



A Study Report by

The Direct Costs of Disability to Families in Tamil Nadu

A study report on the goods and services required by persons with disabilities in Tamil Nadu for full & effective participation



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Glossary

Direct Cost	Expenditures made on goods and services because of needs associated with having a disability. For example, the cost of wheelchairs, sign language interpreters, tactile interpreters, personal assistants and transport cost.
Indirect Cost	Indirect costs are the foregone earnings that people with disabilities have because they face barriers to work, or that their family members have because they have to provide support
Disability specific expenses	These are expenses on goods and services that directly pertain to the needs of people with disabilities. example - assistive devices, support services, including care and personal assistant services, and rehabilitation and other disability specific services
Assistive Device	Supporting devices used by persons with disabilities such as communication device (AAC), Refreshable Braille Display, wheelchairs, crutches, orthoses etc.,.
Human Assistance	This includes personal assistance services, interpretation services, care services, circle of support, peer support, additional child care support required by persons with disabilities to participate in the day-to-day activities.
General Services	These are services that relate to the needs of general population, but may be higher for people with disabilities because of their particular needs. for example, transportation and medical care.
Customisation	The modification and alteration of general goods like mobile phones, kitchen appliances etc.,. required by persons with disabilities to suit their particular needs.
Persons with bench mark disabilities	Persons with disabilities whose level of impairment is assessed to be 40% and above.

Introduction

The commitment to equal participation

With the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the adoption of the Rights of Persons with Disabilities Act 2016 (RPDA), the Mental Health Care Act 2017 (MHA) and the National Trust Act 1999, India has committed to ensure:

1. Full and effective participation and inclusion of all persons with disabilities on an equal basis with others
2. The right to live independently in the community
3. Adequate standard of living for persons with disabilities and their families

The government of Tamil Nadu effectively committed to fulfil its legal obligations to implement the UNCRPD by promulgating the RPDA Rules in 2018¹, giving effect to the RPDA 2016.

Tamil Nadu is one of the few states in the country that has a specific Department for the Welfare of the Differently Abled (DWDA) for implementing the commitments of the RPDA, MHA and UNCRPD. This department implements 82 programs that include cash transfers, assistive devices, skill development and training, and rehabilitation services catering to the diverse needs of persons with disabilities.

Meeting these commitments requires policy- and program-level interventions that remove barriers to participation, as well as provide necessary supports. These barriers and lack of supports impose costs on persons with disabilities. This report examines the structure and extent of the extra expenditures that persons with disabilities must incur to equally participate in society, and offers guidance on how to begin fashioning policies to address them.

Disability Costs

Disability costs fall into two categories: disability specific and general.

Disability Specific	These are goods and services that directly pertain to the needs of people with disabilities. For example, assistive devices, support services, including care and personal assistant services, and rehabilitation and other disability specific services.
General	These are goods and services that relate to the needs of the general population, but may be higher for people with disabilities because of their particular needs. For example, transportation and medical care.

There are two methods of measuring these extra costs. The first is to look at current household expenses related to disability. The second is to consider what expenditures would be necessary to have equal participation.

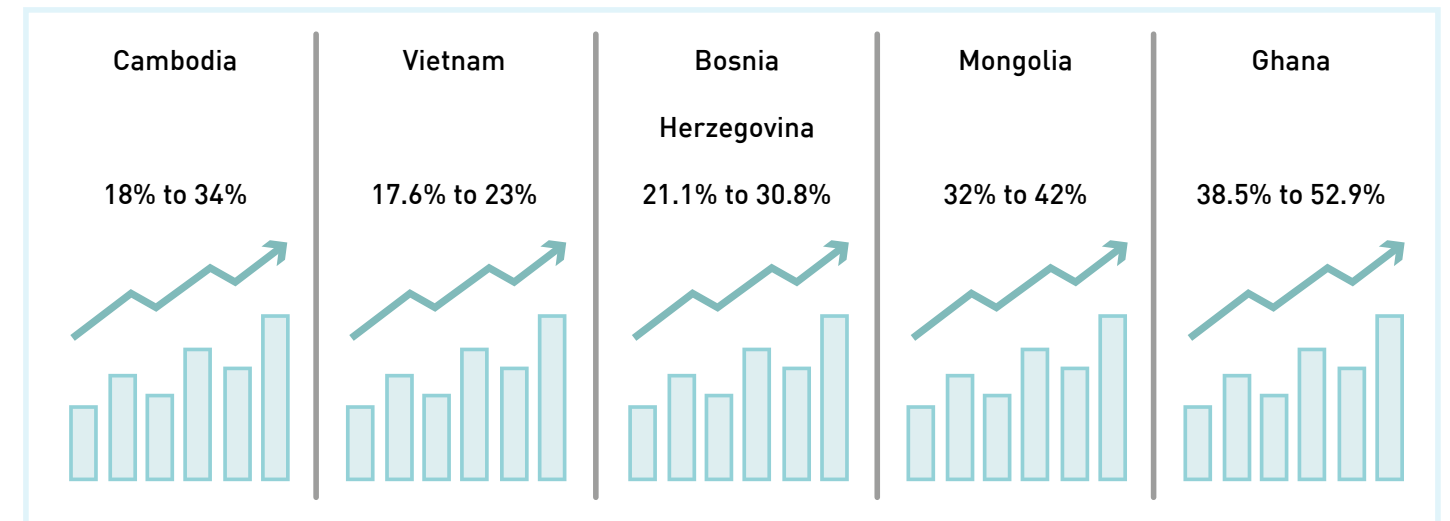
People's current spending may be less than what is needed for many reasons:

1. because they may be unaware of goods and services that could address their support needs.
2. those goods and services may not be available where they live.
3. they may not have sufficient funds to purchase them, and finally
4. discrimination can exist within a household limiting resource allocated to persons with disabilities within the household.

It is the second method of measuring disability costs — determining the goods and services required for equal participation — that is most appropriate for conceptualizing what policies are best for meeting the goals of the UNCRPD. However, the first method provides insight into how current disability-related expenditures are affecting the economic wellbeing of persons with disabilities, and how standard statistics — like the reported poverty gap between households with and without members with disabilities — overstate that economic wellbeing.

For example, consider the poverty line, which is constructed to represent the ability to meet certain essential needs, such as food and shelter. However, people with disabilities have other essential needs for participation. Even though they may be technically over the poverty line, once they spend on these disability-related needs, their remaining income might fall below it. Or, conversely, they may spend on those essential non-disability related needs, but then not have sufficient income to cover their other essential needs, and thus face exclusion.

