Gulati 2020). Persons with disabilities are often required to travel to large cities to have specific tests, which many are unable to do, and are therefore denied their entitlements.

1.3.3. Marriage and family formation

A person's well-being is not determined only by their educational and economic achievements, but also by their relationships. In India, research into the life stories of persons with disabilities highlights that while some families support persons with disabilities, many families show negative attitudes towards them and use derogatory words. These derogatory remarks also come from their communities, where persons with disabilities are labelled 'mad', 'stupid' and 'crazy' (Deepak et al. 2016).

Marriage and family formation are accorded importance in Indian society, and are likely to affect the socio-emotional well-being of a person. Research has highlighted that persons with disabilities often face difficulties in finding suitable partners and they end up marrying at a later age than persons without disabilities do, and 'are more likely to remain single over time' (Adhikari 2020). However, 'persons with disability in hearing and speech are likely to get married easily compared to persons with mental retardation and mental illness' (Sivanandan 2018: 26).

Adhikari (2020) highlighted that persons with disabilities want to get married because they need emotional support and companionship, a stable life, and because of the desire to fulfil their sexual needs. Women with disabilities in particular get married because of family and societal pressure. They are more likely to be apprehensive before marriage as to how their in-laws will react and be treated due to their disability, what their partner's attitude would be, whether they will be able to adjust in the family, as well as having sexual anxiety and anxieties related to childbirth. Persons with disabilities tend to be overprotected and infantilised by their parents, who also believe that sex is only for the able-bodied and of no relevance to the disabled (Menon, Parish, and Rose 2013). Such attitudes are transferred to the person with disabilities, and can result in heightened sexual anxiety (Janardhana et al. 2015).

Analysis of the 2011 Census of India reveals that out of the total population of persons with disabilities, 46.87 per cent never married, while 41.72 per cent were currently married (Table 3) (Ministry of Statistics and Programme Implementation 2016).

Marital status	%
Never married	46.87
Currently married	41.72
Widowed	10.29
Separated	0.81
Divorced	0.31

Table 3: Marital status of persons with disabilities, Census 2011

Source: Ministry of Statistics and Programme Implementation (2016).

Sivanandan (2018), using data from the 2011 Census, shows that even when persons with disabilities do marry, they have a higher chance of divorce and separation compared to persons without disabilities. This was particularly the case among persons with intellectual disabilities, mental illness and multiple disabilities, and more so among women with disabilities. Evidence suggests various reasons for divorce, such as misunderstanding between partners, emotional, sexual and physical violence, sexual incompatibility, adjustment concerns and complexities associated with disability (Adhikari 2020).

1.4. Methodology

This study used mixed methods, with secondary data from five longitudinal survey rounds analysed using quantitative methods, which in turn informed a qualitative study undertaken using primary data. Mixed-method designs do not attempt to reconcile different epistemological orientations, but rather emphasise the complementarity of qualitative and quantitative methods and their practical application to answer the research questions.

1.4.1. Research questions

The primary objective was to study educational and occupational experiences and trajectories of persons with disabilities in order to capture the barriers and enablers that they encountered. The specific research questions were:

- To identify facilitators and barriers to successful completion of primary/secondary education experienced by children and young adults with disabilities.
 - At what age and level of education did children and young adults with diverse needs discontinue education?
 - Who made decisions that affected the educational trajectories of children and young adults with disabilities?
 - What were the factors (school/institutional, public programmes and policies, familial, social and environmental) supporting/hampering the education of children and young adults with disabilities?
- To capture labour market outcomes for young persons with disabilities.
 - What were their trajectories from education to child work and the labour market? How did these experiences differ based on age, gender, type of impairment, marital status and level of education?
 - What factors supported or hindered entry into the labour market?
- How has the pandemic affected the education and livelihoods of persons with disabilities?

1.4.2. Quantitative analysis

Secondary data analysis of the Young Lives longitudinal data from five survey rounds for children identified as having disabilities was undertaken for both cohorts. It is important to note that impairments were self-reported by the participants or their family member and not through diagnostic procedures followed in India for certification.²⁰ In each survey round, household members and children were asked if they had a permanent disability. In Round 5, the Washington Group questionnaire was used to find out the extent of any support needed by respondents.

²⁰ As such, it is possible that some of the young people may not qualify under the benchmark disabilities.

Those who answered that they faced a lot of difficulty in seeing/hearing/remembering/walking were considered persons with disabilities.

A total of 100 young people (70 in the Younger Cohort, age 15, and 30 in the Older Cohort, age 22) had self-identified as having disabilities in the longitudinal survey. Using descriptive statistics, a profile of children with disabilities was built up on educational trajectories, health conditions and caregivers and individual aspirations related to education and occupations across rounds. Variables examined included permanent disability, type of impairment, gender, place of residence, wealth index, caste, marital status, maternal education, subjective well-being, time use, years of education and occupational trajectories of children with disabilities using a life-course perspective. This perspective provided insight into understanding how people's lives are shaped by biological, psychological and social factors. Hutchison (2019) states that human lives are made up of multiple intertwined trajectories which constitute long-term patterns of life.

1.4.3. Primary research

A qualitative case study was undertaken of a sub-sample of 34 Young Lives children with disabilities (24 Younger Cohort and ten Older Cohort) across four districts in Andhra Pradesh and Telangana (Ananthapur and Srikakulam in Andhra Pradesh, and Karimnagar and Mahboobnagar in Telangana), drawing upon a tracking survey undertaken by Young Lives in December 2019. The locations were chosen based on the number of young persons with disabilities identified in the sentinel sites. The purposive sampling also ensured representation of a diverse range of persons with disabilities as well as gender representation (see Annex 2 for details).

A total of 24 Younger Cohort participants age 18-19 were interviewed, 14 boys and ten girls (Annex 4). Ten had hearing and speech impairments, seven had multiple impairments and intellectual impairments, four had a visual impairment, two had a physical impairment and one had a learning disability.

In the Older Cohort, ten young adults age 25-26 were interviewed (Annex 5). Five had physical impairments (one had difficulties with their hand function and four had mobility difficulties), one had visual impairment, three had hearing impairments, and one had mental illness. Eight were young women and two were men. Nine were located in rural areas, with one young woman living in an urban location.

1.4.4. Qualitative research tools

Questionnaires to help guide the interview were prepared that included questions to elicit information to answer the research questions. Caregivers and spouses (where relevant) were included in the interviews to capture their perspectives, with specific questions designed for participants, parents/caregivers and spouses. The questionnaires were validated (face validity) by experts in the field of disability development and modified. They were translated to Telugu and checked for content accuracy by disability experts who are competent in the language.

Appropriate techniques for gathering data from people were explored, with tools adapted to accommodate the needs of people with different types of impairments. including the need to conduct interviews through sign language for people with hearing impairments. A virtual training session was organised for all researchers to familiarise them with the suggested accommodations and adaptations.

1.4.5. Research team

Two teams of local researchers were constituted to ensure that there were no communication barriers. The teams included qualitative researchers (qualified in sociology/social work), as well as disability experts (e.g. qualified special educators in specific disabilities), with extensive research experience and specialisations in vision impairment, hearing impairment and intellectual disabilities. In addition, community guides were recruited in each of the four sites and provided with tablets to enable the interviews to be conducted through video calls.

Prior to the main study, enumerators were trained on the study aims and objectives, protocols, key issues related to interviewing persons with disabilities, and how to conduct record, anonymise, and store virtual interviews.

1.4.6. Pilot

Researchers conducted face-to-face pilot interviews with six young people with different impairments to study the feasibility and relevance of the interview schedules to their needs. The six young people (two each with vision, hearing and intellectual impairments, respectively), were age 17-19 (similar to the Younger Cohort) and 24-26 (similar to the Older Cohort). They were not part of the main study and were picked randomly from the community, with the interviews carried out with their informed consent. The research team and experts considered challenges related to administering the tool, the appropriateness of the questions, accuracy of the translations, issues related to reaching interviewes virtually and technological support, and recording and forwarding interviews to the project investigators, with the key issues addressed. A separate simplified tool for people with intellectual impairment was also developed.

1.4.7. Data collection

Due to the COVID-19 pandemic, it was decided to conduct virtual interviews using tablets. Community guides from the Centre for Economic and Social Studies Hyderabad, who have rapport with the children and their families, assisted in identifying and preparing them for the interviews. The field staff formed teams of two researchers, one specialised in qualitative research and another specialised in a specific disability. The five community guides were given a list of households who had consented to take part in the study, and their location. A WhatsApp group of the project investigators and field staff enabled communication, monitoring of the research process, and mentoring of the field teams.

A coordinator from the research partner Sri Padmavati Mahila Vishwavidlaya (SPMVV) called before the interview to explain the purpose of the study, sought oral consent, and fixed a mutually convenient time for the interview. The community guide went to the household, set up the tablet and checked internet connectivity, and the interviewers then carried out the interviews virtually. Sign language was used to communicate with young people with hearing impairments who were familiar with sign language.

1.4.8. Data management and analysis

Both the quantitative and qualitative data were analysed in the enablers and barriers framework of educational services and labour market systems. At the end of each day, all the interviews were rechecked and sent to the researchers who had conducted the interviews to be transcribed and translated from Telugu to English. This helped in preserving the content and notes of observations made during the interviews. The emerging themes and categories related to the research questions were entered into a grid. The data were then processed and analysed. Biographical analysis of individual cases identified enablers and barriers within a life-history

approach. Interrelationships between various emerging categories/themes were explored throughout the analysis.

An open coding method was adopted whereby the data was categorised by segmenting information, keeping in view the research questions. The segments were coded separately by two researchers and shared with each other, to establish objectivity. These codes were modified and reduced by removing overlapping codes and other codes irrelevant to the research questions, thus collapsing the codes to arrive at themes. These thematic codes are derived following the Cresswell's visual mode of coding process (Elliott 2018).

For the Younger Cohort, the themes included: education and educational decision making; factors that either supported or were barriers to education; ambitions and aspirations; and the impact of the COVID 19 pandemic on their lives. For the Older Cohort, these themes included: educational level and transition to work; supporting or inhibiting factors for employment; family formation and relationships; ambitions and aspirations; and the impact of the pandemic.

1.4.9. Ethical considerations

Ethical approval for the study in India was granted by the ethics committee of the University of Oxford and the ethics committee of SPMVV. Informed consent for interviews were sought from respondents before the interviews were conducted, along with introducing the interviewers, the study's purpose, and clarifying any concerns. All respondents' names have been anonymised.

1.4.10. Research advisory group

A research advisory group of policymakers, academics and practitioners (Annex 9) provided feedback before the study and questionnaire had been finalised, after the first draft, and on the final findings and their policy implications. An example of the feedback received is given in Annex 10.

1.4.11. Limitations

The study was limited to a small sample of persons with disabilities residing in two southern states of India. Furthermore, given that Young Lives was not initially focused on collecting disability data, some data in the previous survey rounds may not have been appropriately captured since no specialists were involved in the data collection. Primary data collection was with 34 young persons with disabilities: we do not have a comparison with young persons without disabilities gathered at the same time.

The COVID-19 pandemic impacted the primary data collection as since the interviews were conducted virtually, these provided limited physical proximity with the respondents, and limited insights into their living conditions. Also, some respondents were not very comfortable using tablets, and some interviews had to be rearranged due to internet connectivity issues.

2. Quantitative research – Descriptive analysis

Key findings

- Most persons with disabilities across the Older Cohort (90 per cent) and Younger Cohort (80 per cent) reside in rural areas, are poor (60 per cent and 50 per cent, respectively, are in the bottom wealth tercile) and belong to disadvantaged castes (90 per cent and 87.1 per cent, respectively).
- Half of the Older Cohort persons with disabilities are physically impaired, followed by other impairments such as learning disabilities (20 per cent).
- Almost a quarter (24.3 per cent) of Younger Cohort adolescents with disabilities have other impairments such as learning disabilities or mental illness, followed by hearing impairments (21.4 per cent).
- In the Younger Cohort, fewer persons with disabilities completed age-appropriate education levels (47.1 per cent) compared to persons without disabilities (77.5 per cent); 11.4 per cent of persons with disabilities were never enrolled in school compared to only 2.9 per cent of those without a disability.
- More than half (51.7 per cent) of the girls with disabilities completed elementary education by age 15, compared to 54.5 per cent of the boys.
- Close to half the children with multiple impairments (45.5 per cent) were never enrolled in school, while more than half of those with intellectual impairments who were enrolled did not complete primary education.
- At 15 years old, 67.1 per cent of Younger Cohort adolescents with disabilities were still studying. The majority were boys (55.3 per cent) and belonged to the bottom wealth tercile households (46.8 per cent).
- More than half the Older Cohort youth with disabilities (53.3 per cent) had completed secondary education by age 22, compared to 76.9 per cent of those without disabilities.
- Among women with disabilities, half completed secondary education, compared to twothirds (66.7 per cent) of men with disabilities. More unmarried young persons with disabilities (66.7 per cent) completed secondary education than ever-married ones (42.9 per cent).
- Of the Older Cohort ever-married women, only 38.5 per cent completed secondary and above education, while 70 per cent of single women completed secondary education. Most of the persons with disabilities who completed secondary education belonged to bottom wealth tercile households (62.5 per cent), with more than half the women (53.3 per cent) from bottom wealth tercile households completing secondary and above education.
- Of the Older Cohort sample, 63.3 per cent were working at age 22. There was a gender divide in occupational status, with just over half the women (54.2 per cent) working for pay at age 22, compared to all the men.
- Almost half of those working had completed secondary and above education, yet most were engaged in non-agricultural irregular wage employment. None of the youth with disabilities were working in the public sector and none had regular contracts.
- A fifth of youth with disabilities (21.1 per cent) reported being satisfied with their job, while half of those who worked as regular salaried employees mentioned that they were satisfied.
- In total, 72.4 per cent of the Older Cohort and 81% of the Younger Cohort with disabilities reported low subjective well-being, significantly higher than that reported by persons without disabilities.
- Skill training remained very low, with only 10.5 per cent having received work-related training.

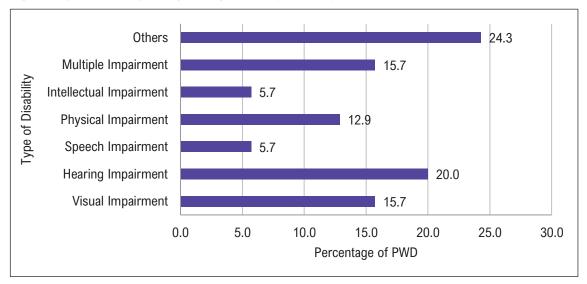
2.1. Young Lives longitudinal survey

In India, Young Lives has studied 3,000 children and their families in undivided Andhra Pradesh (Andhra Pradesh and Telangana, after 2014) since 2002, across five quantitative survey rounds and four qualitative sub-studies.

The study comprises two cohorts of children: the Older Cohort, born in 1994-95, and the Younger Cohort, born in 2001-2002. During the Round 5 survey in 2016-17, the Older Cohort were 22 years old and the Younger Cohort were 15. Responses to the Washington Group questions²¹ recorded in Round 5 were used to identify the persons with disabilities for the present study. Of the total sample, 100 were identified as persons with disabilities (30 from the Older Cohort and 70 from the Younger Cohort), based on their self-assessment.

2.2. Overview of persons with disabilities in Young Lives

Of the 70 children with disabilities among the Younger Cohort at age 15, 17 (24.3 per cent) have other impairments (this included both learning disabilities and mental illness), 14 (20 per cent) have a hearing impairment, eleven (15.7 per cent) have multiple impairments, nine (12.9 per cent) have a physical impairment, four (5.7 per cent) have speech and another four (5.7 per cent) have intellectual impairments (Figure 1).





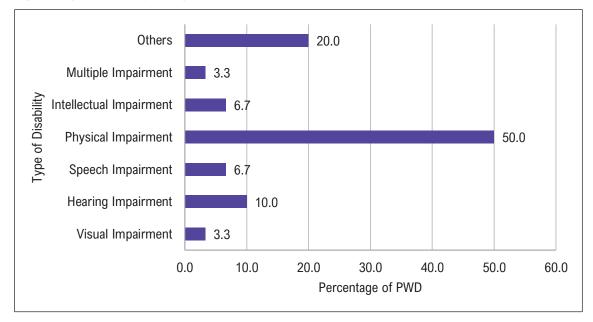
As the longitudinal study sample is pro-poor, 80 per cent of the Younger Cohort adolescents with disabilities reside in rural areas; 44.3 per cent are girls, and a very small minority were married (4.3 per cent) by age 15; 87.1 per cent belong to disadvantaged castes (41.4 per cent Backward Caste, 31.4 per cent Scheduled Caste, 14.3 per cent Scheduled Tribes).²²

Of the 30 persons with disabilities among the Older Cohort, half have a physical impairment, six (20 per cent) have other impairments (including learning disabilities and mental illness), three (10 per cent) have a hearing impairment, two (6.7 per cent) have a speech impairment, and one (3.3 per cent) person each has either visual or multiple impairments (Figure 2).

²¹ See Annex 3.

²² See Table A2 in Annex 3.