Accounting for those extra costs significantly increases the poverty estimates for households with persons with disabilities (as shown in the graph for Cambodia, Vietnam, Bosnia and Herzegovina, Mongolia and Ghana), though these estimates only account for actual expenditures made, not what is needed for full participation.ⁱⁱ



And yet, these estimates do not reflect the full impact of disability costs, because the needed expenditures for full participation may not be being met. In fact, extra expenditures can increase with participation. For example, if a person faces barriers to participation and decides to stay home, they may not require much in the way of goods and services to manage throughout the day. However, if they are employed outside the home, they may face extra costs associated with transportation, additional assistive devices or personal support services in order to do their work. In fact, studies show that extra expenditures associated with disability are higher for people who are employed.ⁱⁱⁱ

Study Objectives

The recently published National Sample Survey Office (NSSO) survey from 2018^{iv} on specific issues related to persons with disabilities observed limited access to assistive devices, social protection and support services.

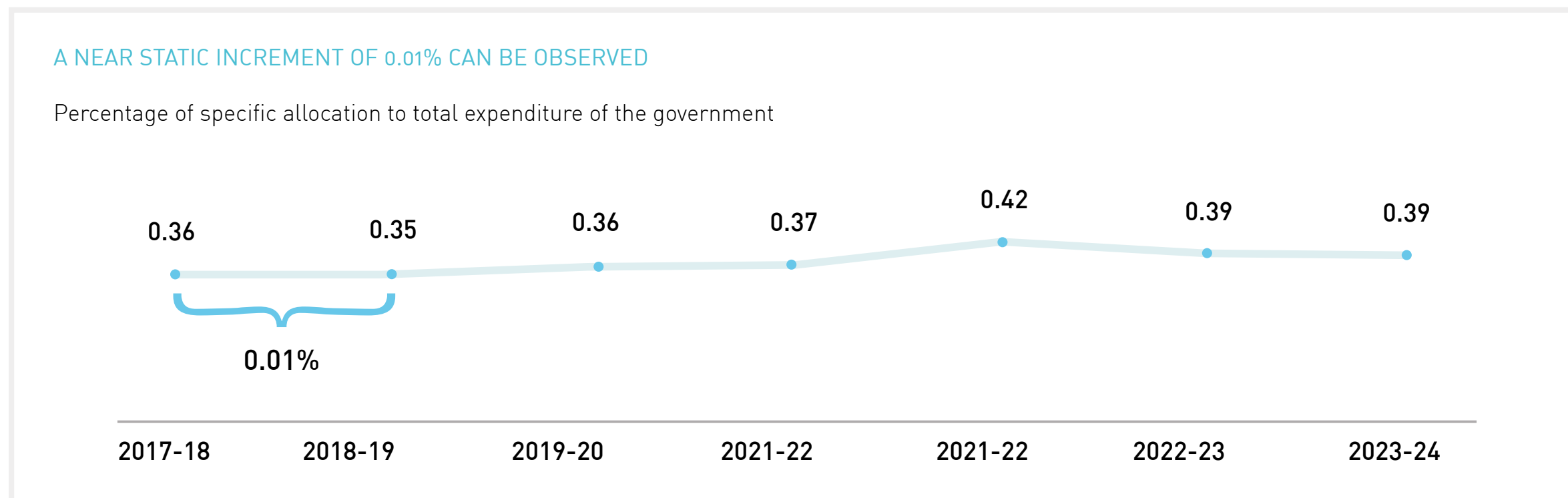
Access to assistive device	21.3%, 28.7%, 18.2% of those with mobility, visual and hearing impairments needing assistive devices have access to one , respectively.
Access to treatment / therapy	17.7% of those who consulted a doctor have access to treatment. Only 0.3 % have access to some form of therapy and 5.5% expressed that they are not aware of such services
Access to aid / help	61.7% of the population of persons with disabilities do not receive any aid / help. Only 36.6% receive support from the government.
Certificate	Only 35.4% of the population of people with disabilities has a disability certificate

The current system is lacking in many ways, including relevant data, budgetary allocations, evolution of schemes and programs to cater to the diversity of needs, and a medical rather than bio-social approach to disability assessment and determination.

As per the Census 2011, the population of persons with disabilities amounts to 1.6%^v of the population of the state, which is less than the national average of 2.21%. This indicates a need for an appropriate survey to generate data on persons with disabilities for effective intervention and

planning. Moreover, even the 2.21% figure is lower than what is generally found in other studies of disability prevalence around the world.^{vi}

In addition to the lack of relevant data, an observed near static increment of 0.01% to a limited budgetary allocation to persons with disabilities in state expenditures is another significant marker that substantiates the gap between what is available and what is required for the actual realisation of the right to full and effective participation and inclusion.



It should also be noted that key programs such as cash transfers, assistive devices and travel concession have evolved over time,^{vii} primarily through expansion to include the diversity of persons with disabilities. However, the programs do not cater to the diversity of needs across the life cycle.

Further, the existing disability assessment mechanism and eligibility determination procedures^{viii} adapt a medical approach instead of a human rights based approach suggested by UNCRPD, which would take into account the support needed and the barriers experienced by persons with disabilities. Therefore, the process does not capture the diversity of needs of persons with disabilities, which in turn limits the availability of information for adequate policy planning and case management that responds to the needs of all persons with disabilities.

Overall, the government takes a one size fits all approach across the various schemes and programs that does not align with the diversity of needs — in type and degree — experienced by people with disabilities.

All of this highlights the need to address the gap between the goods and services required by persons with disabilities and what is available and accessible. To address this gap and to provide for adequate investment, it is important to understand persons with disabilities in all of their diversity.

The Tamil Nadu policy document^{ix} does not commit to a needs assessment survey or research to understand the goods and services required by persons with disabilities for effective programmatic interventions, including budgetary allocations. Instead, the policy has restricted itself to a medical rehabilitation framework.

Persons with disabilities and their families absorb some of the costs related to goods and services required by persons with disabilities, resulting in families experiencing a lower standard of living as compared to families without a person with disability. However, the majority of persons with disabilities have very limited or no access to the required support services and assistive devices. This impacts participation in education, employment and the decision-making processes of the community, resulting in poverty and intersectional marginalisation.

“ My only income is the government pension of Rs. 1500 a month. I used to take tuitions for children in the neighbourhood, which supported my living to some extent but that stopped with Covid outbreak. I need to spend on maintenance of my adapted scooter, petrol, maintenance of my calliper, additional costs on rent to have an accessible toilet. All this works out to at least Rs. 10,000 to Rs. 15,000 a month. These costs are essential for me even to search for a job. I could manage because of my friends, people with good hearts and family members who support my food and shelter. ”

As shared by Kamaraj, aged 40 years, a person with mobility impairment from a rural area, Trichy District, Tamil Nadu

Purpose, Scope & Methodology

PURPOSE OF THE STUDY

The purpose of this study is to understand, document and inform policy makers about:

1. The range and types of goods and services required by the diversity of persons with disabilities to participate on an equal basis with others, and their associated costs.
2. The government's efforts in ensuring access to the goods and services required for participation.
3. The extra cost to families in procuring the goods and services.
4. The gap between the goods and services required and those that are accessible and available to persons with disabilities.

SCOPE OF THE STUDY

The study was conducted in Tamil Nadu,^x one of the southern states of India.

For the purposes of calculating the goods and services required, the study focuses on direct costs, meaning the expenditure on additional goods and services. It does not focus on indirect costs, such as lower income for people with disabilities and their family members because of barriers to education and employment, or the lack of support services that leads to increased care responsibilities for family members.

The study also looks only at expenditures made by people with disabilities on goods and services that are related to their disability, including disability specific items such as hearing aids, wheelchairs and personal assistance, as well as additional spending on general items (for example, higher transportation and medical expenses).

The study is conducted among persons with disabilities whose impairment is listed in the schedule of the RPDA 2016.^{xi} The 21 categories of impairments listed in the RPDA were narrowed into 10 broad categories for the purpose of the study:

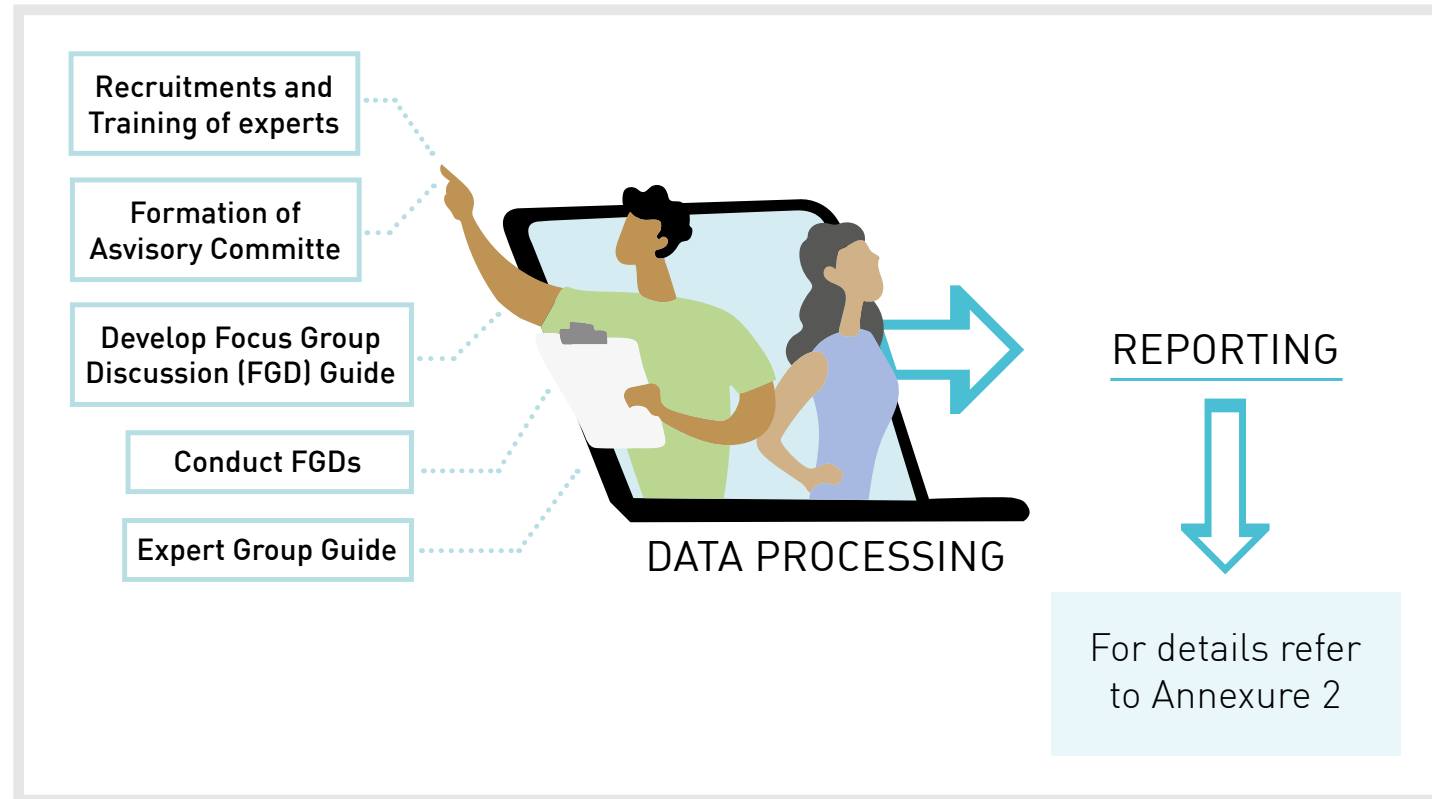
1. Persons with physical disability (spinal cord injuries, muscular dystrophy, cerebral palsy, acid attack survivors, leprosy cured people, dwarfism)
2. Persons with visual impairment
3. Persons with hearing and speech impairment
4. Deafblind people
5. Persons with psychosocial disability
6. Autistic people
7. Persons with specific learning disability
8. Persons with intellectual impairment

- ▲ 9. Persons with complex medical conditions, such as blood disorders or complex neurological impairments (multiple sclerosis, parkinsonism)
- ▲ 10. Persons experiencing multiple disabilities

METHODOLOGY

The study team of experts used participatory processes to create lists of goods and services required by the type of disability and level of support needs, costed those items, and estimated the costs of goods and services that were not currently available. Central to this whole process has been the involvement of persons with disabilities and their representative organisations for:

1. their critical insight into the costs faced by people with disabilities.
2. generating understanding and support for what the project is hoping to achieve.



LIMITATIONS

We could **not reach out to families** of children with psychosocial disabilities. Instead, data was gathered from an expert working with persons with psychosocial disabilities to determine the goods and services required by children with psychosocial disabilities.

Deaf people and persons with visual impairment did not want to distinguish data based on high support and low support requirement and therefore the data is presented under high support requirement based on the advice from the expert group members.

The range of costs generated was based on the individual experience and market research conducted by the expert group members. This might vary at the finalisation of the report depending upon market and the taxation policies.

It is important to note that these estimates are not meant to be precise to the extent that they can be used to generate averages for the population. Rather, they are meant to show the range of potential costs, their structure and the degree to which they can vary by type of disability and level of support needs.

Key Findings



Chapter 1



Children with Disabilities

Highlights

The section is based on the inputs from families of children with disabilities during the FGDs and further inputs from the expert group members. Most of the families that participated in the FGDs belong to low- and middle-income groups with income^{xii} ranging between Rs. 20,000 to Rs. 60,000 per month.