Figure 2: Type of Disability Amongst Older Cohort



Similar to the Younger Cohort, 90 per cent of the Older Cohort with disabilities reside in rural areas, 60 per cent belong to bottom wealth tercile households, and 90 per cent belong to disadvantaged castes (40 per cent Backward Caste, 36.7 per cent Scheduled Caste, 13.3 per cent Scheduled Tribes).²³ Eighty per cent are female, 46.7 per cent were married, and 53.3 per cent had completed secondary and above education.

By the end of Round 5, only people from the Older Cohort were in the working-age group, and therefore the latter section on the working experience of persons with disabilities is based only on them. It is important to highlight that at age 22, occupation and labour market transitions are not complete. In this regard, the qualitative survey findings conducted at age 25 provide a better understanding of the occupational trajectories of persons with disabilities (Section 5).

2.3. Educational trajectories of the Younger Cohort with disabilities age 15

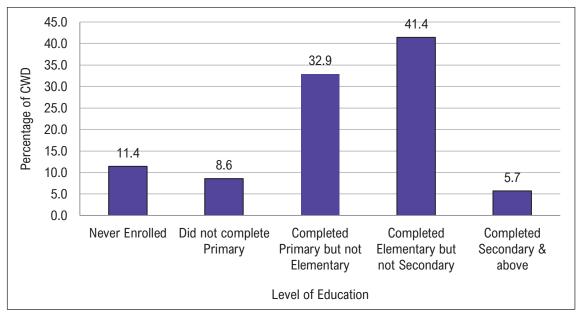
Of the 70 persons with disabilities, 11.4 per cent had never enrolled in school while 47.1 per cent had completed elementary or above education, therefore close to half the children were studying at an age-appropriate grade (Figure 3). It is important to highlight that many children with multiple impairments (45.5 per cent) were never enrolled in school. While all children with intellectual impairments were enrolled, half dropped out and did not complete primary education. Among the visually impaired, 20 per cent did not complete primary education; among the hearing impaired, 6.7 per cent were never enrolled and 6.7 per cent did not complete primary education; among the speech impaired, 11.1 per cent were never enrolled; and among children with other impairments, 5.9 per cent were never enrolled.²⁴

Among 15-year-old adolescents with disabilities who completed elementary and above education, 21.2 per cent have visual impairments, 21.2 per cent hearing impairments, 18.2 per cent physical impairments, 6.1 per cent speech impairments, 6.1 per cent multiple impairments, and 27.3 per cent with other impairments completed elementary and above education. No one with an intellectual impairment had completed elementary and above education. Children

²³ See Table A6 in Annex 3.

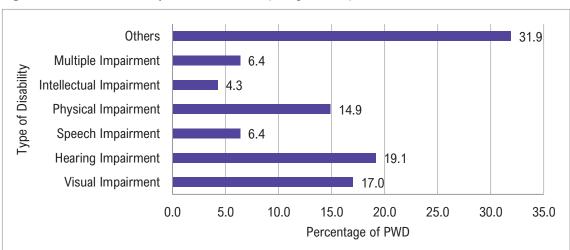
²⁴ See Table A3 in Annex 3.

belonging to Backward Castes were most likely to complete elementary and above education (66.7 per cent) by age 15, followed by Scheduled Caste children (55 per cent). Additionally, while two-thirds of the children with disabilities from top wealth tercile households completed elementary education, fewer than half (46.7 per cent) from bottom wealth tercile households did so.²⁵ Of those married before they were 18 years old, only half had completed elementary education.





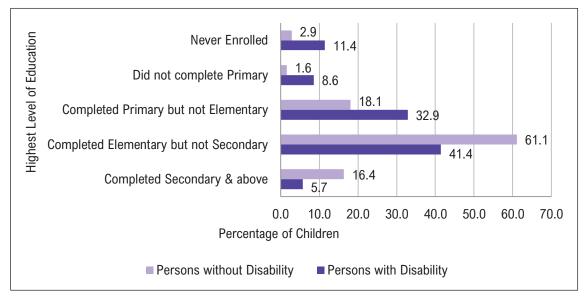
At age 15, 75.8 per cent of those who had ever enrolled in school were still in education. Figure 4 shows their breakdown by type of disability. The majority of these are boys (55.3 per cent), and 46.8 per cent of children with disabilities belong to bottom wealth tercile households. Among those still studying, two young people (one male and one female) were already married. Among bottom wealth tercile households, 46.2 per cent of girls and 47.1 per cent of boys had completed elementary education.





25 See Table A4 in Annex 3.

Since the longitudinal study captures educational trajectories of all Young Lives children living in the sentinel sites, we are able to compare the educational outcomes of children with disabilities with those without disabilities at age 15 (Figure 5). The anlysis reveals that compared to adolescents without disability who completed elementary education (77.5 per cent), a significantly²⁶ lower proportion of adolescents with disabilities (46.9 per cent) did so. Moreover, while 11.4 per cent of children with disabilities were never enrolled in school, this was much lower for those without disability (2.9 per cent).





2.4. Educational experiences of persons with disabilities age 22

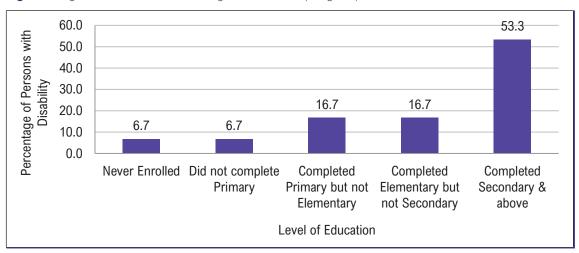
Analysis of young persons with disabilities from the Older Cohort shows that while 6.7 per cent were never enrolled in school, more than half (53.3 per cent) have completed secondary education (Figure 6).

Of those who completed secondary education, half are physically impaired, 31.3 per cent have other impairments, and 18.8 per cent have a hearing impairment. More men with disabilities (66.7 per cent) completed secondary education than women (50 per cent). The majority of Scheduled Caste (72.7 per cent) and Backward Caste (50 per cent) young people had completed secondary education. We also find that while two-thirds of unmarried young persons with disabilities completed secondary education, only 42.9 per cent of those who were married by age 22 did so.²⁷

27 See Table A8 in Annex 3.

²⁶ Based on Fisher's exact test of significance at 1 per cent level.





Similar to the Younger Cohort, a significantly²⁸ lower proportion of young persons with disabilities (53.3 per cent) completed secondary and above education by age 22, compared to 76.9 per cent of young persons without a disability (Figure 7).

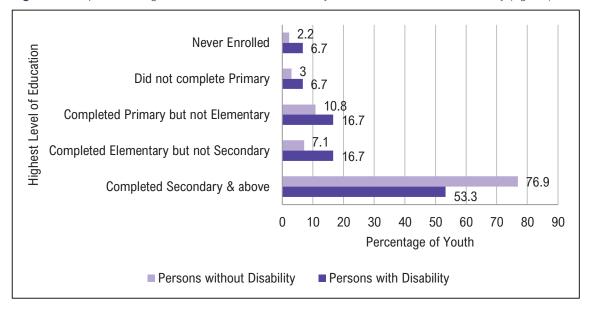


Figure 7: Comparison of Highest Level of Education Attained by Persons With and Without Disability (Age 22)

2.5. Work experiences of persons with disabilities

Based on the Young Lives longitudinal survey analysis, 63.3 per cent of the Older Cohort persons with disabilities were working. The profile of those working by type of disability is mapped in Figure 8. People with physical impairments formed 42.1 per cent of those in the labour force, followed by those with a learning disability (who are captured in the other category).

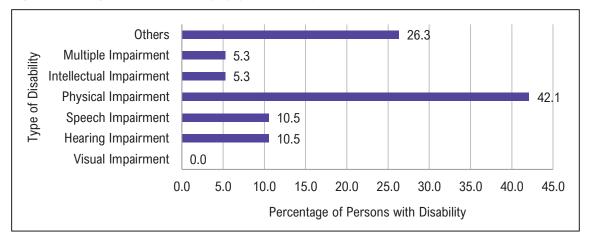


Figure 8: Working Persons with Disability by Type of Disability (OC)

While only 54.2 per cent of women with disabilities were working, all of the young men with disabilities were working at age 22. Of those working, 36.8 per cent were married (92.3 per cent women, 7.7 per cent men) and 57.9 per cent were single (66.7 per cent women, 33.3 per cent men).²⁹ More than a third (39.1 per cent) of women who were not working for pay were married and engaged in childcare and household chores. Of the persons with disabilities engaged in work, 57.9 per cent belong to disadvantaged castes (10.5 per cent Backward Caste, 31.6 per cent Scheduled Caste, and 15.8 per cent Scheduled Tribes), and 89.5 per cent were from rural areas. More persons with disabilities belonging to the bottom wealth tercile were working (72.2 per cent), compared to only half from both the top and middle wealth tercile households.

Figure 9 shows those persons with disabilities who are working at age 22, by level of education. While close to half (47.4 per cent) of the persons with disabilities who are working had completed secondary education, a quarter (26.3 per cent) had only completed elementary education.

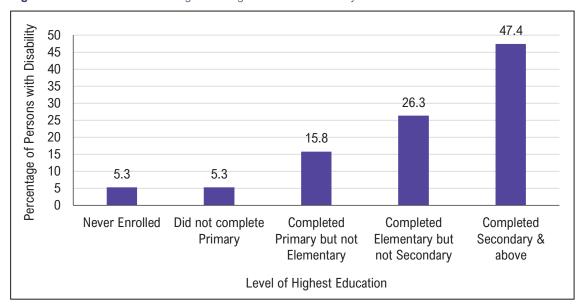
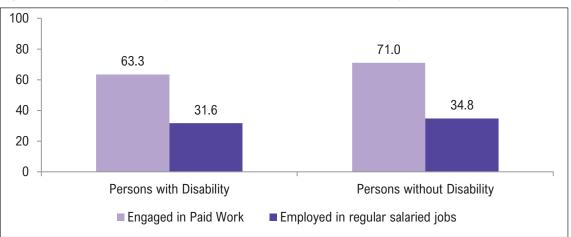


Figure 9: Level of Education Amongst Working Persons with Disability

More than a third (36.8 per cent) of working persons with disabilities were engaged in nonagricultural irregular wage employment, 31.6 per cent in regular salaried employment, 15.8 per cent in agricultural wage employment, and 15.8 per cent were self-employed.³⁰ Most women (61.6 per cent) at age 22 were engaged in wage employment (agriculture and non-agriculture), compared to only a third of the men, with half of men engaged in regular salaried employment.

At age 22, 63.3 per cent of persons with disabilities were engaged in employment, compared to 71 per cent of young persons without disabilities. By type of employment, desegregated data reveal that 31.6 per cent of persons with disabilities were working in regular salaried jobs, compared to 34.8 per cent of young persons without a disabilities (Figure 10).





The Young Lives survey also captured data about earnings. Not surprisingly, the average monthly income was highest for regular salaried employees with disabilities at INR 5,750, while those in irregular wage employment received only INR 2,954. The comparative figures for those without a disability were INR 9,136 and INR 5,424, respectively. This highlights a dramatic variation in earnings based on disability (Singh and Mukherjee, forthcoming).

For 47 per cent of the working youth with disabilities, their main source of job information was reported as being the employer; however, half of those in regular salaried employment stated that their main sources of job information were friends and relatives.³¹

Further analysis shows that largest portion (47.4 per cent) of persons with disabilities were working for a private individual or household (other than their own household). 57.1 per cent of those in non-agriculture wage employment working for private individuals or households, while a third of those in regular salaried employment were doing so. None of the Older Cohort persons with disabilities worked in the public sector/government, and even though half of the regular salaried employees worked for private companies, none had a written contract.

Skill training remained very low for youth with disabilities, with only two out of 19 having received work-related training. One of these was engaged in business, while the other worked as a non-agricultural irregular wage employee for a private household.³²

³⁰ See Table A10 in Annex 3.

³¹ See Table A10 in Annex 3.

³² See Table A10.

2.6. Job opportunities and job satisfaction

For the Older Cohort we also collected information related to job satisfaction in Round 5. Only one out of every five (21.1 per cent) of the Older Cohort persons with disabilities reported that they were satisfied or very satisfied with their job (Figure 11), mainly those people who were in regular salaried employment. Work being tiresome (83.3 per cent) and low pay (16.7 per cent) were recorded as the only reasons for dissatisfaction with jobs.

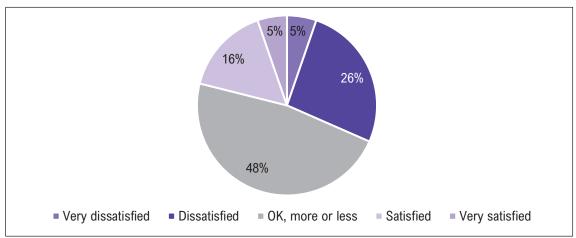
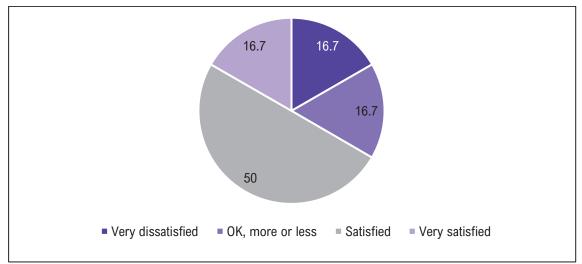


Figure 11: Level of Job Satisfaction Reported by Persons with Disability (OC)

Approximately a third of the persons with disabilities were not working for pay at age 22. Those with physical impairments constituted the largest proportion of these. Of those not working for pay at age 22 66.7 per cent were women involved in childcare and housework, 22.2 per cent were people continuing education, and 11.1 per cent were not working due to health reasons.

Analysis of the time-use data collected in Round 5 reveals that 26.1 per cent of women with disabilities spent six or more hours taking care of others. Of these, a third have a physical impairment, a third have a hearing impairment, 16.7 per cent have a visual impairment, and 16.7 per cent have other impairments. While 47.8 per cent of women reported spending four or more hours in domestic chores, men with disabilities spent a maximum of two hours a day, with some not spending any time on household chores. Half the women expressed satisfaction with being engaged in household chores or caring for children (Figure 12), with only one married woman very dissatisfied and keen to work outside her home.





2.7. Subjective well-being

Young Lives has collected data related to subjective well-being using the Cantril ladder across all survey rounds, including Round 5. This a simple visual scale which makes it possible to assess well-being and has been used for over 50 years (Mazur et al. 2018). Children and youth were shown a picture of a ladder and asked:

There are nine steps on this ladder. Suppose we say that the ninth step, at the very top, represents the best possible life for you and the bottom represents the worst possible life for you. Where on the ladder do you feel you personally stand at the present time?

2.7.1. Subjective well-being of the Younger Cohort

Among the full Younger Cohort sample, 79.6 per cent reported low subjective well-being at age 15. A significantly higher proportion of persons with disabilities at age 15 recorded low subjective well-being – 80.7 per cent, compared to 67.6 per cent of persons without disabilities at the same age.³³ Among persons without disabilities, similar numbers of girls (32.1 per cent) recorded as high subjective well-being as boys (32.6 per cent) at age 15; however, among persons with disabilities a substantially higher proportion of boys recorded low subjective well-being.³⁴ Of the persons with disabilities, 23.1 per cent of girls record high subjective wellbeing at age 15, against only 16.1 per cent of boys with disabilities. Among the young persons with disabilities who reported high subjective well-being, 54.5 per cent had not completed elementary education and 45.5 per cent had.

2.7.2. Subjective well-being of the Older Cohort

Almost three quarters of youth with disabilities (72.4 per cent) reported low subjective well-being at age 22; half of the men recorded high subjective well-being, compared to less than a quarter (20.8 per cent) of women.³⁵ Among those who had recorded high subjective well-being, 62.5 per cent had completed secondary education.³⁶

It is also important to highlight that a higher proportion of persons with disabilities (72.4 per cent) reported low subjective well-being than persons without a disability (66.9 per cent).

2.8. Summary

As Young Lives is a pro-poor sample, most persons with disabilities across both cohorts reside in rural areas (90 per cent of the Older Cohort and 80 per cent of the Younger Cohort), were poor (60 per cent and 50 per cent, respectively, in bottom wealth tercile) and belonged to disadvantaged castes (90 per cent and 87.1 per cent, respectively).

Half of the Older Cohort persons with disabilities are physically impaired, followed by other impairments such as learning disabilities (20 per cent). Almost a quarter (24.3 per cent) of Younger Cohort adolescents with disabilities have other impairments such as learning disabilities or mental illness, followed by one-fifth (21.4 per cent) with hearing impairments. While the gender distribution among Older Cohort youth with disabilities was skewed towards women (80 per cent), the Younger Cohort sample was a little skewed towards boys (55.7 per cent).

³³ Based on Chi-squared test of significance at 5 per cent level.

³⁴ See Table A5 in Annex 3.

³⁵ See Table A11 in Annex 3.

³⁶ See Table A8 in Annex 3.

Among the Younger Cohort at the age of 15, 47.1 per cent of those with disabilities had completed elementary education, with a higher proportion of boys (54.5 per cent) than girls (51.7 per cent). At the same age, 75.8 per cent of Younger Cohort adolescents were still studying.

More than half of the Older Cohort youth with disabilities (53.3 per cent) had completed secondary education by age 22, with more men (66.7 per cent) than women (50.0 per cent). A higher proportion of unmarried young persons with disabilities (66.7 per cent) had completed secondary education than married people (42.9 per cent).