Cost to the families	3 to 6 times more than the family income (For families having the highest income in the range of low- and middle-income families mentioned above)
Proportion of categories of goods and services required	Human assistance consumes the major proportion of goods and services required by children with disabilities with high support requirements. This is followed by assistive devices and health and rehabilitation services. However, among children with physical and multiple disabilities with low support requirements assistive devices occupy the largest proportion. Among children with complex medical conditions, health care occupies the highest proportion irrespective of the level of support required.
Government's efforts in ensuring goods and services	0 to 30% of the goods and services required by children with disabilities. Highest (30% approximately) coverage for persons with physical and visual impairments. Government of Tamil Nadu covers 20 to 30% of the WHO list of priority assistive devices.
Cost incurred by families	Families take a lot of responsibility in ensuring the goods and services that are required by their children and absorb the cost of services like child care and personal assistants that is not available or affordable. A large proportion of goods and services required are either not accessible or affordable.

RANGE OF COSTS OF GOODS AND SERVICES REQUIRED BY THE DIVERSITY OF PERSONS WITH DISABILITIES FOR FULL AND EFFECTIVE PARTICIPATION

This section highlights the monthly costs of goods and services required by children with disabilities.

Note:

The monthly costs of assistive devices are calculated by dividing the total cost of device by the number of months it is used before it needs to be replaced. For example, if it is assumed that children with disabilities using a wheelchair might require replacement once every two years, then the cost of the wheelchair is divided by 24 to arrive at the probable monthly cost.

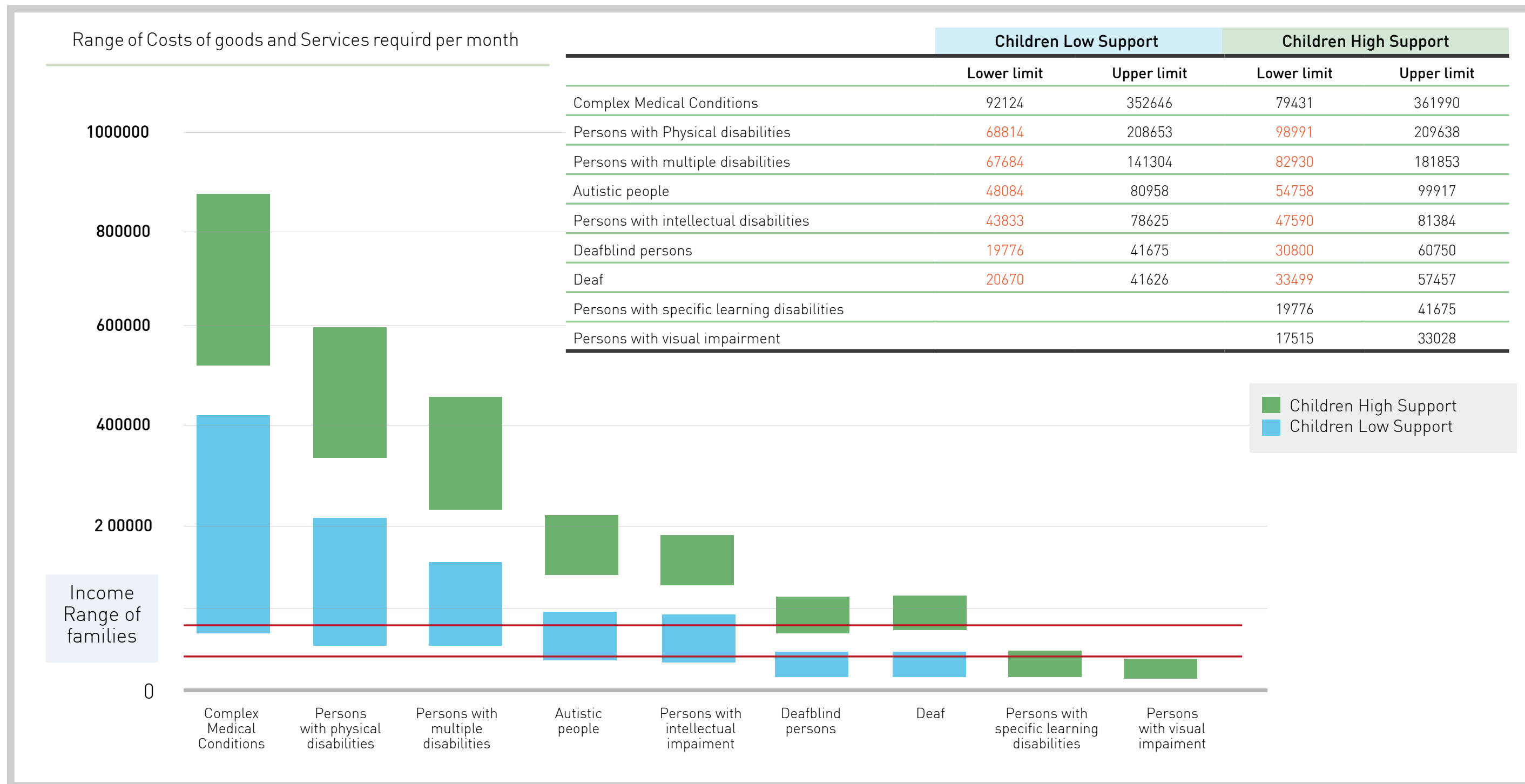
Figures 1.1 reveals:

1. Considerable cost differences based on the level of support required could be observed among autistic children, deafblind children and children with multiple disabilities.
2. Considerable difference in cost could be observed at the lower range and not at the higher scale Among children with physical disabilities.
3. Cost of participation is the same irrespective of the nature of support requirements among children with specific learning disabilities and among children with intellectual impairment.

Families of children with visual impairment and deaf children felt that they cannot be distinguished as high support and low support, and require similar services and goods for ensuring participation of their children.

The cost of goods and services required for participation is two to six times more than the family income for a majority of families that participated in the FGDs.

Figure 1.1: Range of costs of goods and services required per month - children with disability



“In [the] case [of] children with intellectual impairment, once the families identify the difference, they spend a lot of resources on locating the probable services since information is not readily available. Then they go through the same processes of early intervention services irrespective of the level of support. So, the costs tend to remain the same for both children with high support and low support requirements.





As far as persons with specific learning disabilities, the cost will [be reduced] based on the support requirement once they grow up and establish their own coping mechanisms.

On the other hand, for persons with intellectual impairment the cost will vary depending on the level of participation.

Most often children with specific learning disabilities in rural areas will remain unidentified and will not get the specific attention and services they need. They may not even go through the process of assessment. They lose out on their learning and academic development.”

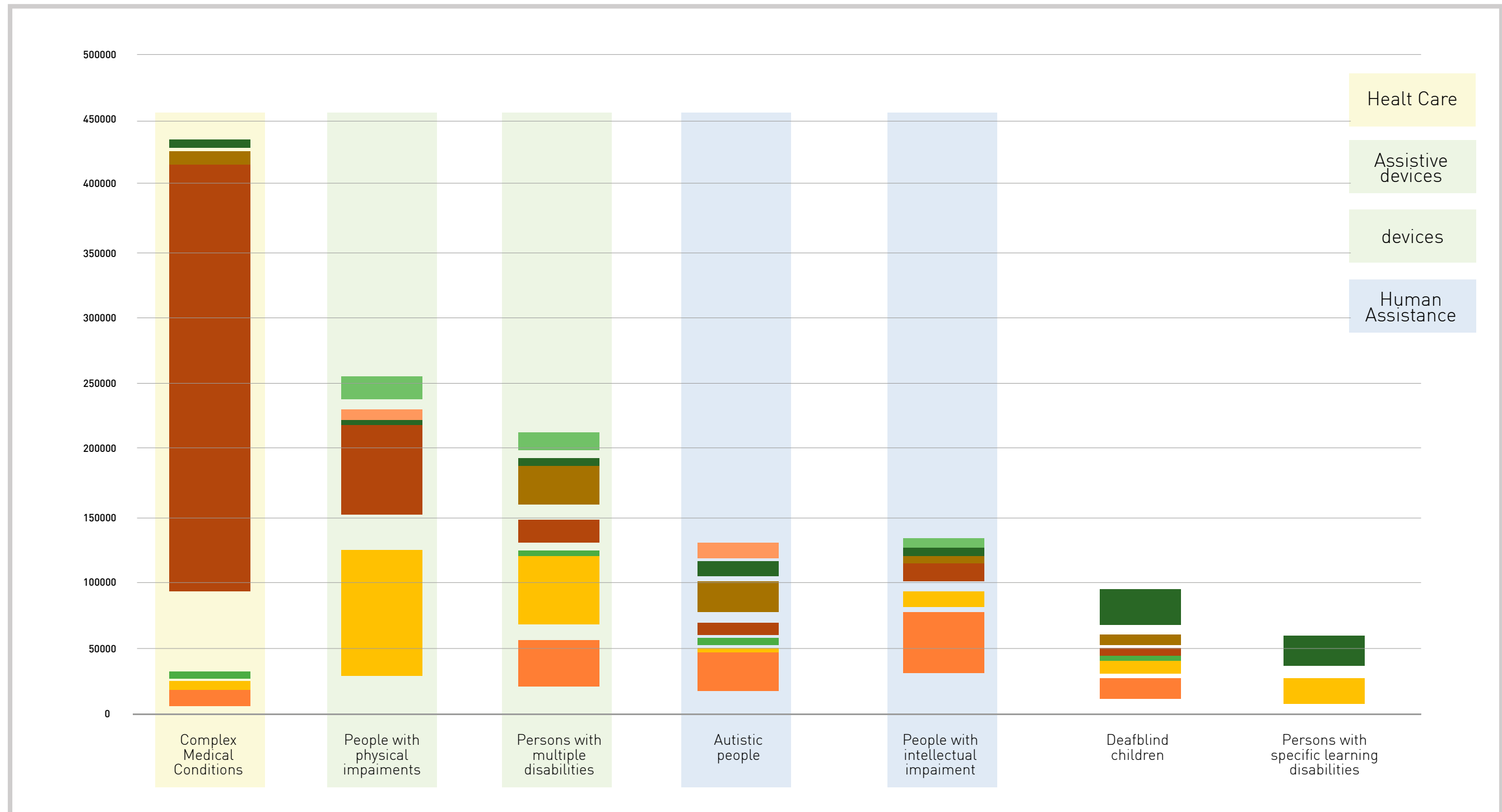
Radha Ramesh, Expert group member

Figures 1.2 highlights the goods and services required such as human assistance, assistive devices, home adaptations, health services and transportation to participate in activities like education, leisure and community life. These goods and services vary according to the nature of impairment and the extent of impairment.

	<p>Cost of assistive devices are highest among children with physical impairments, multiple disabilities with low support requirements and second largest cost among children with high support requirements</p>
	<p>Child care services have been one of the key services required by all children irrespective of the support requirements. This cost is highest among children with high support requirements.</p> <p>“We usually accompany our children while they access schools, rehab centers and other services and facilities in order to provide care support. If we get that support, we could work and support the family better. We used to ask the schools if we could do some maintenance work when we are at school when our kids do not need our support.”</p> <p>As shared by parents during various FGDs conducted for the purpose of this study</p>
	<p>Healthcare costs are high among children with complex medical conditions and children with extensive physical impairments using equipment for breathing</p>
	<p>Transportation costs are high among children with physical, multiple and intellectual impairments. Parents of children with visual impairments and deaf children shared that the cost of transport while accompanying their children is not compensated by the government.</p>

Goods and Services required vary according to the nature and the extent of impairment

Figure 1.2 Goods and services required by children with low support requirements (INR)



All children with high support requirements require intensive human assistance

Figure 1.3: Goods and services required by children with high support requirements (INR)