Significantly higher proportions of persons without disabilities had completed age-appropriate education levels than persons with disabilities. Among children age 15, 77.4 per cent of those without disabilities completed age-appropriate education compared to 47.1 per cent of persons without disabilities. Additionally, many more persons with disabilities were never enrolled in school (11.4 per cent), compared to those without disabilities (2.9 per cent).

Of the Older Cohort youth with disabilities, 63.3 per cent were working for pay at age 22. It is important to note that the majority of the Older Cohort persons with disabilities had a physical impairment (50 per cent). There was gender inequity in the occupational outcomes, with all of the men working compared to only half of the women (54.2 per cent).

Among those who were working at age 22, almost half had completed secondary and above education, yet the majority were engaged in irregular wage employment and self-employment (livestock, food crops, and business). Even those who were engaged in regular salaried employment did not have a written contract. Despite the legislative provisions that reserve a percentage of public sector jobs for persons with disabilities, none of the youth with disabilities were working in the public sector. Less than a quarter of youth with disabilities (21.1 per cent) reported being satisfied with their job, with half of those who worked as regular salaried employees doing. Low salaries and tiresome work were recorded as the reasons for job dissatisfaction.

Lastly, 72.4 per cent of the Older Cohort and 80.7 per cent of the Younger Cohort with disabilities reported low subjective well-being, significantly higher than the proportions reported by Older Cohort (66.9 per cent) and Younger Cohort (67.6 per cent) individuals without a disability.

Qualitative research – Educational experiences and trajectories

Key findings

- The education of adolescents and youth with disabilities is influenced by factors at the systemic level as well as the individual and household levels.
- Enablers for education include individual-level factors such as personal resilience and motivation to study. Household-level enablers include parental support and aspirations. Systemic enablers include sensitive teachers, the existence of government schools and residential schools, and private colleges for those who can afford them.
- Barriers to education include systemic factors as well as those at the family and individual levels. Systemic barriers include inadequate capacity to provide developmentally appropriate services, limited capacity of teachers to make appropriate accommodations, teacher insensitivity, corporal punishment, bullying by peers, inaccessible school infrastructure and lack of school transport facilities. Barriers at the family and individual levels include difficult familial circumstances, death of a family member and lack of awareness about available services.
- None of the adolescents and youth with disabilities were provided with assistive devices and aids, or adaptations in mainstream schools. Only the three students studying in special schools were provided with adaptations to support their education.
- Marriage is one of the factors affecting the smooth transition of girls with disabilities to secondary education.

3.1. Educational experiences

Education plays a vital part in the transition to adulthood by both structuring the acquisition of skills and determining the timing of subsequent life transitions. The experience of schooling is important not only from an academic standpoint but more importantly to develop social skills. Successful educational trajectories, including the transition from primary to upper primary and then secondary and higher education, is important for all young people. Education that empowers can be a very powerful tool for young persons with disabilities to be independent and become contributing members of society.

This section draws upon qualitative data to understand the educational trajectories of young people with varied impairments, as well as factors that facilitated or hindered their educational attainment.

3.1.1. School enrolment and type of school attended

With the exception of three Younger Cohort persons with disabilities, who had intellectual and profound speech and hearing impairments, 21 (out of 24 Younger Cohort persons with disabilities, age 18), had been enrolled in formal schools.

Vedanth, an 18-year-old Scheduled Caste young man with multiple impairments, was never enrolled in school. He has high support needs and is dependent on his household members, including his sisters, for all his personal care needs. This had implications on the educational trajectories of his sisters, who were unable to attend school regularly. One explained: He was taken for regular check-ups and visited many hospitals, but it was in vain. When our parents went for agriculture work, we used to attend [to our] brother ... if our parents did not go to work, there would be a [financial] problem at home ... [so we] used to attend only during exam time. Otherwise, we did not attend classes and used to stay at home to attend to our brother.

Only three of the adolescents (all boys, one with a visual impairment and two with hearing impairments) attended special schools, while the rest were enrolled in mainstream schools.

At the time of the interviews, one Younger Cohort person with a disability was in college and five were in higher secondary or enrolled in professional courses such as at industrial training institutes (ITI). Four of the Younger Cohort young people had discontinued education in primary/upper primary classes, around the ages of 9 to 12.

Nithin (a Younger Cohort boy with an intellectual impairment) only started walking at age 6, after which his parents sent him to a nearby private school. However, he stopped attending school after three months, after the school complained that he was beating the students. His elder brother shared that Nithin did not want anyone to sit next to him and he pushed the attendant, causing an injury that required stiches.

Two-thirds (16) of those who had attended primary school had completed elementary education, nine of whom had successfully transitioned to secondary education (Grade 10) by age 18. It is important to note that seven out of the 24 Younger Cohort adolescents had multiple impairments or intellectual impairments.

Of the ten Older Cohort persons with disabilities (age 25-26), only one had never been enrolled in school. Seven had completed secondary education, while four among these (all with physical impairments) had enrolled in college. One discontinued college in the final year because of marriage, one was studying to be a teacher, and the other two had graduated. Only one young woman with a disability of the three who had graduated was pursuing further studies as an auxiliary nurse midwife. Eight of the ten respondents were female, and all ten belonged to either Other Backward Class or Scheduled Caste households.

3.1.2. The value of education

Among Young Lives families, education is widely considered the main route out of poverty for the younger generation and a requirement to access decent work (Singh et al. 2018). The families and young participants in this study prized education highly for these reasons. Living with a disability did not prevent young people from aspiring to continue studying to make a better future. In some cases, education appeared to represent to young people a source of empowerment and a way to overcome some of the constraints of living with a disability. For example, Aruna, an Older Cohort, Backward Caste young woman with a physical impairment living in an urban area, endorsed the importance of education for her future:

With my hand like this, I knew that only if I educate myself, I will be able to find a job. That's the reason ... Even my parents never looked down upon me because of my hand. They let me study till my degree [graduation].

Parents too encouraged their children with disabilities to study to ensure a better future. The mother of Jayanthi, a Younger Cohort adolescent with a hearing impairment who is currently pursuing her bachelor's degree, said she encouraged her daughter to study because, 'if she gets a good job after her education, she will be leading [a] better life we are expecting that to happen.'

Given that a majority of the young persons with disabilities belonged to the bottom wealth tercile as well as disadvantaged caste groups, education was also seen as a means of overcoming social marginalisation and improving their social status. The caregiver of Sridevi, a Younger Cohort, Scheduled Tribe girl with a physical impairment who is pursuing her intermediate (senior secondary) degree and studying biochemistry, microbiology and anatomy so that she can become a laboratory scientist, remarked, 'what more can I ask other than her studying well and bringing [us] a good name!'

Some young people, despite their impairments, were committed to helping their families financially, and becoming educated was seen as a prerequisite to secure the jobs that would make this possible. Kishore, a Younger Cohort, Scheduled Caste boy with a hearing impairment who is in Grade 12, wanted to complete his Bachelor of Education degree and become a teacher, but his disability sometimes left him feeling low. He said, 'I want to take care of my parents'.

Returning to education remains an aspiration for some of the young people who left school before they wanted to and who continue to see education as way to improve their lives. Vindhya, a 25-year-old with a hearing impairment, fell in love and decided to get married after completing intermediate (Grade 12) in sciences at a private junior college. Married and with two daughters, she still has aspirations to continue studying so that she can eventually take up a job.

3.2. Barriers to education for young persons with disabilities

Based on the accounts of young people and their caregivers, the study identified numerous barriers to education that spanned all levels of the bio-ecological model, with particular emphasis on systemic barriers and those at the family and individual levels. These barriers were similar across the Younger and Older Cohorts, and are therefore reported together.

3.2.1. Systemic barriers

Poor access to disability certification and pensions

The majority of the young persons with disabilities did not have disability certificates, which allow the holder to access schemes and benefits provided by the Government of India. Only 15 (12 Younger Cohort and three Older Cohort) of the 34 young people had gone through the formal assessment procedure and had a disability certificate issued by the government, and were therefore able to draw a monthly disability pension of INR 3,000.

Various reasons for not having procured the disability certificate were given by the young people. Raghavan, Sulochana and Soumya tried but were unable to secure a certificate. Vijaya said that she had initially faced difficulty, whereas Bharti had to pay a bribe to get a certificate. Others reported that they were given erroneous certificates; Sathya, who has a hearing impairment, said 'I also have a certificate on mental disability.' Shyam was cheated by someone who promised him a disability certificate in exchange for money, but after two to three attempts to get the certificate, he lost hope and gave up.

Krishnaveni has a mental illness but no disability certificate, and her mother shared that 'in the village they say that to be disabled you have to be either blind or become immobile, the *Sarpanch*³⁷ asks, "is your daughter blind or mute?" Clearly, the local authorities were not aware of the provisions of the Rights with Persons with Disability Act, which includes mental illness.

Indira, who has multiple impairments (physical impairment and seizures), also does not have a disability certificate. She mentioned that she faced challenges primarily because of her seizures: '[the teachers] said that I had a disability and they would not retain me in school ... peers called me crazy'.

³⁷ The head of the Panchayat, the local self-governance institution at the village level.

Notably, epilepsy is not currently included in a list of disabilities in any legislation, and therefore affected children and families do not receive any benefits. However, our evidence suggests that epilepsy is a disabling condition affecting children's right to education and their capacity to lead a full life.

Lack of assistive devices and necessary accommodations in schools

Only the three Younger Cohort boys studying in special schools reported being provided with help to support their study. Ramana, age 18, a Scheduled Caste boy with a visual impairment, attended a residential special school and used braille to read and write. He was given support to study, including extra time for exams and a scribe to assist in writing them, in line with government regulations. According to him,

The challenge lies with my mobility ... I never had any difficulty in studying ... I pull myself up by telling myself that I am like any other person and that I don't have any disability ... When someone guides me to move around, and as they hold me, if they describe what's around, I feel very happy since I know where I am.

Currently in Grade 9, Ramana aspires to become a lawyer.

Venkat, an Other Caste boy with a hearing impairment, also studied in a special school. He was provided a hearing aid, learned how to communicate with sign language, and the school followed teaching methods appropriate for him. He had completed Grade 10, was doing a course in ITI, and he planned to go further in his studies.

Children in mainstream schools were often made to make do without any special provision. None of the children and young persons with disabilities studying in mainstream schools were provided with assistive devices and aids or adaptations. Many struggled to keep up with lessons.

Among the Older Cohort, most of the young people who had dropped out during primary school had experienced difficulty in coping with their studies, as extra attention and support was not provided. Neeraja who is visually impaired and dropped out of school in Grade 3 said, 'I didn't want to discontinue, but the letters in the book were not clearly visible for me ... I couldn't understand what the teachers taught.' Narasamma, a Scheduled Tribe girl with a hearing impairment, discontinued in Grade 9 when she was 11 years old, because she found it difficult to cope due to her hearing and speech impairments, and lack of necessary aids. Similarly, Sulochana, a Backward Caste girl with a physical impairment, dropped out after Grade 6 because she was unable to understand the content of the lessons, despite help from her favourite teacher.

Indira, a Scheduled Caste girl with multiple impairments, discontinued schooling at around 11 years old while in Grade 5, due to frequent seizures and poor support from the school. Even when she attended regularly, she was not given any support in class nor any extra time to write her exams, despite having difficulty with the functioning of her hands. Her mother shared, 'She would see others studying and feel bad and try to learn on her own by trying her level best to study'. Despite her eagerness to learn, Indira eventually left school.

The theme of rejection emerged in many of the interviews as explanations for why children with disabilities left mainstream schools. For example, Nithin, an 18-year-old Older Cohort boy with an intellectual impairment, was rejected from primary school. He had behavioural problems and was made to sit separately because of his tendency to hit other students. He only spent an hour a day at school since he would constantly ask for his mother. After three months, the principal asked Nithin's parents to stop sending him to school, blaming him for being violent. He was later enrolled

in an *Anganwadi*³⁸ for 16 months. His brother maintained, 'if he did not have a disability, we would have educated him up to graduation and enrolled him in [the] police service.' Neither Nithin nor his parents and brother received any intervention or training in order to help Nithin. Apart from the disability pension, the family was not aware of any services for people with high support needs.

Similarly, even though Bharati, a Backward Caste girl, was diagnosed with profound hearing loss at 3 years old, she had not received any early intervention. She studied in a government school but was not provided with auditory training. Her family paid for her to go to auditory training. However, they were told by the centre not to bring her back since she could not speak.

At a much younger age, Raghavan a Scheduled Tribe boy with a hearing impairment, was also turned away from his mainstream school a month after his family had enrolled him. According to his brother: '[the] teachers said, "He is unable to communicate. How do we teach him? ... This is a normal school! ... don't bring him" ... So, I didn't send him to school [anymore].'

Schools found it difficult to manage children with epilepsy (even though they were all on medication). Several children were excluded from the mainstream schools they attended because of their seizures and the inability of the schools to support them. Vardhan, a Scheduled Caste boy with a visual impairment and seizures, had missed school due to seizures and was suspended for irregular attendance. Surekha, a Scheduled Caste girl with multiple impairments (intellectual impairment, a seizures disorder and visual impairment) discontinued her studies in Grade 3 as she had frequent seizures (which began at age 8) and the government hostel where she was boarding sent her home because they could not accommodate her. Her mother explained:

We put her in [the] hostel when she was very young. We put both Surekha and her sister there. They stayed there for over three years until she [started having] fits. Once she had fits, they did not allow her to stay there. They refused to take her in. From then she has been at home and does not go anywhere.

Sometimes parental fears for children's safety lead to school withdrawal, as was the case of Raghuram, a Scheduled Caste boy with multiple disabilities, including epilepsy, who discontinued his education in Grade 3. His parents tried all possible treatments in different hospitals but did not see much improvement in his seizures. His mother explained:

We kept on forcing him to go [to school] and eventually he went with his younger sister who took care of him. As he was getting epileptic convulsions, we thought he would get hurt so we stopped him from going to school.

Lack of support from teachers

Teachers were barriers to children's schooling when they were not trained, lacked the tools or were unwilling to accommodate students with special needs in their classrooms. Several of the young people remembered specific teachers who treated them poorly, such as Sridevi who was visually impaired and remembered being beaten by her physics teacher at the residential government school she attended. Aruna, age 25, who has a physical impairment, said she was afraid of most her teachers during her schooling, particularly her Hindi teacher who used to beat her if she made a mistake. Narasamma, a Scheduled Tribe girl who is intellectually impaired, complained that her teachers used to beat her since she frequently forgot to take her plate for the midday meal.

Teachers' lack of belief in a young person's academic capabilities was another barrier identified by some respondents, including Prabhakar, a 25-year-old Backward Caste man with a physical impairment, who was part way through a bachelor's course in a private college. He recalled

³⁸ An early childhood centre.

finding the transition to a new school in Grade 6 difficult on account of his teachers' attitudes towards him: 'if they [teachers] assigned a task, they would say I could not do it ... They believed only other students could do it and I could not, due to my problem'.

School environment, safety and bullying

Girls and boys with disabilities were subject to teasing, bullying and safety concerns at school, which contributed to feelings of social exclusion. Prabhakar, the physically impaired Backward Caste young man who was discouraged by his teachers' lack of belief in his capabilities, was also subject to taunts from classmates:

From [Grades] 6 to 8, people called me nicknames because I was handicapped ... Nobody included me in things like sports ... When they went to play sports like kabaddi or volleyball and I asked if I could play with them, they told me I was disabled and could not play ... I thought if I was like everybody else, this wouldn't have happened to me. .

Sridevi, a Younger Cohort girl, was teased about her visual impairment by peers in her residential school, and recalled: 'People used to talk about my eyes ... Some of them used to tell me that I will not be able to learn ... I knew that only by becoming educated would my knowledge increase.' Another Younger Cohort girl, Indira, who was physically impaired and had epilepsy, lashed out at her peers when they bullied her, which was a risk to herself and others. She remembered, 'They used to call me a crazy girl. If they did that, I would get high blood pressure. If I hit them, their parents would come ... if anyone was scolding and angry with me, I never liked it.' Her mother explained that they were unable to afford good treatment for Indira, and that the seizures caused her to behave inappropriately:

I think she used to have a different mentality, used to be angry, but she is better now with medication. The children used to tease her for being how she was. They would say she was different. So, she would get angry and beat them ... she would injure herself during the seizure episodes ... they [peers] would join together and tease her.

For some of the persons with disabilities, the insults were too much and led to them leaving school. Sulochana, an Older Cohort, Backward Caste girl with a physical impairment, left school after upper primary because she was bullied, explaining, 'because of my leg, my classmates teased me ... It made me cry thinking why this happened to me.' Most of the young people had experienced feeling socially isolated at school at some point in their lives. For example, Jayanthi, a rural Other Caste adolescent with a hearing impairment who was pursuing a Bachelor of Commerce degree, lamented that she was unable to make friends easily: 'I'd have liked to make friends, but who would speak with me?'

Being in a special school did not eliminate the risk of safety concerns, as was the case for Nirup, age 18, who had a profound hearing impairment and attended a special school for children with diverse disabilities. He communicated in sign language that he had discontinued his studies in Grade 8 on account of being frequently beaten by some of the intellectually impaired students in his school. His mother stated, 'he could not mingle with [different] disabled children ... in the school mentally retarded children were also there, who beat him.'

Lack of transport facilities

Lack of school transportation posed another barrier for some children with disabilities. Sarada, an Older Cohort girl with polio, complained about the long distance to the upper primary school. She had a bus pass, but often buses would not stop, and she did not have the money to buy a ticket on a private bus, and therefore got to school late on many occasions. She shared that:

At first, I was afraid to get on the bus. Then I said to myself that everyone is getting on it and there's no need to panic, then I got used to the bus. Sometimes it [was] crowded, and I [got] pushed down.

3.2.2. Family and individual-level barriers

Parental death

Family shocks, such as the death of a parent, were disruptive on many levels, often causing financial and emotional strain and new care needs. In Vardhan's case (a Younger Cohort, Scheduled Caste boy with visual impairment and epilepsy), the death of his mother when he was a young child, combined with lack of school transport contributed to his leaving school in Grade 9. His two elder sisters were also visually impaired, and his father, a farmer, was the only breadwinner. One sister explained:

My brother is still young. My mother passed away when Vardhan was 3 years old. From then on, I am taking care of him. When he was in [Grade 9], he could not go ... He was not well. We never had bus facilities. He had to walk ... so, we decided not to send him.

The shock of a parent's death upset children's academic trajectories, and children often lacked the support systems to keep them on track. For example, Sulochana, a physically impaired young woman, was doing well in a government co-educational boarding school, having completed Grade 6. She said she had loved the school and was motivated to do well. However, her father died, leaving her mother on her own. She returned home, explaining, 'my mother couldn't manage, so I discontinued my studies. My mother was staying alone, so I wanted to help her.'

Krishanveni, an Older Cohort young woman who had been living with a mental illness for the past few years, also experienced her father's death as a tipping point. She had won awards and recognition for her academic achievements, but the trauma of her father's passing lowered her self-confidence and she lost the desire to continue beyond Grade 10. According to her mother, 'she had shown [interest in] becoming a doctor but with the death of her father, she lost interest.'

Shyam a Scheduled Caste young man with a physical impairment, also discontinued his education after completing Grade 10 from an English-medium government school where he had enjoyed participating in school functions. He explained, 'our situation was bad ... my father died, we didn't have anyone to take care of us, so I discontinued my education. But I have an interest in continuing my studies'.

Poverty and financial strain

Poverty was a major threat to the educational trajectories of the young people, as families strategised to make limited resources stretch. In Rajamma's case (a Backward Caste young woman with hearing and speech impairments), her father could not afford to send all four of his children to school, so he sent his two sons, whereas Rajamma and her sister were never enrolled. It is unclear the extent to which Rajamma's disability factored into his decision, which seems instead to reflect strong gender norms.

Many of the young women wanted to study until Grade 10, but left school before then. Soumya, a Scheduled Tribe adolescent, had wanted to be a tailor and study up to Grade 10, but she left school in Grade 8 and was married to an agricultural labourer. She explained, 'mother's health was not good. We are four sisters, and we had so many financial struggles at that time ... that is the reason I discontinued my studies.' When asked whose decision it was for her to leave school, she said, 'My own decision ... I felt emotional at that time, I would have liked to have continued my studies.'

Marriage

Marriage was a risk to girls' education, depending on girls' perceived suitability for marriage and families' circumstances. In a few cases, marriage cut short girls' education. Kalavathi, for example, a rural Scheduled Caste girl with a physical impairment, had studied until the final year of her graduation (bachelor's degree) but had to quit when her marriage was arranged. She regretted that she could not finish, saying, 'I feel I should have written the exams.'

However, some families saw marriage as a protective factor, as many wanted to secure their daughters' futures in light of their disability and the family's economic fragility. Most parents worried about finding an appropriate match for their daughters and wanted them 'settled in marriage'.

Loss of interest in continuing education

Some children lost interest in their studies, for different reasons, and did not wish to continue. Vijaya, a physically impaired adolescent living in a rural area, had attended school part-time because she was needed at home to help in the farm. She noticed many of her friends had dropped out, and she too lost interest after failing in Grade 6.

3.3. Enablers to education for young persons with disabilities

Young people fared well in their educational journeys when they had multiple sources of support and the resources to overcome the many challenges they faced. They benefited from support at all levels of the bio-ecological system, and when individual, family, school and societal support reinforced one another. The young people and their caregivers identified the following facilitating factors.

3.3.1. Systemic enablers

Support from teachers

Teachers were pivotal in the educational journeys of young persons with disabilities, in both positive and negative ways. A sympathetic teacher could make a big difference in helping a young person overcome challenges related to their disabilities. For example, Narasamma, age 18, a Scheduled Tribe girl who is intellectually impaired, repeated Grade 5 twice and then dropped out. However, after her teachers visited her at home and counselled her to re-join, she returned to school.

Sarada, age 25, an Older Cohort, Backward Caste girl whose physical impairment made it difficult for her to walk or stand for long periods, was also positively influenced by teachers from a young age. When she was 14, she said:³⁹

'My Sirs [teachers] used to continuously say that one should be confident ... I always wanted to be first in my studies. I kept thinking that Sir would beat me. But they didn't say anything to me. They took me closer and taught me. They told me, 'You read very well; don't be afraid of coming to stage'. Now I am used to it. Now I am always being called [to answer questions] in class. When Sir started praising me, I became brave.'

39 Sarada is one of 50 children recruited into the qualitative longitudinal component of Young Lies, comprising four waves of interviews from 2007 to 2014. The excerpt is from 2008.

Government pensions and NGO support

Those who had obtained disability certificates received a monthly pension which made a difference in their lives and alleviated some of the economic pressures in relation to their schooling. Sarada, for example, was able to use her pension as a bargaining chip to persuade her parents to release her from working on the family farm. She also became involved in her local disability self-help group where information and advice were shared among members. Prabhakar, a Younger Cohort, Backward Caste boy with a physical impairment, declared his appreciation for the Rural Development Trust (an NGO) who had supported him over the years.

3.3.2. Enablers at the family and individual levels

Individual competencies and resilience

Young persons with disabilities had many inner resources they brought to bear on the challenges they faced in their educational journeys; social resources like the ability to make friends and to garner support from teachers; academic skills needed to advance through the grades; and perseverance in navigating school environments that were not designed with their special needs in mind, were important skills that some were able to develop.

Most of the young persons with disabilities in this study had not been provided with special accommodations by their mainstream schools. Some said they had not required these, depending on the nature and severity of their impairment, and some were able to adapt. Aruna, for example, despite having a physical impairment, said she was able to access the school facilities and learning materials; she wrote her exams on her own using her left hand.

Support from parents and siblings

Parents were a vital source of encouragement, aspiration and moral support behind the educational journeys of children with disabilities, despite households having limited economic means. For example, Rajan, a hearing-impaired Scheduled Tribe boy studying in a vocational institute, said that he felt supported by his farming parents because they were happy that he was studying, even though they only occasionally inquired about his studies. Some families hired tutors to support their children, since many parents did not themselves have formal academic experience.

Siblings also played key caretaking roles and provided practical support, for example, helping with travel to school. Indeed, family support appeared to be an essential ingredient in the educational journeys of children with disabilities. Children who lacked family support were therefore at a disadvantage and required compensatory resources within other areas of support.

Support from friends and peers

Friends and peers also played both negative and positive roles in the educational trajectories of children with disabilities. They provided friendship as well as practical help, such as loaning books. For example, although Sridevi who was visually impaired was teased by some of her peers, she also had friends who she could depend on for help, copying notes for her from the board, and helping her to move around the school premises since she did not use a white cane. Similarly, Sulochana (an Older Cohort young woman with a physical impairment) credited her friends for helping her to navigate the school and hostel premises where she resided, and for fetching materials that she was unable to access on her own due to her limited mobility. In the same vein, Kishore, a Backward Caste boy with a hearing impairment, spoke of having 'many friends and one close friend who helped me a lot in my studies'. Sathyawith, who has a speech impairment, also claimed to have many friends in his junior college: 'I have three best friends who support me very well'.

3.4. Summary

It is encouraging that most of the young adults with disabilities in the Older Cohort (seven out of ten) had completed secondary education, and four had gone on to pursue higher education; and that among the Younger Cohort, several had gone on to higher secondary or vocational courses and one was in graduate school. While the majority of the young people had attended regular schools, a small minority attended special schools. It was the children with the most severe disabilities who were never enrolled in any school or were pushed out in early grades.

The bio-ecological approach illuminated the layers of support that helped young persons with disabilities in their educational journeys, as well as the layers of barriers they faced, with each young person navigating a unique set of resources and circumstances in their home and school environments. Key constraints include difficult family circumstances, poor school infrastructure, lack of support from teachers, teasing and bullying, difficult school journeys and poor access to disability certification.

Disability was one axis of social difference along with others, such as gender, affecting their varied experiences of schooling. Efforts to ensure their rights to education are fulfilled must account for their specific disabilities, as well as address the other sources of disadvantage affecting their pathways in and out of education.

Qualitative research – Occupational experiences and trajectories

Key findings

- Most of the young persons with disabilities were engaged in occupations such as working as daily wage earners on farms or factories, domestic help, running their own grocery shop, and as autorickshaw drivers or mechanics.
- Only one youth with a disability was working in a regular professional job.
- None of the young people with high support needs were engaged in any work activities.
- None of the young persons with disabilities had been able to procure a government job, despite the requirement that 4 per cent be reserved for people with disabilities.
- Only two young persons with disabilities had received on-the-job training, and only two were enrolled in ITI and receiving vocational training.
- Despite completing elementary, secondary, or even graduating, most young women were happy to either get married and become homemakers or were involved in domestic chores.
- Most of the young persons with disabilities had come to terms with their realities and their aspirations were aligned to the opportunities available to them.
- Those who discontinued education early have come to terms with their current livelihoods, but a few still hope that the future will allow them to realise their dreams.

This section draws on the qualitative data to look at how persons with disabilities transition into young adulthood and the labour market at age 18 (Younger Cohort) and 25 (Older Cohort).

4.1. Diverse occupations and experiences of work

The young persons with disabilities in this study had varied experiences of work (from never having worked to formal employment) and were in a range of occupations (from homemaker to professional).

Disability did not automatically preclude a young person from pursuing a working life. A combination of factors came into play, including educational background, economic circumstances, gender and marital and family status, as well as personal ambition and the nature of the young person's impairment relative to work opportunities and requirements.

Five individuals (one Older Cohort young woman, and four Younger Cohort boys) with severe or multiple impairments were unable to work or contribute to household chores. They depended on others for their care and would likely continue to require care throughout their lives. For example, Vedanth, a Scheduled Caste boy with multiple impairments, never enrolled in school and was unable to move or talk, and depended on his sisters who were his main caretakers. One sister remarked that even at his age (18 years), they were still 'giving him a bath and taking him to the washroom ... if brother was fine, everyone would be fine!' Subash, a Backward Caste adolescent with profound intellectual impairment, and who was unable to speak, was dependent on his family to meet his basic needs. He had a tendency to self-harm (biting), and spent his time playing with dolls and watching TV.

Raghuram, an 18-year-old Scheduled Caste boy with multiple impairments (including epilepsy), who studied until Grade 3, identified his disability as his reason for not working. Unable to walk without support he explained, 'my legs and arms do not function properly, so I can't work'. Krishnaveni, the young woman who left senior secondary school due to the mental trauma she suffered when her father died, depended on her mother for most things and is unable to work, though she had been high functioning prior to her father's death. She did not receive any counselling support and the trauma has impacted her ability to transition to the labour market.

Two of the Younger Cohort boys were able to contribute to their families. Raghavan (who has a profound hearing impairment) spent his time supporting his mother with indoor household chores: his brother hopes he can learn farm work in the future. Vedanth (who has a visual impairment), helped his father on their farm.

Meanwhile, eight of the 24 Younger Cohort were studying and were not in work. Among the ten married young women whose disabilities were relatively mild, six were homemakers and not in paid work. Being a homemaker appeared to reflect gendered family roles and childcare responsibilities, rather than their disabilities prohibiting them from working outside the home. For example, Soumya, with a mild hearing impairment, had married age 18 and was pregnant with her second child. Talking about her present situation she said, 'I have a daughter, after marriage. I have more responsibilities and have to take care of my child and family. I stay at home.'

The young people who reported working were in a range of jobs, largely in the informal sector, including paid domestic work, daily wage workers on farms or in factories, running a grocery shop, or being an autorickshaw driver, mechanic's apprentice and professional maternity nurse. Only two had received on-the-job training, and another two were enrolled in ITI for vocational training.

Many of the young people who were working got their jobs through friends and family contacts and none had received any formal career counselling. For example, a classmate told Sarada, an Older Cohort young woman with a physical impairment, about a job opening for a nurse in the local maternity hospital, to which she successfully applied. Shyam (an Older Cohort young man with a hearing impairment) credited his friends for helping him to secure work as an autorickshaw driver, which he viewed as a big improvement from the agricultural work he had been doing.

For Prabhakar (an Older Cohort young man with a physical impairment), family made a difference to his current working life. He was both studying and working, running a small grocery store owned by his father close to their family home. He explained that his father:

supports me a lot ... He gives me money when I need it and also keeps me mentally happy. If I have a problem, I tell him. I am provided with love, care, and facilities in my home. I feel this is the best thing that has happened to me.

Meanwhile, neighbours had told Neeraja, an Older Cohort young married woman with multiple impairments, and also a mother of two, about the paid domestic work she could do in their neighbourhood. In Neeraja's view this was better than the agricultural work she had been doing because it offered a regular income.

4.2. Challenges faced in working lives

While a minority of the young people had disabilities so severe they were unable to work, many took work that was available for them. For example, Shyam's mild unilateral hearing loss did not prevent him from becoming a driver. Thulasi, despite having hearing and speech impairments, took up daily wage work (mainly cotton seed work) to earn a living. Prabhakar managed the sales in the grocery shop, while his father took care of purchasing and bringing items from the market. Meanwhile, Sarada, the maternity nurse, said that her physical disability was only a barrier when

she was required to traverse multiple floors of the hospital. No accommodations had been made in the workplace and she became exhausted if she had to work overtime.

Crucially, our findings suggest that many of the challenges that young persons with disabilities faced in their working lives reflected the wider social and economic environments in which they lived and were therefore similar to the challenges faced by other youth in their communities.

4.2.1. Poor working conditions

Poor working conditions included work that was low paid, informal, low status and tiring; late payments; and a lack of training and development opportunities.

Daily wage work, for example, remains one of the most vulnerable occupations since it provides no job security nor regular income, and was widely regarded by the young people as undesirable work. Five of the young people were engaged in daily wage work: none had disability certificates nor understood the process for applying for them. Rajamma, a hearing impaired, young married woman who had never attended school, earned around INR 2,000 per month working from 7 am to 6 pm removing weeds and paddy cutting. This type of work allows for day-to-day survival but makes it difficult to live a better life.

Young people faced other problems. Neeraja, who worked as a domestic worker, said her employers often were late in paying her, 'they give salary late ... give rice and curry', although domestic work is more appealing than agricultural work because it promises a regular income.

Nirup (a Younger Cohort boy with a hearing impairment) was also poorly paid while undertaking an internship as a mechanic. His mother said that due to his lack of expertise, he earned a nominal INR 10-20 per day, amounting to INR 1,000-2,000 per month. At the time of the interview, Nirup's salary was reportedly pending for more than four months.

4.2.2. Lack of qualifications limiting job prospects

Many of the young people left school before completing secondary education. Furthermore, although access to equitable inclusive vocational training courses that build livelihood skills are critical for young persons with disabilities, a lack of such opportunities often left them with low educational qualifications and without the requisite skills to obtain a secure job. None of the young persons with disabilities had been able to procure a government job, despite the 4 per cent reservation policy.

4.2.3. Young marriage and motherhood

Girls' and young women's roles in marriage and childcare affected their capacities to engage in paid work, as was common for all young women in their communities. Lack of creches and childcare services was another barrier to young women's paid work. For example, Sulochana, an Older Cohort woman, was married with two daughters (8 months and 5 years old). She used a walking stick to move around, and explained that at home, 'I cook. I have two daughters, so I take care of them. They are very young.' Similarly, Vindhya had a love marriage, and had two daughters and a son. Although she had completed her intermediate (Grade 12) schooling from a private junior college, she was currently a homemaker, saying that 'I stay at home and take care of my children'.

4.2.4. Lack of disability pension

Formal recognition of disability affords young people access to a disability pension. In situations where a disability, poverty or family circumstance renders a young person vulnerable, a monthly pension can make a difference, for example, if they are unable to work or are limited to low-paid,

informal or daily wage work. None of the young people in this study who engaged in daily wage work had obtained disability certificates or pensions, and they lacked information about how to apply for a certificate. Their monthly income from daily wage work was often less than they would have been able to receive from a disability pension. Information about their rights did not reach the young people who needed it.

4.3. Aspirations and transitions to adulthood

Living with a disability did not erase young people's hopes and desires to live well within their capabilities and to work towards a better life for themselves and their families. They were in differing phases of transition to adulthood and were guided by implicit gender norms informing expectations around schooling, work and marriage that also pertained to other youth in their communities. Many had followed or aspired to normative transition pathways, despite their limitations.