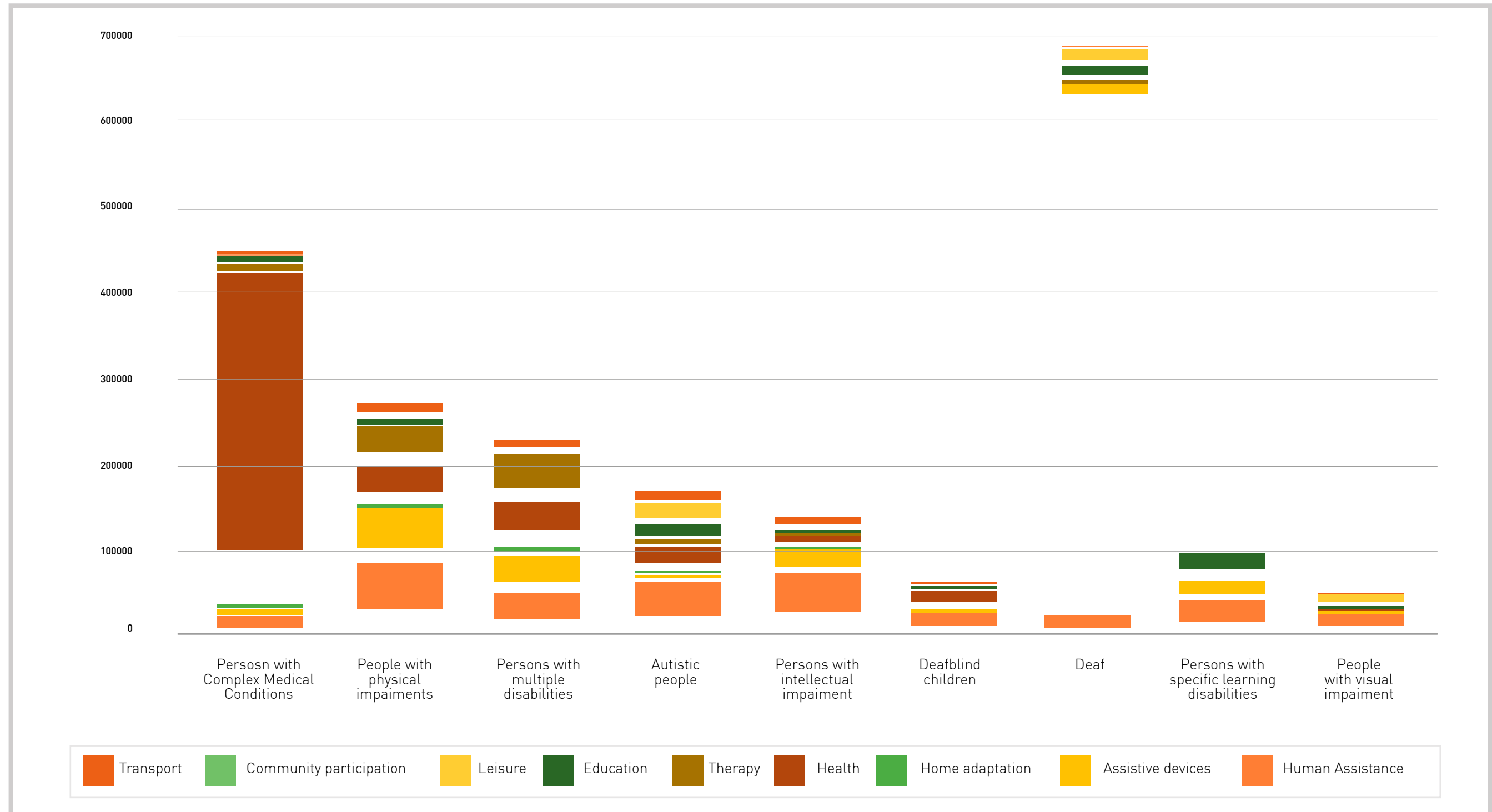


Figure 1.3 includes the costs of cochlear implants. Though it is a one-time cost that ranges between Rs. 600000 and Rs. 650000 provided by the government, huge maintenance expenses are borne by the family that range between Rs. 50000 to Rs. 100000 per year.

Status of children with disabilities with high support requirements in rural areas

“

“In my experience of working in the field, I have observed that children with physical and multiple disabilities who requires extensive support do not survive due to the intersectional impact of poverty, lack of services and facilities in the villages and lack of information among parents.”

As shared by Sudha Ramamoorthy, Expert Group Member

“**Women or girl children** with my conditions do not generally live beyond 15 years in rural areas. Families allow them to starve for blood, nutrition and so on. People even asked my parents “why do you have to spend on a girl child.”

As shared by Mumtaz, person with thalassemia

”

Most of the parents who participated in the focus group discussions expressed that they had to migrate to the city in order to access various services for their child with disability.

This considerably increased their cost of accommodation and has also led to lack of support from the extended families, which they would have had otherwise.

Government's efforts in ensuring access to goods and services required by children with disabilities

Programs implemented by the government include:^{xiii}

- Early intervention services for children with hearing and speech impairments, visual impairments and children with high support needs. The aim of these centers is to identify children in the age group of 0 to 6 years and ensure medical and rehabilitation services. There are 92 centers in all the district headquarters of the state.
- Scholarships for students with disabilities are provided to students from the 1st standard to post graduation. The value of scholarships varies according to the educational level.
- Government-run special schools and mobile therapy units provide rehabilitation services for children with disabilities, particularly those with high support requirements. Most deaf schools and blind schools are funded by the government of Tamil Nadu.
- There are schemes for the provision of assistive devices such as wheelchairs, callipers and hearing aids as well as cash transfers through the DWDA.
- The government provides free blood transfusions for children with thalassemia. (some groups of children with thalassemia, full coverage for health care and medication for children with haemophilia and
- Children with disabilities are also eligible for cash transfer programs, such a maintenance grant and pension. However, they cannot access both benefits together. Children with high support needs can access both a maintenance grant and carer's allowance. The number of people benefiting from the carer's allowance is very small compared to those who need the benefit.

Table 1.1: Ratio between goods and services required and what is supplied by the government across the diversity of persons with disabilities

Persons with disabilities	Ratio of goods required to what is supplied by the government – Children	Ratio of services required to what is supplied by the Government - Children
Persons with Complex Medical Conditions	Covers one out of 9 goods required, which is 11% of the total requirement and 25% of the WHO list	Covers one out of 8 categories of services (12.5% coverage)
Deafblind persons	Covers one out of 7 goods required (14.2% coverage)	Covers one out of 5 required services (20% coverage)
Persons with Multiple Disabilities	Covers 2 out of the 8 required goods (25% of the required goods and services and 10.5% of the WHO list)	Covers 1 out of the 8 required services (12.5% coverage)
Persons with physical disabilities	Covers 5 out of the 17 required goods (29.4 % of the required goods and 26.31% of the WHO list)	Required Services – 7, Coverage - Nothing
Autistic people	Required goods 5, Coverage - Nothing	Required services – 6, Coverage -Nothing
Persons with Intellectual Impairments	Required goods 3, Coverage - Nothing	Covers one out of the 6 required services
Persons with Psychosocial disabilities	Required – 1, Coverage - Nothing	Required services -2, Coverage - Nothing
Persons with visual impairment	Covers 3 out of the 8 required goods (37.5% of the required goods and 21.4% of the WHO list)	Covers one out of the 2 required services
Deaf	Covers 1 out of the 5 goods required (20%)	Covers one out of the five required services (20% coverage)
Persons with specific learning disabilities	Goods required 7, Coverage - Nothing	Required services – 4, Coverage - Nothing

Families of children with disabilities who live in cities are in a better position to explore the various goods required by their child. This is in part due to support from civil society organisation (CSOs).

People from rural areas are aware of the most familiar products such as wheel-chairs, hearing aids and canes. Most often their focus is on accessing different forms of therapeutic interventions.

It is to be noted that accessing government programs is common among families in rural areas compared to urban areas.

“We used to access government therapy centers in the district headquarters hospital. We are not happy since the service is available only for 2 days a week and the duration of the session will only be for 15 to 20 minutes. Sometimes, we will return without any session. This is because

1. Most often the doctors will be busy with disability certification process and the therapist may not be enough to cater to the large numbers of children visiting.
2. We also have to spend a lot of money for transport to reach the hospital, which is in the district headquarters (almost 25 kms away from our village).

We also access private centers for more therapy sessions but now due to COVID and loss of family income we are managing at home with whatever I have gathered from those sessions.”

As shared by a parent of an autistic child during the FGD, Tiruvallur

Cost to the family in procuring the goods and services; availability, accessibility and affordability of the required goods and services

Figures 1.4 & 1.5 make it explicit that

1. Families shoulder almost 70 to 80% of the cost of the goods and services required by their children irrespective of the level of support. The higher the level of support, the higher the cost to the families.
2. Government’s compensation amounts to 2 to 8% of the overall cost of goods and services required by children with disabilities

Care support is one of the key requirements across all constituencies of children with disabilities, and is particularly high among those who have high support requirements.

This service is currently unavailable and mostly provided by family members, particularly the mother of the child.

The care service absorbed by the family members remains unpaid. Most of the parents present in the FGDs expressed that they left their jobs to support their children. Therefore, this data is presented as services not available but absorbed by the family.

“Complex Neurological Disorders such as multiple sclerosis and parkinsonism mostly manifest at a later stage in life. These days we have identified lot of children with multiple sclerosis but their parents do not want to disclose their identity and therefore, [are] not included here.”

As shared by Smitha Sadasivan, person with multiple sclerosis, expert group member

“Most of the cost that we incur for our children is due to medication and treatment whenever there is a bleed. We also have huge hospitalisation costs. However, all expenses related to treatment and medications are covered by the Government. The State Insurance can be used for this purpose and all our members use it.”

As shared by Ambica, parent of a child with haemophilia, expert group member

70 to 80% of the cost of the goods and services required are borne by the family

Figure 1.4: Costs incurred by families, those compensated by Government –children with high support requirement

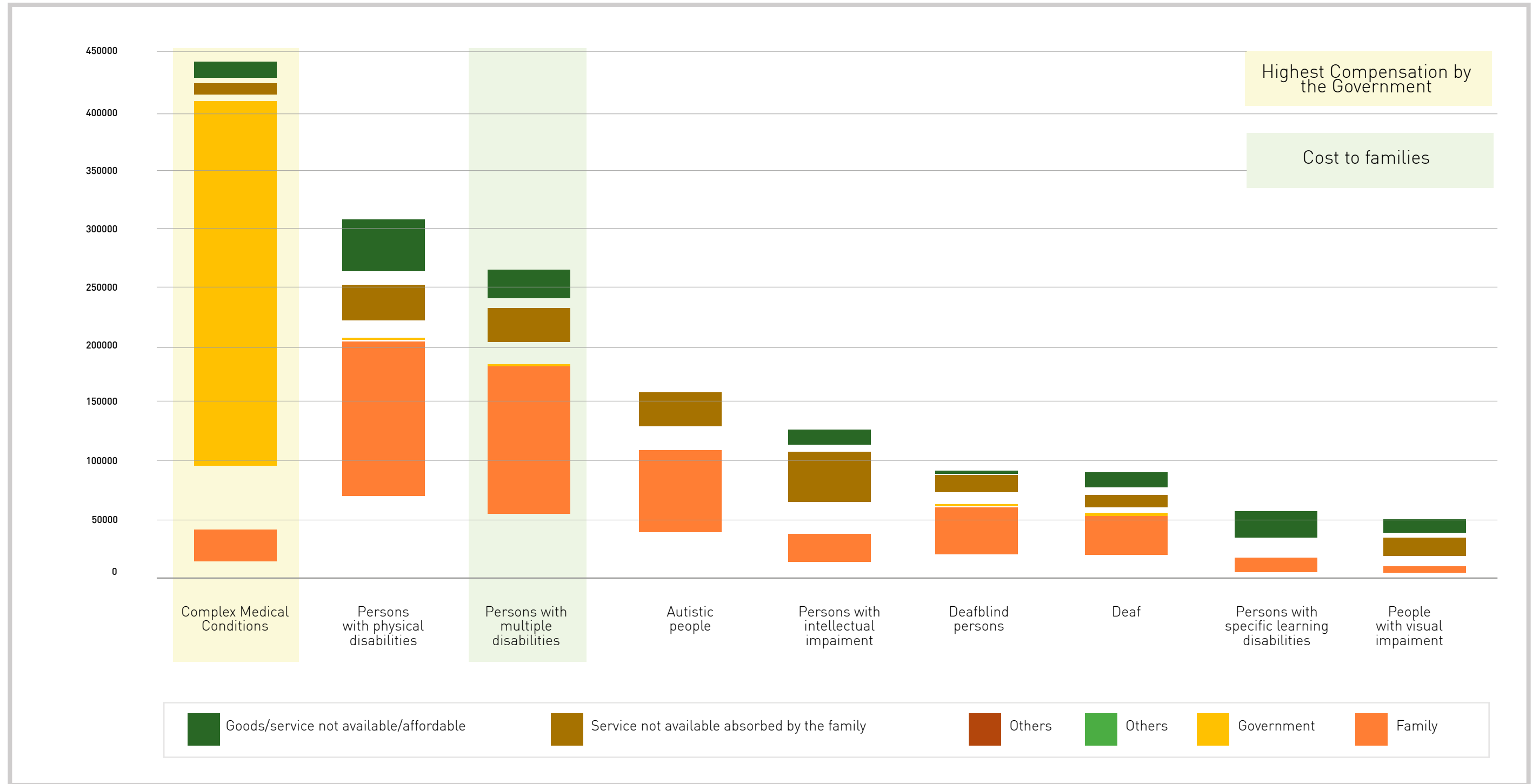
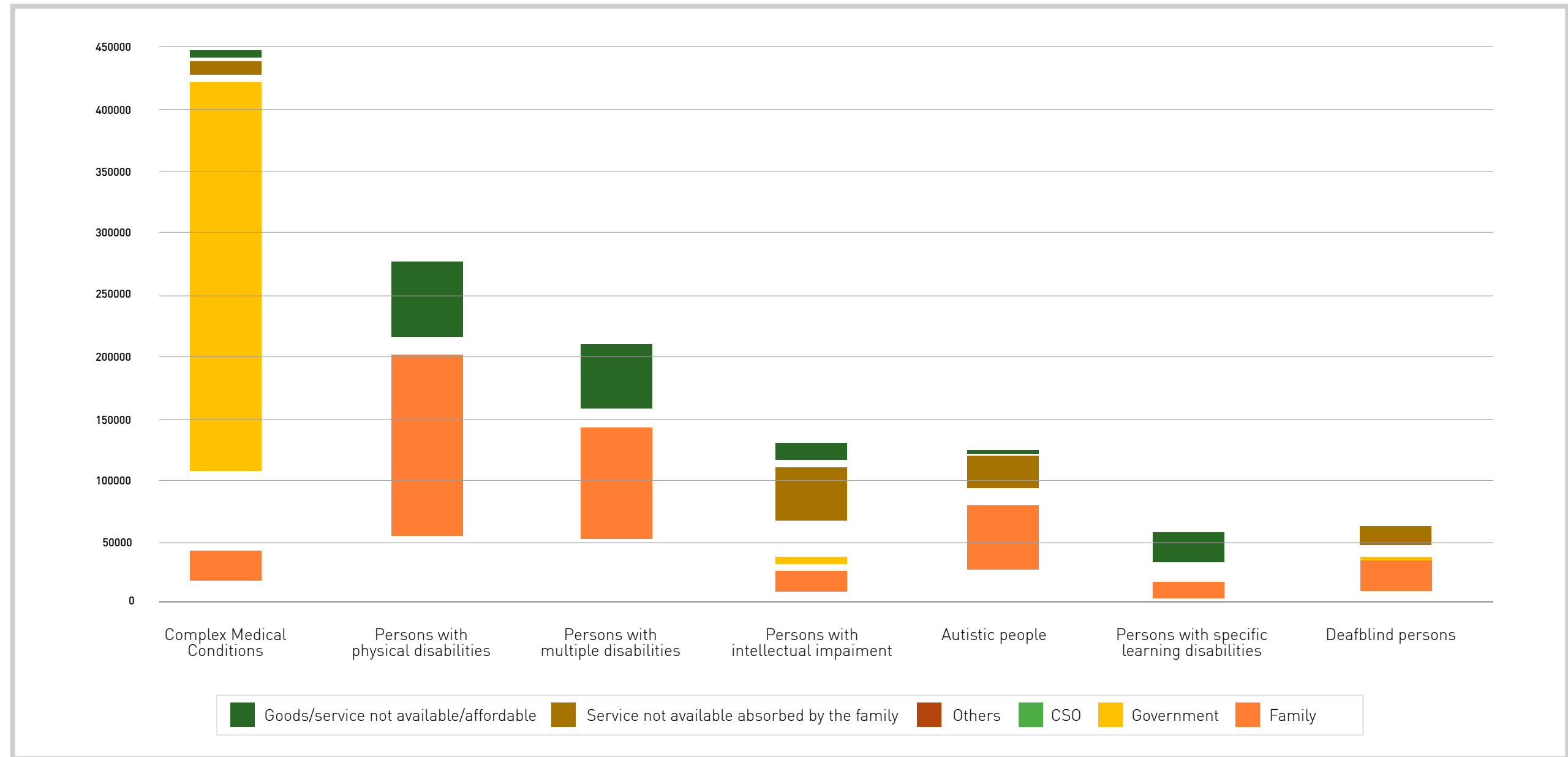