Their aspirations reflected their sense of what might be possible for their future selves, considering the personal, social and economic factors that shaped and constrained their opportunities, and over time, they adjusted their aspirations in light of the realities of their circumstances. Indira (from the Younger Cohort), for example, was physically impaired and had epilepsy, and only studied until Grade 5. The unpredictability of her seizures meant she rarely left her home, and she and her mother (a state government employee) felt self-employment was a good option in the future.

Some of the young women whose educational trajectories were disrupted by marriage and childbirth wished to resume their studies or find paid work in future. Vindhya (an Older Cohort young woman), mother of two, had completed Grade 12 before marrying, and harboured intentions to return to education to find a good job in the future. Kalavathi also discontinued her college education due to marriage, but aspired to return to education and become a teacher, a plan her husband supported. Aruna discontinued her Bachelor of Education degree and gave up her job as a primary school teacher after giving birth. Her husband, who works in a bank, stated, 'after marriage, I wanted her to continue her studies. Initially she was interested and later was not, so I adjusted accordingly.'

Meanwhile, Vijaya and her husband wanted to start a grocery store together, work hard and save money. But not all young women felt their aspirations were supported by their husbands. Such was the case for Sarada, the maternity nurse. Though proud of her educational accomplishments, she was disappointed that her husband and in-laws were pressuring her to stop working on account of her pregnancy. She was a second wife since her husband's first wife had not conceived. Nevertheless, she was pursuing a para-medical course in auxiliary nursing midwifery and was keen to continue working.

Boys and young men also wanted to improve their lives through work, including Prabhakar (an Older Cohort young man with a physical impairment) who planned to migrate to a larger town and drive a taxi. Rajan (a Younger Cohort boy with a hearing impairment) was studying in ITI and wanted to apply for wiring and electrical-related jobs. Though Vardhan (a Younger Cohort boy with a visual impairment) discontinued his education in Grade 10, he helped his father on their farm, while his relatives were trying to arrange a desk job for him in a hotel.

4.4. Summary

When it comes to the working lives of young persons with disabilities, we find that many persons with disabilities show agency and do not let their impairments limit their potential. However, there are a large number of systemic barriers, including lack of information and career guidance, that hampers their trajectories into the labour market. It is critical that windows of opportunity,

particularly in rural areas, exist to provide young persons with disabilities with skills linked to the labour market and their own strengths, so as to ensure an enhanced quality of life as they enter adulthood.

Persons with disabilities face various barriers to inclusion in mainstream society. Growing evidence across low, middle, and high income countries shows that persons with disabilities of working age have much lower rates of employment than persons without disabilities. According to the International Labour Organization (2015), fewer than 20 per cent of persons with disabilities globally are currently working.

The most obvious function of work is economic, which is to provide an income (Handicap International 2016). But work also has other important functions. It provides a sense of standing in relation to society, community, and family by improving social status. Employment gives people the opportunity to have social contact, while the lack of employment reinforces social isolation. Smooth transitions from education to employment therefore provide opportunities for persons with disabilities to prove that they can contribute to and participate in society, leading to improved self-esteem and enhanced quality of life as they enter adulthood.

5. Qualitative research – Family formation and relationships

Key findings

- · Close to one third of the young persons with disabilities were married.
- · All 11 young persons with disabilities were married to people without a disability.
- Only two young women with disabilities had love marriages, the rest had arranged marriages.
- The age at marriage ranged between 15 and 22, and there were two women who got married as child brides.
- There were reports of dowry being given as part of the marriage.
- Not having children was a cause of anxiety for women with disabilities, lowering their selfesteem.
- Women with disabilities experienced varied marital relationships, ranging from good to not so desirable. However, marital discord between couples was not reported to be centred around the impairments of young persons with disabilities.

Eleven of the 34 young persons with disabilities in the qualitative sub-study were married at the time of interview. Ten were female, three from the Younger Cohort (one intellectually impaired, one hearing impaired and one physically impaired) and seven from the Older Cohort (two hearing impaired, four physically impaired and one visually impaired). Only one young man (hearing impaired, from the Older Cohort) was married. Notably, all 11 had married partners without a disability.

The age at marriage ranged between 15 and 22, while the spousal age gap was 8 years or more for four couples; in the case of Sarada, the age difference was 12 years, for Narasamma 11 years, Vijaya nine years, and eight years for Neeraja (see Annex 7 for further details).

5.1. Marriage decision-making

The marriage experiences of young persons with disabilities were in line with local marriage practices. Most marriages (nine out of 11) had been arranged by the family elders, as is the norm in their communities, and only two girls had chosen their own partners ('love marriages'). Although most young people continue to be socialised to believe that their parents are best equipped to choose a partner for them, it is increasingly common for parents to consult them to ascertain their interest in the proposed union. With the two love marriages, Kalavathi's parents approved of her choice of partner. However, Vindhya's was an inter-caste marriage and her parents initially did not approve, but they came to accept the union over time.

Most of the young women believed that their natal families were relatively better off financially than their marital households. Dowry was given (from the bride's to the groom's family) in most cases. We cannot say for sure whether the impairment of a potential spouse influenced marriage negotiations, particularly with arranged marriages, but it is likely to have been a consideration of both parties.

Sarada's disability was an ongoing concern for her parents even after they had arranged her marriage to an already married man (12 years her senior) and despite her having graduated and working as a nurse. She had managed to reject a number of proposals before marrying, as she was keen to avoid marrying a farmer (worried she would be required to do agricultural work,

despite her mobility issues). Her mother (who was interviewed since Sarada did not wish for her husband to be interviewed) said, '[Sarada] wanted to study and go for a job. She said she could not work in the fields and cook. She preferred a job she could manage. She was very firm in that.'

Concern over Sarada's disability and what would happen to her when the parents died drove their decision for her to marry the groom they chose. Her mother explained, 'Her disability is the greatest challenge ... We are worried about her life. In case we die, what will happen to her? We cannot have girls left unmarried for so long, right?' However, six months into her marriage, Sarada was unhappy: '[S]he is not happy over there. He married her because he needed a child. We got her married. We are afraid she might be left alone.' The mother reasoned that they thought Sarada would be happy in her marriage and that her husband would be a like a son to them. They had wanted to secure Sarada's future. Sarada did not want to marry nor give up work to raise a family.

5.2. Marital life and relations

5.2.1. Joy and challenges

Young persons with disabilities had varied experiences of married life that included both joy and challenges. In some, but not all cases, their impairments affected their relationships. For example, Soumya's in-laws claimed they were not informed of Soumya's hearing impairment, and only became aware of it after the marriage was sealed. Soumya, who was married at age 17, said her husband was very good to her: 'my husband is taking care of me, that is the reason for my happiness.' Her husband realised she was hearing impaired only when she would not respond when he called to her after their marriage. Although he accepted her disability, his parents said they felt cheated, even suggesting their son should divorce Soumya so he could remarry. Soumya's husband was adamant that her hearing impairment did not affect their relationship. Soumya's main concern was their poor financial situation and an INR 300,000 loan they had yet to clear.

Economic struggle was also Vijaya's worry. Age 15, her family paid INR 170,000 dowry for her to marry a farmer without disability (earning INR 9,000 per month), and later gave birth to a son with a medical condition (hole in the heart). Her husband explained:

Prior to my marriage I saved some money and thought of buying a house. However, after the birth of my son the money was spent on his treatment ... From that time, problems started and we don't have any savings ... because of lack of money the situation is like this.

Though he was satisfied with their married life, he mentioned the 'only matter is regarding [no] earnings from her side', since Vijaya was an unpaid homemaker, though she did receive a disability pension of INR 3,000 per month.

5.2.2. Working together

Many couples described cooperating to improve their lives. Narasamma (a Younger Cohort girl with an intellectual impairment) was six months into her marriage and said she was happily married. She and her husband both worked as daily wage labourers. Her husband explained that 'her handicap does not get it in the way in our married life. Things are going on smoothly ... things are good and going on well.'

Shyam (an Older Cohort young man with a hearing impairment) was an auto-rickshaw driver and had married a distant relative, having received a dowry of INR 50,000 and 30 grammes of gold. His wife (who has no disability), who he described as very supportive, contributed to the family

income by working as a daily wage labourer, and helped at home by collecting water and firewood. His wife exclaimed, 'we are leading a happy life!'

In the same vein, Sulochana, a mother of two, claimed she was able to lead a dignified life in her marriage. Though she met her husband for the first time on the day of the wedding, she said they share a good relationship and his family has also accepted her, despite her physical impairment. Her husband helped fetch water and with other household chores that she could not manage. He said that her disability did not create difficulties in their relationship: 'I never think that she is physically handicapped. She had a small issue in her leg that's all I know.'

5.2.3. Social pressures to conceive amid fertility issues

Newlyweds frequently face societal pressures to conceive within the first few years of marriage, and not having children was a cause of anxiety for some of the young women with disabilities, lowering their self-esteem. Infertility can bring shame and stigma, and many married women were keen to become mothers. Two of the Older Cohort young women, Rajamma (who has hearing and speech impairments) and Kalavathi (who has a physical impairment) reported being happy and well-supported in their marriages but were upset about not having children.

Married for three years, Kalavathi and her husband said they were in a happy marriage and were supported by both sides of the family. The husband said of Kalavathi, 'she helps me, and I help her'. They were doing well, having built their own house. Kalavathi received a monthly disability pension of INR 3,000 and the couple also received a one-time payment of INR 70,000 from the state government under the *Kalyan Lakshmi Pathkam* scheme.⁴⁰ However, Kalavathi had sought treatment for her infertility. None of the couples mentioned that disability had prevented them from trying to have children.

5.2.4. Conflict

Three married young women reported troubled relationships. Although Aruna (an Older Cohort young woman with a mild physical impairment) had an arranged marriage on which large sums of money had been spent, she felt her life had changed after marrying. She gave up her teaching job to care for her daughter, and was pregnant again. Though her husband was supportive and wanted her to complete her Bachelor of Education degree and become a government school teacher, Aruna complained that, 'I don't have the freedom as I had before my marriage ... It is because of my husband. He does not allow me to go to my parents.' She mentioned there had been fights that she did not wish to speak about. Her husband claimed that:

she does not know the values of the family ... Whatever we try to do, she considers only her side of the family. After marriage, the first preference should be her husband and his family ... she is not like that. She thinks negative.

Neeraja (an Older Cohort woman with a visual impairment) had met her husband for the first time on their wedding day. She reported that they quarrelled when he became drunk. This had become a regular feature, and she felt doubly burdened as he did not work and the entire responsibility of running the family fell to her, through her daily wage work. Her parents supported her in difficult times. Their marital trouble, according to Neeraja, was not due to her impairment, rather to her husband's impropriety and failure to fulfil his family role.

Young couples relied on the informal support of family when they experienced relationship difficulty, and did not appear to access formal relationship counselling services. Any infertility

⁴⁰ Kalyana Lakshmi/Shaadi Mubarak is a welfare scheme of the Government of Telangana, that provides financial assistance for marriages, and is given to the bride's family at the time of marriage to meet the marriage expenses. It is a novel scheme for all poor people in the state.

treatment resulted in out-of-pocket expenses, thus making it difficult for couples who lacked the finances to access such services.

5.3. Marriage is part of life aspirations

Marriage is part of the hoped-for imagined futures of many of the unmarried young people in the study. The characteristics they desired in a spouse included being 'good at heart' (Vardhan) and 'beautiful and affectionate' (Kalyan). Sridevi wanted someone who could take care of her and her family; likewise, Pujitha's father wanted to marry her to 'a good family'. Jayanthi was looking for 'a person who will understand and support me ... never comment on my disability and take care of me like my parents'. Meanwhile, Nirup's mother wanted him to marry a 'normal girl, because if both of them [are] impaired, they will face problems in future.'

Others had reservations for the time being. For example, Sathya, Samara and Ramana wanted to delay marriage until after they had jobs and were financially secure. Rajan and Thulasi wished to remain single, as did Surekha on account of not knowing how to cook. Raghuram wanted and was ready to marry but feared that, 'no one will give me their daughter'.

Marriage was perceived as an important step in the pathways to adulthood for most of the young people. For many families, it was considered a way to secure a girls' future security in societies in which female independence is not encouraged. Caregivers of people with high support needs, particularly caregivers who were growing old, were very concerned about the future of the person with disabilities and wondered what would happen to them after they were no longer capable of caring for them or passed away.

5.4. Summary

Marriage and parenthood were expected life transitions in the trajectories of most of the young persons with disabilities; around a third of the sample were married and most of the others hoped to marry in the future. The nature and degree of disability combined with family circumstances influenced their marriage pathways. There were many examples of good marital relations too, including for young people with intellectual, visual and hearing impairments, all of whom had married spouses who did not have disabilities.

Disability was infrequently the root of the problems faced by the married young couples, though disability mediated their life experiences and capacities to cope with life's challenges. Unsurprisingly given the pro-poor nature of the sample, many of their problems stemmed from economic difficulties.

Although many young women described being in a mutually supportive relationship with their spouse, husbands nevertheless were the main decision-makers and in-laws wielded significant influence over couples, reflecting prevailing patriarchal power relations.

The quality of marital relations varied, with mixed experiences of joy and challenges, harmony and discord, which is not dissimilar to the wider population. Having a supportive spouse and inlaws, economic security and opportunities to improve one's life through education, work or family, contributed to the well-being and aspirations of married young people.

Qualitative research – Experiences of the COVID-19 pandemic

Key findings

- Most persons with disabilities (90 per cent) stayed in their communities during the lockdown and went out only for their basic requirements.
- Persons with disabilities (other than those with high support needs) were well versed regarding the safeguards and took adequate care to protect themselves. Only a few reported having been directly infected by the pandemic.
- The financial problems of persons with disabilities and their families were compounded due to COVID-19, and they had limited support systems. All the Older Cohort households faced financial problems.
- The livelihoods of persons with disabilities and their family members were negatively
 affected, particularly for those engaged in the unorganised sector, who rely on irregular
 sources of income with little to no social safety nets.
- Education came to a halt for the adolescents and youth with disabilities, since many families did not have access to digital devices.
- Many households faced food insecurity, despite receiving rations from the government. Many were forced to reduce their consumption of essential items, while some households skipped meals.
- There was perceived improvement in their lives after the lockdown was lifted.

The COVID-19 pandemic has been a unique human experience in that it is the first time in the modern era that the world has collectively experienced such a transmissible disease. The pandemic has had many socio-economic and livelihood consequences, and also poses a real threat to achieving the SDGs of ending poverty by 2030 (Sumner et al. 2020). WHO (2020) observed that persons with disabilities may be at greater risk of contracting COVID-19 because of barriers to implementing basic hygiene measures, difficulty in enacting social distancing because of additional support needs, and the need to touch things to obtain information or for physical support. They may also have barriers to accessing public health information depending on underlying health conditions, and may be at greater risk of developing more severe cases of COVID-19 if they become infected, with COVID-19 exacerbating existing health conditions, particularly those related to respiratory functions, immune systems, heart disease or diabetes. Persons with disabilities may also have barriers to accessing healthcare, or be disproportionately impacted because of serious disruption to services they rely on.

Since the data gathering took place after the lifting of lockdown, the initial interviews focused on eliciting information related to difficulties faced during the lockdown, help received, use of technology and the general effect on households' routines.

6.1. General awareness and practices related to COVID-19

Among the respondents, there was widespread awareness of physical distancing, the use of masks, the necessity of hand hygiene and the symptoms of COVID-19. Most stayed in their communities during the lockdown and went out only for their basic requirements. The majority of respondents took adequate steps to protect themselves, except for those with intellectual impairments or multiple disabilities who needed additional support and care. Prabhakar, an Older

Cohort young man, explained that: 'coronavirus is like any other virus ... we have to be careful about it. We have to wear masks and use sanitisers. We get a cough, cold, throat pain, and fever. These are some symptoms.'

Surekha's mother, the main earner in the family, shared that while she and an elder daughter went out to work wearing masks, due to her intellectual impairment Surekha 'did not understand and had to stay at home'.

6.2. Impact of the COVID-19 pandemic

Out of the 34 households, only a few reported having been directly infected. Raghuram, an 18 year old with a physical impairment and epilepsy, shared that he and three other family members were infected by coronavirus and isolated in a hut on the farm, which he said was scary and difficult. He was quite overwhelmed during the interview and narrated that:

In the beginning both my elder sister and my father got it. Then my elder brother took all of us to get checked. Then they said that my brother's son, I and my father got it. We were very terrified. We came to know only after testing. We stayed near the farm for some time. We took medicines for two or three days and then it came down. For two or three days they did not allow [us to enter the house]. Then at last my brother brought us home. My brother and father told me not to cry. I cried a lot. I was afraid.

Fortunately, all the family members recovered after medical treatment.

The caregiver of Indira, a young girl with a physical impairment and epilepsy, said that the lockdown was a bad time as they could not visit the neurologist for follow-up consultations. Sridevi, a young girl with a visual impairment, said that her education was affected due to the pandemic. She lamented, 'my education for one year has been washed out'. Luckily, she has a disability certificate and was therefore receiving a disability pension, so did not face any financial difficulties.

6.2.1. Loss of income and livelihoods

The prolonged lockdown had a massive impact on the livelihoods of the households, who largely work in the unorganised sector, and often rely on irregular sources of income with little to no social safety nets. The worst affected were those engaged in daily wage work, including in construction and agriculture. But those with monthly incomes also faced hardship, including those who worked as drivers, TV mechanics, nurses, housemaids, and doing tailoring work.

Some families received rations and rice from the government, which helped them cope, while a few received financial help from relatives. The family of Nithin, a young man with an intellectual impairment, conducted marriages in the community. They suffered a great deal financially, as no marriages were being conducted.

All the Older Cohort households reported financial problems due to the pandemic. Aruna, an Older Cohort married woman with a physical impairment, said that:

We had to stay back in the village for three months due to the pandemic. My husband was jobless. Earlier he was working in the bank ... but lost his job. He used to help collecting the loans ... Even when we came back, he faced difficulty finding a new job. Almost for a month [after coming back from the village], we had to suffer without any monthly income.

Prabhakar, who ran a grocery shop, mentioned that sales plummeted due to lockdown since people were not going out to shop, and getting supplies was difficult due to markets being shut down and a lack of transport. Shyam, an auto rickshaw driver with a hearing impairment, mentioned that due to the lockdown no one travelled and he had to borrow money to meet his daily expenses.

Sarada's mother shared that during the lockdown:

not going for the job [daily wages] and not having sufficient money was the most challenging situation. It is difficult to manage [the family expenses] ... nobody helped. We were at home doing the household chores and managed.

6.2.2. The need to borrow money

Poorer households took out loans, primarily to pay for basic needs such as food, mostly from private, informal sources, including grocery shops. Most of the respondents who worked for daily wages reported having very little cash in hand when the lockdown was announced. They had to buy essentials, and many took these on credit from the shop. Cash from friends and family, either through the recovery of old dues or interest-free transfers, was used by households as a cash reserve.

The mother of Surekha, a Younger Cohort girl with multiple impairments, said:

for over three months we could not go anywhere. I was dealing with five people. [we] underwent tough times ... only if we work [does] our family run. So, we asked the mesthri [contractor] for INR 5,000, and could manage for over three months.'

She also stated that: 'I could not go to work for three months ... no one helped us and we only got some rice, that is not enough'.

Sulochana, an Older Cohort married woman with a physical impairment, has two children. Her spouse said: 'We didn't have money to spend and eat. We took loans. We have taken money on interest.' Likewise, Kishore, a Younger Cohort boy with a hearing impairment, does labouring work during the school holidays to support his parents. He recounted that: 'we got credits from people to manage for food ... I borrowed money from my neighbours. We didn't have money [to] recharge [our phones]. We faced money problems.'

Ramana is congenitally blind from birth, and his mother also has a visual impairment with some residual vision. He needs a sighted guide to move around, and is studying in Grade 9 at a special school for the blind. Ramana was at home due to the pandemic and helping his mother. Both have a disability pension and they run a small shop in the village. He said:

In the lockdown, the shop did not run well. No one had work and they had to stay at home. There were no transport facilities and it resulted in financial difficulties ... We took a loan with great difficulty, [from one of the] big shots in the village. We are in the process of repaying. It was difficult because we had no work and no food to eat. I could not even go out to get the medicine for my ear [infection].

6.2.3. Reduced consumption and limited access to government welfare measures

Loss of livelihood and restrictions on movement led to food insecurity among many of the families. Many households were forced to reduce consumption of essential items, while some skipped meals.

Most of the families (28 out of 34) had received some government support during the pandemic, including food grains and grocery items, and cash. However, in many cases this was seen as insufficient. Many of the households with didn't have access to other government schemes such

as *Pradhan Mantri Garib Kalyan Yojana*.⁴¹ They obtained sporadic free rations and small amounts of cash (INR 50-500).

Soumya, a Younger Cohort girl, is married and has one daughter. She has unilateral hearing loss. The couple (who married very young) had to set up a separate household immediately after getting married with limited resources and found it very difficult to meet their household expenses. She expressed that, 'we do not get food [on the table] if we don't go to daily wage work. That's the reason we struggled a lot to get food.'

Vijaya, a Younger Cohort girl, is married with a son. Her husband mentioned that:

We had to struggle for daily food. We faced problems securing food, we are accustomed with our regular [wage] work, other than that we cannot do anything ... for that we need to commute 5 to 6 kilometres, but we were not permitted to go out. [Therefore] we had to consume food once in a day.

Vijaya complained that despite having a disability certificate, she was not able to access her pension for four months during the lockdown. Her husband was also not able to go to daily wage work, due to which the family suffered financial difficulties.

Krishnaveni, an Older Cohort young woman, has had mental illness for more than eight years. When asked about the challenges faced and support received during the COVID-19 pandemic, her mother said:

No one helped; the government supplied free rice, but from this month they are charging. During the lockdown we had more problems: prices increased and instead of getting sufficient provisions, we bought little and consumed less. During lockdown it was announced that we would get ration cards and rice, but we haven't got [them]. We purchase everything from private stores ... At the time of lockdown, it was mentioned the rents ... would not be taken, but after lockdown they are charging once more.

Thulasi, a Younger Cohort girl aged 18 who had dropped out of elementary school, said that her household has suffered a lot and faced food insecurity. They lost their livelihood and her uncle and grandmother supported them by giving them money. Her family had to consume rice with red chilli powder and dal, and she also suffered from severe leg pain during the lockdown.

Neeraja's caregiver said the household was accessing the Public Distribution Scheme and held *Antyodaya Anna Yojana* (subsidised food) and *Rajiv Aarogyasri* (health insurance) cards. As with all those who held *Antyodaya Anna Yojana* cards, they were receiving daily essentials such as rice, lentils, sugar, kerosene and oil.

Kalavathi said that her family received INR 1,500 per month in cash from the government during the lockdown. However, the families of Vindhya, Aruna, Indira, Narasamma, Thulasi, and Soumya did not receive any government support during the lockdown.

While assistance was provided by the state governments of Andhra Pradesh and Telangana in terms of free rice and cash transfers, it is evident that the support received was not sufficient to provide the families with the financial assistance they needed, and many faced food insecurity and a loss of livelihood.

Overall, the impact of COVID-19 on persons with disabilities and their families has been along the same lines as that of the general public, other than the lack of health services during the pandemic.

⁴¹ After the imposition of lockdown in March 2020, the Government of India announced relief of INR 1.70 lakh crore under the Pradhan Mantri Garib Kalyan Yojana, providing free rations as well as direct cash transfers to families living in poverty.

7. Conclusion

This study combined panel survey analysis from the Young Lives longitudinal study data collected over five rounds, with analysis of a follow-up in-depth qualitative study with a subset of 34 young persons with disabilities and their families, undertaken during the COVID-19 pandemic.

It analysed the education and occupational experiences of young persons with disabilities from diverse socio-economic backgrounds, and notes that despite global goals and national policies that emphasise equal rights to education and access to work, young persons with disabilities are deprived of their right to education and to opportunities to learn skills and gain meaningful employment. The study identified both the structural and everyday barriers that people with disabilities encounter, as well as the enablers that influence their trajectories. The key implications are outlined below.

Intersecting vulnerabilities

Gender, poverty, location and the nature and severity of impairment compounded exclusion from education and economic opportunities for persons with disabilities. Persons with disabilities were less likely than persons without disabilities to complete age-appropriate levels of education, and were less likely to have ever enrolled in school. However, there was considerable variation in the socio-economic backgrounds and disability experiences of persons with disabilities.

Gender disparities are evident, with a greater proportion of young men completing secondary education than young women, by age 22, with young men also more likely than young women to be working for pay. Poverty and shocks are major sources of vulnerability among young people in the study and often underpinned their reasons for dropping out of school. Economic insecurity and a desire to secure girls' futures were also reasons why some families married their girls at young ages; girls who were not married early went further in their education than those who had married.

Young persons with multiple impairments or with severe disabilities were the most vulnerable, regardless of gender, and nearly half of them were never enrolled in school. Those with high support needs were dependent on their families, and poverty and lack of services created challenges for these families, coupled with social ostracism.

Lack of recognition, information and services

Only 44 per cent of the qualitative sample of young persons with disabilities had a disability certificate, thereby excluding a large proportion of families from accessing government schemes. These findings highlight the need for policymakers to more closely evaluate and analyse the implementation of schemes on the ground. Many families are not aware of concessions and schemes for persons with disabilities, nor are they familiar with the provisions of the RPWD.

Parents of children with severe impairments did not have access to early intervention services (stimulation/training for activities in daily life/speech and occupational therapy) which means that many of the aging parents as well as their siblings are currently struggling to take care of young adults who had not received any professional help. Educational institutions lack the capacity to support the health needs of young persons with disabilities, such as those with epilepsy and mental illness, often leading to their eventual exclusion.

Moreover, the young people in the study had limited information about training opportunities and career choices and relied mainly on friends and family for information. This shows the importance of providing relevant and timely career guidance and avenues to employment, including

vocational training based on competence, individual preferences and labour market demands, removing barriers and extending opportunities to young persons with disabilities.

Enablers of education

A combination of factors both within and outside school facilitated young people's access to and transition through education. Supportive relationships are vital, especially support from parents (even those with no formal education) and the aspirations they maintained for their children despite their impairments. Encouraging teachers and friends also made a difference, as did young people's own determination, resilience and sense of purpose. It is encouraging to note that many young persons with disabilities transitioned successfully through education in mainstream schools and were socially included within the learning environment.

Barriers to education

Qualitative interviews with young people and their families helped identify the different barriers they faced in their diverse education journeys. Only a small minority (three out of 34) of the young people were enrolled in special schools and provided with the necessary accommodations and devices to aid their schooling. It was more common for children and young persons with disabilities to be enrolled in regular schools, but they were often not provided with the necessary accommodations to meet their specific needs.

Some of the barriers were located within schools, including lack of provision of developmentally appropriate services for children with severe disabilities, limited capacity of teachers to make the necessary accommodations, teacher insensitivity, and even corporal punishment. Teachers were clearly not trained in behaviour management and young children with intellectual impairments and those with no verbal skills were rejected by schools. A large number of children in mainstream schools were not provided with basic devices such as a cane, or mobility and auditory training, did not have access to school transport, and faced bullying by peers.

Several children lost interest in schooling, so did not continue beyond primary school, with many failing their examinations and repeating classes.

As young adolescents with disabilities transitioned to secondary schooling, they found it difficult to cope with the academic load without the accommodations they needed. Out-of-school barriers included households' poor financial situations, and persistent gender bias wherein boys were sent to school and girls were expected to help in household chores. Death of a caregiver and other household shocks also led to discontinuation of education for young persons with disabilities, often resulting in increased risk of child marriage.

Barriers to employment

Irregular and informal work

The majority of the young persons with disabilities in their early twenties were working. Although nearly half of working youth had completed at least secondary education, most were in irregular wage employment and self-employment (livestock, food crops, and business), reflecting a lack of economic opportunities for young people, particularly those living in rural areas. Although many had aspired to obtain government jobs, none of the young people in the study had managed to secure a government job. The survey uncovered gender disparities in work among young persons with disabilities, with only half of the young women working at age 22, compared to all of the young men working for pay.

Lack of vocational training and career guidance

The fact that none of the young persons with disabilities in the study had secured a government job, despite 4 per cent of these officially being reserved for people with disabilities, highlights the gap between policy and actual implementation on the ground. Very few young people had entered vocational training and none were given any formal career guidance. Young persons with disabilities were not aware of the schemes applicable to them and had no idea who to approach for support and guidance.

Navigating marriage and gender norms

A positive story emerged from the qualitative interviews related to family formation and marriage. For some, disability was not a barrier to marriage and to enjoying a typical family life. All of the married young people in the study (11 out of 34 respondents) had married people without a disability, and most had become parents.

Gender norms influenced expectations and the division of labour within marital households, reflecting wider societal dynamics. Irrespective of professional aspirations and type of disability, young women were expected to have the domestic skills for managing a household, and men expected to be the main financial providers. As is typical in their communities, most of the young married women were occupied with managing their homes and with childcare, and were therefore financially dependent on their spouses, though many had aspirations to earn money when their situations allowed in the future.

Social expectations that married couples should have children soon after marrying also affected the young people and explained why those who had been unable to conceive were extremely unhappy. Much pressure falls on young women, and despite facing financial constraints, the young couples who struggled to conceive were paying for fertility treatment.

Vulnerability during the COVID-19 pandemic

The COVID-19 pandemic deepened the vulnerability of families who were already struggling before the crisis, contributing to food insecurity, school closures, lack of access to digital devices for learning, and loss of livelihoods. Young people's disabilities mediated their experiences of the pandemic and created challenges for them to access health and educational services, and to earn a living. The families of young persons with severe disabilities struggled to cope since they often had weak social networks of support.

Aspirations and hope for the future

It is crucial to acknowledge that each person with a disability is unique and that their impairments do not erase their capacities. Neither does vulnerability diminish their hopes. Eager to resume their lives and return to school and work, many of the young people in the study nevertheless remain hopeful. Generally, many of the young people seem to have come to terms with their impairments and adjusted to their life circumstances. Yet like their able-bodied peers, they dream of improving their and their families' lives. Many want opportunities to continue to learn and gain skills, and to earn in good working conditions. That most do not consider their impairment a major obstacle to living a good life does not diminish the need for tailored and targeted support that is their right.

Listening to and learning from young persons with disabilities is key to making sure the support provided to them is relevant and effective. As Shah (2005) argued:

The support systems and barriers for young disabled people outlined in the government's policy agenda may well differ from young disabled people's perceptions about what facilitates and restricts their educational development, and transition to meet occupational aspirations. If young disabled people's needs are to be met, their own accounts are important in developing services.

8. Policy implications

Build awareness among caregivers and persons with disabilities about government provisions

It is important to build awareness of disability rights as well as the provisions of various laws and government schemes. In the qualitative study, fewer than half of the young people (three Older Cohort and 12 Younger Cohort) had a disability certificate and many families and youth with disabilities were not aware of existing government schemes. Those who had a disability certificate received the monthly pension of INR 3,000, but many were either not able to get a certificate, had only done so with difficulty, or had received an erroneous certificate.

Since many respondents were not aware of their entitlements, it is important that all public officials (for example, Integrated Child Development Services and Accredited Social Health Activist (ASHA) workers, regular and resource teachers, District Early Intervention Centres (DEIC) and District Disability Rehabilitation Centre staff) are aware of the provisions of various laws and schemes, to be able to provide the requisite information to children with disabilities and their families.

Communication materials such as animated films, information brochures and both social media and national radio/television could be used to generate awareness of existing policies, programmes, and entitlements.

Enhance inter-sectoral convergence

Better convergence of various schemes using a life-course approach is needed in order to provide seamless services for persons with disabilities. Under the leadership of district magistrates/district collectors, all departments (including *Panchayati Raj* institutions and municipalities) should work towards greater convergence to ensure the smooth transitions of persons with disabilities from early intervention services, to school and into the labour market. It would be useful to prepare convergent action plans at the district level, clearly defining the roles and responsibilities of the line departments and specifying accountability mechanisms, so that nobody with a disability is left behind.

Strengthen existing programmatic provisions

National and state governments must aim to strengthen existing programme facilities such as the district disability rehabilitation centres, with clearly defined roles and responsibilities to ensure greater accountability and effective implementation of services at district and sub-district levels. This would include augmenting the financial and human resources allocated to these provisions.

Expand the RPWD to cover epilepsy

Epilepsy is a disabling condition that affects children's right to education and their capacity to lead a full life. Though chronic neurological conditions are a category in the RPWD Act 2016, epilepsy is not explicitly mentioned. It is important to expand the list of disabilities under this category to include epilepsy, to ensure that affected children and families receive the benefits they need.

Provide inclusive learning environments

All learning environments should be equitable and provide a level playing field for persons with disabilities through the necessary accommodations and adaptations. Only then will be able to realise SDG4 and the vision of the National Education Policy 2020, which aims to provide quality education to *all* children. While special schools are important to provide resources to children with high support needs, it is critical for all regular schools to become inclusive in word and spirit. Inclusive education must go beyond mere placement in a regular school and adopt practices that make both academic and social inclusion a reality. Removing exclusion in and from education is part of the process of reducing exclusion in society, which involves constantly challenging inequalities of power and recognising and removing the oppression faced by a large number of excluded children. It is impossible to overstate the point that the children with disabilities are children first – who have same characteristics and needs as so-called 'typical' children. All children, no matter how significantly challenged, will benefit from best practices which create supportive, non-prescriptive and nurturing environments. The key towards inclusion is to find ways to change school culture to enable, rather than disable children (Oliver 1995).

School development plans must therefore plan for inclusion and identify strategies for both the academic and social inclusion of students with disabilities. Ensuring the active participation of a parent of a student with disability in the school management committee may also provide impetus towards this effort. Curriculum developed under the new National Education Policy 2020 must also use a gender lens to ensure that true inclusion is adopted by learning environments.

Build frontline workers' capacity for inclusion

The success of inclusion lies with preschool and school teachers, who must plan for the success of diverse learners (Singh 2005). Given the importance of early years, it is crucial that families and young children have access to quality early intervention services. It is also essential to ensure that all teachers have the requisite competencies and adopt a rights-based attitude towards all students, including those with disabilities. To meet the challenge of inclusion, teachers have to build a wider teaching repertoire that addresses and interrogates the pressures of exclusion that exist within the cultures of school, by working on the key aspects of the context, the content of learning, and pedagogy (Singh 2009).

To achieve this all pre-service and in-service teacher training courses need to be transformed and all regular teachers must be trained to modify the teaching and learning process to include each student. Given that India has a very small number of special schools and insufficient special educators, the lines between general education and special education must become blurred and eventually disappear.

Modular courses on inclusive education need to be developed using a hybrid model, and teachers undertaking such courses granted accredited certificates to acknowledge their efforts. Focus on building capacities of staff in *Rashtriya Bal Suraksha Yojana* (RBSY) as well as Integrated Child Development Services (ICDS) such as *Anganwadi* workers is urgently required, so that there is effective early identification of developmental delays and early intervention services provided. The Disability Commissioner's Office in each state may also recognise and

reward teachers and other officials who are considered role models in fostering inclusion, and spread awareness of best practices.

Focus on skill development

For persons with disabilities to reach their full potential it is important to remove the barriers they face in accessing employment opportunities and skill training. The Skill Council for Persons with Disability, established to offer meaningful, industry relevant, skill-based training, must aim to reach persons with disabilities in rural and remote locations and provide them meaningful vocational opportunities. Efforts toward creating awareness of the Prime Minister's skill development scheme, *Pradhan Mantri Kaushal Vikas Yojana* (PMKVY), particularly for persons with disabilities, and encouraging them to benefit from it will provide meaningful vocational opportunities. The government must also allocate funds to raise awareness of skill development schemes such as *Divangjan Svavalamban Yojana* (which provides concessional loans to young entrepreneurs with disability) and the ADIP Scheme (which provides aids and appliances).

Smooth transitions to the job market

It is important to mainstream the practice of preparing comprehensive individual employment plans to facilitate the smooth transition of persons with disabilities to the job market. Career guidance and counselling, training on work ethics and soft skills, accessibility audits of the workplace, as well as sensitisation of employers should be integral to these plans. Furthermore, guidance and standards for making reasonable accommodations in workplaces need to be given priority. Networks must also be established between schools/vocational training institutes and industries to facilitate entry of persons with disabilities into the job market.

Provide help for caregivers and people with high support needs

The anxiety of caregivers on the future of their wards as to who would look after them cannot to be ignored. The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation (now intellectual disabilities), and Multiple Disabilities Act (1999) was enacted to provide guardianship support to those who are dependent due to their impairment. Implementation of the Act needs to be improved so as to reach all those who need this support.

A new scheme should be considered to provide specialised services to people with high support needs. This could include provision for professional training/certification courses to create a cadre of trained caregivers to support such people. As well as generating jobs for unemployed youth who have completed their education, this would also provide much-needed respite and support for aging families of persons with disabilities.

Parent support groups could also be established at the sub-district level to provide assistance to parents to cope with their own feelings, and share information about available services and best practices.

Create a database of persons with disabilities

National and state governments should consider creating a comprehensive database that allows for year-on-year tracking of persons with disabilities, with the data made available to practitioners so they can utilise it for effective planning, including through developing individual rehabilitation plans.

Scale-up research related to the experiences of persons with disabilities

Given the socio-cultural variations within India, it would be useful to conduct similar qualitative research in other parts of the country to get a broader picture of the lived realities of persons with disabilities. Funds should be specifically allocated to undertake research on the lived experiences of persons with disabilities to inform and educate policymakers of their experiences in different contexts, so as to ensure implementation and that policy gaps are identified and addressed.

It is imperative that the voices of persons with disabilities remain at the centre stage and that their experiences guide the development of government policies and programmes, so as to ensure laws and policies address their needs, and their rights are realised.

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Annexes

Annex 1. Excerpt from Young Lives Round 5 questionnaire: Washington Group questions

Say: The next questions ask about the level of difficulty you may have doing certain activities.

Q1 Do you have difficulty seeing, even if wearing glasses?

- 00=No, no difficulty
- 01=Yes, some difficulty
- 02=Yes, a lot of difficulty
- 03=Cannot do at all

Q2 Do you have difficulty hearing, even if using a hearing aid?

- 00=No, no difficulty
- 01=Yes, some difficulty
- 02=Yes, a lot of difficulty
- 03=Cannot do at all

Q3 Do you have difficulty walking or climbing steps?

- 00=No, no difficulty
- 01=Yes, some difficulty
- 02=Yes, a lot of difficulty
- 03=Cannot do at all

Q4 Do you have difficulty remembering or concentrating?

- 00=No, no difficulty
- 01=Yes, some difficulty
- 02=Yes, a lot of difficulty
- 03=Cannot do at all

Q5 Do you have difficulty (with self-care such as) washing all over or dressing?

- 00=No, no difficulty
- 01=Yes, some difficulty
- 02=Yes, a lot of difficulty

03=Cannot do at all

Q6 Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

- 00=No, no difficulty
- 01=Yes, some difficulty
- 02=Yes, a lot of difficulty
- 03=Cannot do at all

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Annex 2

Table A1: Qualitative sub-study sample

State	Andhra Pradesh				Telangana				Total	Í
District Gender	Anantapuram		Srikakulam		Karim Nagar		Mahbubnagar			
	Female	Male	Female	Male	Female	Male	Female	Male		%
Hearing and speech impairment	1	1		4	2	1	2	1	12	35.2
Intellectual impairment				1			2		3	8.9
Physical impairment		2			1		4		7	20.5
Visual impairment		2	1				1	1	5	14.7
Speech impairment								1	1	3
Multiple impairments						1	2	1	4	11.8
Others							2		2	5.9
Total	1	5	1	5	3	2	13	4	34	100

Parameter	Vis impai		Hea impai	ring rment	Spe impai	ech rment	Phys impai			ectual rment		tiple rments	Oth	ers	To	tal
	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N
Location																
Rural	70.0	7	80.0	12	100	4	88.9	8	50	2	90.9	10	76.5	13	80.0	56
Urban	30.0	3	20.0	3	0	0	11.1	1	50	2	9.1	1	23.5	4	20.0	14
Total	100	10	100	15	100	4	100	9	100	4	100	11	100	17	100	70
Gender																
Female	60	6	40	6	25	1	55.6	5	50	2	45.5	5	35.3	6	44.3	31
Male	40	4	60	9	75	3	44.4	4	50	2	54.5	6	64.7	11	55.7	39
Total	100	10	100	15	100	4	100	9	100	4	100	11	100	17	100	70
Caste																
Backward Caste	40.0	4	33.3	5	25	1	55.6	5	50	2	27.3	3	52.9	9	41.4	29
Other Caste	10.0	1	26.7	4	25	1	0	0	25	1	0	0	11.8	2	12.9	9
Scheduled Caste	40.0	4	26.7	4	25	1	33.3	3	0	0	45.5	5	29.4	5	31.4	22
Scheduled Tribes	10.0	1	13.3	2	25	1	11.1	1	25	1	27.3	3	5.9	1	14.3	10
Total	100	10	100	15	100	4	100	9	100	4	100	11	100	17	100	70
Wealth tercile																
Top tercile	30	3	13.3	2	25	1	22.2	2	25	1	0	0	29.4	5	20.0	14
Middle tercile	30	3	40	6	50	2	0	0	50	2	54.5	6	11.8	2	30.0	21
Bottom tercile	40	4	46.7	7	25	1	77.8	7	25	1	45.5	5	58.8	10	50.0	35
Total	100	10	100	15	100	4	100	9	100	4	100	11	100	17	100	70
Marital status																
Married	0	0	0	0	0	0	11.1	1	0	0	9.1	1	5.9	1	4.3	3
Single (never married)	100	10	100	15	100	4	88.9	8	100	4	90.9	10	94.1	16	95.7	67
Total	100	10	100	15	100	4	100	9	100	4	100	11	100	17	100	70

Table A2: Younger Cohort persons with disabilities by type of disability

Table A3: Highest level of education by type of disability (Younger Cohort)

Highest level of education	-	ual rment		ring rment		ech rment	Phys impai	sical rment	Intelle impai			ltiple rments	Oth	ers	To	tal
	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N
Never enrolled	0	0	6.7	1	0	0	11.1	1	0	0	45.5	5	5.9	1	11.4	8
Did not complete primary	20.0	2	6.7	1	0	0	0	0	50	2	9.1	1	0	0	8.6	6
Completed primary but not elementary	10.0	1	40	6	50	2	22.2	2	50	2	27.3	3	41.2	7	32.9	23
Completed elementary but not secondary	70.0	7	46.7	7	50	2	44.4	4	0	0	9.1	1	47.1	8	41.4	29
Completed secondary	0	0	0	0	0	0	22.2	2	0	0	9.1	1	5.9	1	5.7	4
Total	100	10	100	15	100	4	100	9	100	4	100	11	100	17	100	70

Table A4: Younger Cohort persons with disabilities by level of education

Parameter	Comp eleme		Did not o eleme	omplete entary	То	tal
	%	N	%	N	%	N
Disability						
Visual impairment	21.2	7	10.3	3	16.1	10
Hearing impairment	21.2	7	24.1	7	22.6	14
Speech impairment	6.1	2	6.9	2	6.5	4
Physical impairment	18.2	6	6.9	2	12.9	8
Intellectual impairment	0	0	13.8	4	6.5	4
Multiple impairments	6.1	2	13.8	4	9.7	6
Others	27.3	9	24.1	7	25.8	16
Total	100	33	100	29	100	62
Location						
Rural	55.1	27	44.9	22	100	49
Urban	46.2	6	53.8	7	100	13
Total	53.2	33	46.8	29	100	62
Gender						
Female	51.7	15	48.3	14	100	29
Male	54.5	18	45.5	15	100	33
Total	53.2	33	46.8	29	100	62
Caste						
Backward Caste	66.7	16	33.3	8	100	24
Other Caste	44.4	4	55.6	5	100	9
Scheduled Caste	55	11	45	9	100	20
Scheduled Tribes	22.2	2	77.8	7	100	9
Total	53.2	33	46.8	29	100	62
Wealth tercile						
Top tercile	61.5	8	38.5	5	100	13
Middle tercile	57.9	11	42.1	8	100	19
Bottom tercile	46.7	14	53.3	16	100	30
Total	53.2	33	46.8	29	100	62
Marital status						
Married	50	2	50	2	100	4
Single (never married)	53.4	31	46.6	27	100	58
Total	53.2	33	46.8	29	100	62
Subjective well-being						
5 and below	53.5	23	46.5	20	100	43
6 to 9	45.5	5	54.5	6	100	11
Total	51.9	28	48.1	26	100	54

Table A5: Younger Cohort subjective well-being

Subjective well-being	5 and	below	6 to	9	Тс	otal
	%	N	%	Ν	%	Ν
Disability						
Visual impairment	17.4	8	9.1	1	15.8	9
Hearing impairment	19.6	9	9.1	1	17.5	10
Speech impairment	8.7	4	0	0	7.0	4
Physical impairment	10.9	5	27.3	3	14.0	8
Intellectual impairment	4.3	2	9.1	1	5.3	3
Multiple impairments	10.9	5	9.1	1	10.5	6
Others	28.3	13	36.4	4	29.8	17
Total	100	46	100	11	100	57
Gender (persons with disabilities)						
Female	76.9	20	23.1	6	100	26
Male	83.9	26	16.1	5	100	31
Total	80.7	46	19.3	11	100	57
Gender (persons without disabilities)						
Female	67.9	576	32.1	272	100	848
Male	67.4	663	32.6	321	100	948
Total	67.6	1239	32.4	593	100	1832

Table A6: Older Cohort persons with disabilities by type of disability

Parameter	Vis impai			ring rment	Spe impai			sical rment	Intelle impai			ltiple rments	Oth	ers	То	tal
	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N
Location																
Rural	100	1	100	3	50	1	93.3	14	100	2	100	1	83.3	5	90.0	27
Urban	0	0	0	0	50	1	6.7	1	0	0	0	0	16.7	1	10.0	3
Total	100	1	100	3	100	2	100	15	100	2	100	1	100	6	100	30
Gender																
Female	100	1	66.7	2	50	1	93.3	14	50.0	1	100	1	66.7	4	80.0	24
Male	0	0	33.3	1	50	1	6.7	1	50.0	1	0	0	33.3	2	20.0	6
Total	100	1	100	3	100	2	100	15	100	2	100	1	100	6	100	30
Caste																
Backward Caste	0	0	33.3	1	50	1	53.3	8	0	0	0	0	33.3	2	40.0	12
Other Caste	0	0	0	0	50	1	6.7	1	0	0	0	0	16.7	1	10.0	3
Scheduled Caste	100	1	66.7	2	0	0	33.3	5	50.0	1	100	1	16.7	1	36.7	11
Scheduled Tribes	0	0	0	0	0	0	6.7	1	50.0	1	0	0	33.3	2	13.3	4
Total	100	1	100	3	100	2	100	15	100	2	100	1	100	6	100	30
Wealth tercile																
Top tercile	0	0	33.3	1	100	2	26.7	4	0	0	0	0	16.7	1	26.7	8
Middle tercile	100	1	0	0	0	0	6.7	1	50.0	1	0	0	16.7	1	13.3	4
Bottom tercile	0	0	66.7	2	0	0	66.7	10	50.0	1	100	1	66.7	4	60.0	18
Total	100	1	100	3	100	2	100	15	100	2	100	1	100	6	100	30
Marital status																
Married	100	1	100	3	50	1	46.7	7	50.0	1	0	0	16.7	1	46.7	14
Separated	0	0	0	0	0	0	6.7	1	0	0	0	0	0	0	3.3	1
Single (never married)	0	0	0	0	50	1	46.7	7	50.0	1	100	1	83.3	5	50.0	15
Total	100	1	100	3	100	2	100	15	100	2	100	1	100	6	100	30

Table A7: Highest level of education by type of disability (Older Cohort)

Highest level of education	-	ual rment		ring rment	-	ech rment	Phys impai		Intelle impai			tiple rments	Oth	ers	To	tal
	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N
Never enrolled	0	0	0	0	50	1	0	0	50.0	1	0	0	0	0	6.7	2
Did not complete primary	100	1	0	0	50	1	0	0	0	0	0	0	0	0	6.7	2
Completed primary but not elementary	0	0	0	0	0	0	26.7	4	50.0	1	0	0	0	0	16.7	5
Completed elementary but not secondary	0	0	0	0	0	0	20	3	0	0	100	1	16.7	1	16.7	5
Completed secondary	0	0	100	3	0	0	53.3	8	0	0	0	0	83.3	5	53.3	16
Total	100	1	100	3	100	2	100	15	100	2	100	1	100	6	100	30

Table A8: Older Cohort persons with disabilities by level of education

Parameter		d secondary		complete	То	tal
	edu %	cation N	secondary %	education N	%	N
Disability						
Visual impairment	0	0	7.1	1	3.3	1
Hearing impairment	18.8	3	0.0	0	10.0	3
Speech impairment	0	0	14.3	2	6.7	2
Physical impairment	50	8	50.0	7	50.0	15
Intellectual impairment	0	0	14.3	2	6.7	2
Multiple impairment	0	0	7.1	1	3.3	1
Others	31.3	5	7.1	1	20.0	6
Total	100	16	100	14	100	30
Location						
Rural	51.9	14	48.1	13	100	27
Urban	66.7	2	33.3	1	100	3
Total	53.3	16	46.7	14	100	30
Gender						
Female	50.0	12	50.0	12	100	24
Male	66.7	4	33.3	2	100	6
Total	53.3	16	46.7	14	100	30
Caste						
Backward Caste	50	6	50	6	100	12
Other Caste	33.3	1	66.7	2	100	3
Scheduled Caste	72.7	8	27.3	3	100	11
Scheduled Tribes	25.0	1	75.0	3	100	4
Total	53.3	16	46.7	14	100	30
Wealth tercile						
Top tercile	50	4	50	4	100	8
Middle tercile	50	2	50	2	100	4
Bottom tercile	55.6	10	44.4	8	100	18
Total	53.3	16	46.7	14	100	30
Marital status						
Married	42.9	6	57.1	8	100	14
Separated	0	0	100	1	100	1
Single (never married)	66.7	10	33.3	5	100	15
Total	53.3	16	46.7	14	100	30
Subjective well-being						
5 and below	50.0	11	50.0	11	100	22
6 to 9	62.5	5	37.5	3	100	8
Total	53.3	16	46.7	14	100	30

Table A9: Older Cohort persons with disabilities by working status

Parameter	Not w %	orking	Wor %	king N	То %	1
Disability	%	N	%	N	%	N
√isual impairment	9.1	1	0	0	3.3	1
	9.1	1	10.5	2	10.0	3
Hearing impairment						
Speech impairment	0.0	0	10.5	2	6.7	2
Physical impairment	63.6	7	42.1	8	50.0	15
ntellectual impairment	9.1	1	5.3	1	6.7	2
Nultiple impairments	0.0	0	5.3	1	3.3	1
Others	9.1	1	26.3	5	20.0	6
Total	100	11	100	19	100	30
Location						
Rural	37.0	10	63.0	17	100	27
Jrban	33.3	1	66.7	2	100	3
Total	36.7	11	63.3	19	100	30
Gender						
Female	45.8	11	54.2	13	100	24
Vale	0	0	100	6	100	6
Total	36.7	11	63.3	19	100	30
Caste						
Backward Caste	33.3	1	66.7	2	100	3
Other Caste	33.3	4	66.7	8	100	12
Scheduled Caste	45.5	5	54.5	6	100	11
Scheduled Tribes	25.0	1	75.0	3	100	4
Total	36.7	11	63.3	19	100	30
Wealth tercile						
Top tercile	50	4	50	4	100	8
Viddle tercile	50	2	50	2	100	4
Bottom tercile	27.8	5	72.2	13	100	18
Total	36.7	11	63.3	19	100	30
Marital status						
Varried	50	7	50	7	100	14
Separated	0	0	100	. 1	100	1
Single (never married)	26.7	4	73.3	. 11	100	15
Total	36.7	11	63.3	19	100	30
Highest level of education			0010			
Did not complete primary	75.0	3	25.0	1	100	4*
Completed primary but not elementary	40	2	60	3	100	5
Completed elementary but not secondary	-+0 0	0	100	5	100	5
Completed elementary but not secondary	43.8	7	56.2	9	100	16
Total	40.0	12	60.0	18	100	30
Subjective well-being	40.0	12	00.0	10	100	30
5 and below	40.9	9	59.1	13	100	22
	40.9 25	2	75	6	100	8
6 to 9	26					

Note: * Also includes two adults who were never enrolled in education

Parameter	Se empl (fo cro	oyed od	empl	elf- loyed stock)	Wage employn (agricult	nent		lf- oyed ness)	Wage employm (irregula non- agricultu	ient ar;	sala	ular ried yment	Tota	1
	%	N	%	N	%	N	%	N	%	N N	%	N	%	N
Type of disability														
Hearing impairment	0	0	50	1	0	0	0	0	0	0	50	1	100	2
Speech impairment	0	0	0	0	50	1	0	0	0	0	50	1	100	2
Physical impairment	0	0	0	0	25	2	12.5	1	25	2	37.5	3	100	8
Intellectual impairment	0	0	0	0	0	0	0	0	100	1	0	0	100	1
Multiple impairments	0	0	0	0	0	0	0	0	100	1	0	0	100	1
Others	20	1	0	0	0	0	0	0	60	3	20	1	100	5
Total	5.3	1	5.3	1	15.8	3	5.3	1	36.8	7	31.6	6	100	19
Gender	5.5	•	5.5	•	15.0	5	5.5		50.0	'	51.0	v	100	15
Female	7.7	1	7.7	1	23.1	3	0	0	38.5	5	23.1	3	100	13
Male	0	0	0	0	0	0	16.7	1	33.3	2	50	3	100	6
	0	0	0	0		0	10.7	- 1		2	50		100	
Form of payment None	100	1	100	1	0	0	100	1	28.6	2	0	0	26.3	5
Cash (including pocket money)	0	0	0	0	100	3	0	0	20.0 57.1	4	100	6	20.3 68.4	13
Both in cash and in-kind	0	0	0	0	0	0	0	0	14.3	1	0	0	5.3	1
Total	100	1	100	1	100	3	100	1	14.5	7	100	6	100	19
Average monthly salary (INR)	0	0	0	0	2766.67	3	0	0	2954.17	4	5750	6	4201.28	13
Source of job informati	on													
boss/employer	0	0	0	0	33.3	1	0	0	100	5	33.3	2	47.1	8
friends/relatives	0	0	0	0	0	0	0	0	0	0	50	3	17.6	3
own or household's farm/business	100	1	100	1	66.7	2	100	1	0	0	16.7	1	35.3	6
Total	100	1	100	1	100	3	100	1	100	5	100	6	100	17
Type of organisation	_													
Private company/enterprise or cooperative	0	0	0	0	0	0	0	0	0	0	50	3	15.8	3
For a household member	100	1	0	0	0	0	100	1	42.9	3	0	0	26.3	5
Other private individual/household (excluding own household)	0	0	0	0	100	3	0	0	57.1	4	33.3	2	47.4	9
Public sector/government	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Own account/self- employed (own business or farm)	0	0	100	1	0	0	0	0	0	0	0	0	5.3	1
Other, specify	0	0	0	0	0	0	0	0	0	0	16.7	1	5.3	1
Total	100	1	100	1	100	3	100	1	100	7	100	6	100	19
Work-related training s	ince 20	09/10												
No	100	1	100	1	100	3	0	0	85.7	6	100	6	89.5	17
Yes	0	0	0	0	0	0	100	1	14.3	1	0	0	10.5	2
Total	100	1	100	1	100	3	100	1	100	7	100	6	100	19
Job satisfaction														
Very dissatisfied	0	0	0	0	50	1	0	0	0	0	0	0	5.3	1
Dissatisfied	100	1	0	0	50	1	0	0	12.5	1	33.3	2	26.3	5
OK, more or less	0	0	100	1	0	0	0	0	75	6	33.3	2	47.4	9
Satisfied	0	0	0	0	0	0	100	1	12.5	1	16.7	1	15.8	3
Very satisfied	0	0	0	0	0	0	0	0	0	0	16.7	1	5.3	1
Total	100	1	100	1	100	2	100	1	100	8	100	6	100	19

Table A10: Older Cohort persons with disabilities by type of work

Table A11: Older Cohort subjective well-being

Subjective well-being	5 and	below	6 t	o 9	То	tal
	%	N	%	N	%	N
Type of disability						
Visual impairment	4.5	1	0	0	3.3	1
Hearing impairment	13.6	3	0	0	10.0	3
Speech impairment	0.0	0	25	2	6.7	2
Physical impairment	50.0	11	50	4	50.0	15
Intellectual impairment	9.1	2	0	0	6.7	2
Multiple impairments	4.5	1	0	0	3.3	1
Others	18.2	4	25	2	20.0	6
Total	100	22	100	8	100	30
Gender (persons with disabilities)						
Female	79.2	19	20.8	5	100	24
Male	50	3	50	3	100	6
Total	73.3	22	26.7	8	100	30
Gender (persons without disabilities)						
Female	65.8	297	34.2	154	100	451
Male	68	300	32	141	100	441
Total	66.9	597	33.1	295	100	892

Name	Gender	Impairment/disability	Caste	Location	Wealth tercile	Education
Sridevi	Female	Visual impairment	Scheduled Tribe	Rural	Middle	Studying in intermediate second year
Raghavan	Male	Hearing impairment	Scheduled Tribe	Rural	Bottom	Went to school for one month
Indira	Female	Multiple impairments (physical impairment and seizure disorder)	Scheduled Caste	Rural	Bottom	Studied until Grade 5
Vijaya	Female	Physical impairment	Backward Caste	Rural	Bottom	Studied until Grade 6
Nithin	Male	Intellectual impairment	Other Caste	Urban	Тор	Went to school for three months. Later went to <i>Anganwadi</i> and continued for 16 months
Narasamma	Female	Intellectual impairment	Backward Caste	Rural	Middle	Studied until Grade 9 but did not take the exam and then discontinued
Pujitha	Female	Others (learning disability)	Scheduled Caste	Rural	Bottom	Studied until Grade 8
Raghuram	Male	Multiple impairments (physical impairment and epilepsy)	Scheduled Caste	Rural	Bottom	Studied until Grade 3
Surekha	Female	Multiple impairments (intellectual impairment, seizure disorder and visual impairment)	Scheduled Caste	Urban	Middle	Studied until Grade 3
Subash	Male	Intellectual impairment	Backward Caste	Rural	Middle	Went to Anganwadi
Rajan	Male	Hearing impairment	Backward Caste	Rural	Middle	Studied until Grade 10, currently doing ITI
Thulasi	Female	Hearing impairment	Scheduled Caste	Rural	Bottom	Studied until Grade 8
Vedanth	Male	Multiple impairments (intellectual impairment and polio)	Scheduled Caste	Rural	Bottom	Never went to school
Soumya	Female	Hearing impairment	Scheduled Caste	Rural	Middle	Studied until Grade 8
Vardhan	Male	Visual impairment	Scheduled Caste	Rural	Bottom	Studied until Grade 9; enrolled in Grade 10, but did not continue
Bharati	Female	Hearing impairment	Backward Caste	Rural	Bottom	Completed intermediate (Grade 12)
Venkat	Male	Hearing impairment	Other Caste	Rural	Middle	Studied until Grade 10, joined ITI (special school)
Kalyan	Male	Visual impairment	Scheduled Caste	Rural	Bottom	Studying in Grade 12
Nirup	Male	Hearing impairment	Scheduled Caste	Urban	Тор	Studied until Grade 8 (special school)
Ramana	Male	Visual impairment	Scheduled Caste	Rural	Bottom	Studying in Grade 9 (special school)
Kishore	Male	Hearing impairment	Scheduled Caste	Rural	Bottom	Studied until intermediate (Grade 12)
Jayanthi	Female	Hearing impairment	Other Caste	Rural	Middle	Pursuing Bachelor of Commerce degree
Sathya	Male	Speech impairment	Other Caste	Rural	Bottom	Studying in college
Samara	Male	Physical impairment	Scheduled Caste	Urban	Тор	Completed intermediate (Grade 12)

Table A12: Details of the Younger Cohort sample

Table A13: Details of the Older Cohort sample

Name	Gender	Impairment/disability	Caste	Location	Wealth tercile	Education
Sarada	Female	Physical impairment	Backward Caste	Rural	Bottom	Pursuing paramedical course (auxiliary nurse midwifery)
Rajamma	Female	Hearing impairment	Backward Caste	Rural	Тор	Never attended school
Kalavathi	Female	Physical impairment	Scheduled Caste	Rural	Bottom	Discontinued in final year of Bachelor of Commerce degree
Shyam	Male	Hearing impairment	Scheduled Caste	Rural	Bottom	Completed Grade 10
Neeraja	Female	Visual impairment	Scheduled Caste	Rural	Middle	Studied until Grade 3
Vindhya	Female	Hearing impairment	Backward Caste	Rural	Тор	Studied until intermediate (Grade 12)
Prabhakar	Male	Physical impairment	Backward Caste	Rural	Тор	Aiming to graduate
Sulochana	Female	Physical impairment	Backward Caste	Rural	Bottom	Studied until Grade 6
Aruna	Female	Physical impairment	Backward Caste	Urban	Middle	Completed BA in economics
Krishnaveni	Female	Other (mental illness)	Other Caste	Rural	Тор	Was enrolled in Grade 11, but discontinued after six months

 Table A14:
 Occupational status of Younger Cohort and Older Cohort persons with disabilities

	Occupation	Younger Cohort girl	Younger Cohort boy	Older Cohort girl	Older Cohort boy	Total
Domestic work	Married homemaker	2	-	4	-	6
	Unmarried domestic work	3	2			5
Regular employment	Driver				1	1
	Domestic help			1		1
	TV mechanic		1			1
	Professional job and studying			1		1
Entrepreneur	Self-employed and studying				1	1
Irregular work	Daily wages	3	1	1		5
Student	Only studying	2s	6			8
Unemployed	Not working		4	1		5
	Total	10	14	8	2	34

Table A15: Profile of the married respondents

Name	Cohort	Disability type	Age at marriage
Soumya	Younger Cohort girl	HI	17
Vindhya	Older Cohort girl	HI	19
Rajamma	Older Cohort girl	HI	20
Shyam	Older Cohort boy	HI	20
Narsamma	Younger Cohort girl	II	18
Sarada	Older Cohort girl	PI	25
Sulochana	Older Cohort girl	PI	21
Aruna	Older Cohort girl	PI	20
Kalavati	Older Cohort girl	PI	20
Neeraja	Older Cohort girl	VI	19
Vijaya	Younger Cohort girl	PI	15

Annex 8. Schemes implemented by the Department of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment, Government of India

Divyangjan Swavalamban Yojana

This scheme provides concessional loans to persons with disabilities to, for example, start an activity that contributes either directly or indirectly to income generation, to pursue higher education or vocational and skills-related courses which will help them gain employment, or to help them buy specialist equipment (National Handicapped Finance and Development Corporation n.d., a).

Assistance for Disabled Persons (ADIP) Scheme

This scheme aims to help citizens with disabilities in procuring modern aids and appliances, so long as they meet certain conditions, such as having a disability certificate (with 40 per cent benchmark disability), and a monthly income of less than INR 20,000 from all sources. Based on their income, beneficiaries receive either full or partial financial assistance (Department of Empowerment of Persons with Disabilities 2017).

Financial Assistance for Skill Training of Persons with Disabilities Scheme

This scheme aims to provide financial assistance to help with skills training provided through training institutes recognised by the Department of Empowerment of Persons with Disabilities (National Handicapped Finance and Development Corporation n.d., b).

Scheme for Implementation of Rights of Persons with Disabilities Act, 2016

This scheme aims to help various agencies effectively implement the provisions in the RPWD Act, through providing financial assistance for activities such as providing barrier-free environments and skills development training, supporting rehabilitation centres, and conducting research on disability (Department of Empowerment of Persons with Disabilities n.d.).

Annex 9. Research Advisory Group

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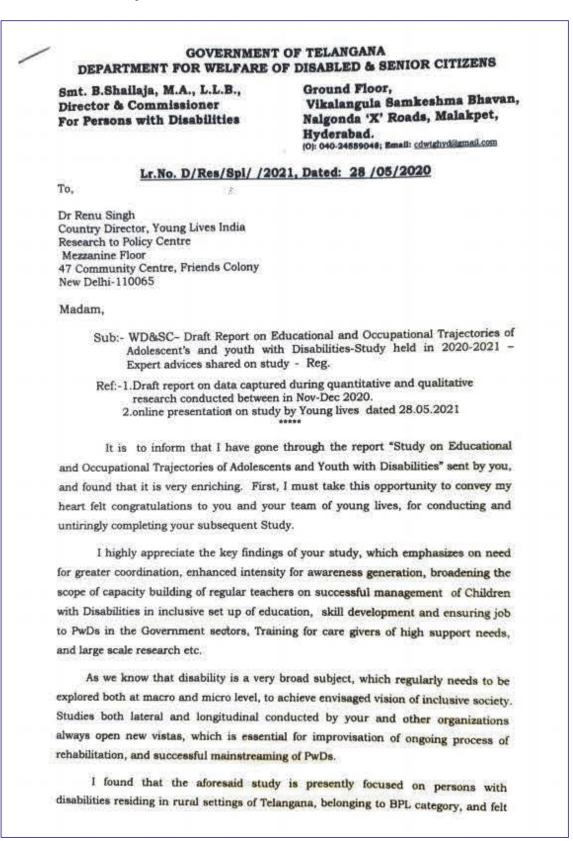
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Annex 10. Example of feedback received



that there is a dire need to further expanded the study identifying children with disabilities residing in urban areas too.

I also felt very glad to have the suggestive outcomes for policy etc, and I would like to mention here that the Department for Welfare of Disabled and Senior Citizens, is regularly endeavoring to realize the envisaged vision of Government of Telangana State, and also are open to take best practices, schemes, programs in account so that no persons with disabilities is deprived of any opportunity needed for their empowerment.

This department has undertaken a number of initiatives right from early identification to proper assessment, certification, encouragement in Education, Employment, and social security etc to make the PwDs an integral part of all poverty alleviation, developmental and welfare schemes of the Government. There are a number of schemes in Telangana which are replicable for other states such as Disability Pensions, which is providing financial support of Rs.3016/-, the quantum of disability pension is the highest in India proving social security to BPL families of PwDs.

With the intention to maintain transparency, accuracy and expediting the process of benefit of various schemes to reach the PwDs, it is streamlined through development and designing of online system of registration and related procedure for selection of beneficiaries. The Government has always tried to transfer the benefit of best technology in assistive devices, to the Persons with Disabilities free of cost, and this year most modern technological assistive Aids worth of Rs. 24.00 Crores is distributed, free of cost to PwDs, which is facilitating them in enhancing their mobility, communication and facilitating them in pursuance of Education.

The Department has established a dedicated tollfree help line number 1800-572-8980 exclusively for the Persons with Disabilities in Telangana, which has played a crucial role especially during the prevailing COVID 19 and is regularly assisting the needy PwDs, guiding them to avail the necessary benefits from Government and is also facilitating in registration for Vaccination.

In the Field of Employment the State has issued orders for 4% reservation for PwDs in direct recruitments and since 2002 onwards continuously conducting state wide Special Recruitment Drive to fill backlog vacancies reserved for various categories of PwDs. Apart from this to further expand the Job opportunities in Private Sectors or encourage Self Employment, the department has launched large scale skill development & Economic rehabilitation program with placement and financial assistance facility, to establishment of own business. The department is also playing a vital role in bridging the gap between the MNC (Employers) and PwD Aspirants (Employees) by conducting regular Job melas.

It is true that a lot has been done and a lot needs to be done for empowerment of PwDs and every positive step towards success will minimize the ill impact of disability on an individual as such while complementing your team to sensitize the target group towards the facilities available for PwDs by the Government and also help in expediting to create an attitudinal and barrier free environment for PwDs so that they could live an independent, secured and dignified life, contributing positively and constructively in development of our Society.

Yours faithfully

DIRECTOR & STATE COMMISSION



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