Figure 1.5: Costs incurred by families and those compensated by the Government – children with low support requirement





Gaps between goods and services required but not available / accessible or affordable

In rural areas, there is a lack of awareness among families about various goods and services that could facilitate participation of their children.

The focus of families is primarily in accessing services such as therapeutic interventions. However, it is again limited to the information they gather through the Community Based Rehabilitation (CBR) workers in places where such services exist.

1	 <p>Most of the products are available particularly for those with physical and multiple disabilities but they are concentrated in cities or have to be procured online by the families. The major gap between rural and urban areas is the lack of availability of information and lack of suppliers for the product and the costs involved, which could include the high transportation costs.</p> <p>As shared by Sudha Ramamoorthy, Rehab Professional, expert Group Member</p>
2	 <p>“Usually, all learning materials and products including those that are expensive are available to students with specific learning disabilities only if they access the specific training centres. They are not available at home or for enhancing their participation skills.</p> <p>In rural areas the knowledge about the condition is very limited and so they drop out of education and lack specific training services.</p> <p>There are no Government schemes except exam related support like scribe during public exams.”</p> <p>As shared by parents of children with specific learning disabilities during the FGD</p>
3	 <p>“Children with muscular dystrophy has lots of challenges with respect to muscle strength, trunk balance and control apart from other physical complications.</p> <p>They need more support than what is generally assumed. For example, the mobility equipment like wheelchairs that they use have to suit their body structure that allows for postural management and the body should be properly positioned. This requires different types of cushions that should be custom made</p>

4	 <p>that prevent secondary disability</p> <p>in close consultation with an occupational therapist, orthotist and the family including the child with disability.</p> <p>This entire process does not happen due to the lack of expert services and lack of information to families about these requirements.</p> <p>Though the government provides a powered wheelchair to those children accessing government services, these specific requirements are not considered and ensured. This has a huge impact on the health and survival of the child.”</p> <p>As shared by Dr. Gnana Bharathi, Founder member of SIPA, Expert group member for this study</p>
	 <p>Innovations do not reach rural areas on an equal basis</p> <p>“There are a lot of innovations to access information and communication for persons with visual impairment on a daily basis.</p> <p>However, it takes a lot of time to reach people particularly in rural areas. Even if it reaches, children with visual impairments are not exposed to those products and devices during their primary learning age in the environment in which they learn. This has an impact on their academic choices.</p> <p>Further, because of this gap during childhood, persons with visual impairment have to spend a lot of time after schooling to access different services and employment to keep pace with the changing scenario and the demands of the market.”</p> <p>As shared by Professor Raghuraman, person with visual impairment, Expert Group Member</p>

Inputs on children psychosocial disability from Dr. Kotteeswara Rao, Assistant Director, SCARF India, Senior Research Fellow SCARF, Ex-Officio member, State Mental Health Authority Tamil Nadu.

Recently families are accessing support for psychosocial issues such as addiction to alcohol, drugs, social media (particularly after COVID outbreak), stealing and so on. Previously parents did not have adequate awareness to seek support.

There is no visible rural/urban divide in terms of addiction. I have screened almost 22 villages and have found that in around 10 villages, children age 15 and less are addicted to drugs. I could also observe suicidal tendencies among children due to issues in relationships between besties, breakups and academic performance.

In these circumstances the child will need the support of a neurologist, psychologist, medication and sometimes hospitalisation for various services like behavioural modifications. Sometimes children who come to us might need support for other conditions such as seizures.

If the child needs behaviour modification therapy, this may require up to three to four sessions in a month costing between Rs. 2500 to 5000 per session. These services are not available in rural areas, therefore the family have to travel to cities where services

are available. Most often an issue with the child will affect and disturb the entire family. Usually, the entire family accompanies the child, particularly if it is a girl child. This increases the cost of transportation and accommodation in the city for the family. This could work out to at least Rs. 5000 to Rs. 10000 per month.

During this phase, the child might require care support services for at least four to eight hours a day. This service usually costs Rs. 8000 to Rs. 12000 per month. When we suggest computer-based therapeutic interventions, this requires the family to have access to a laptop. We feel occupational therapy helps better than psychologist intervention. This cost around Rs. 10000 to 15000 a month. The services are available only in cities or sometimes district headquarters.

The key issues are:

1. Lack of government schemes
2. Lack of services such as psychologists, occupational therapists, etc. In the entire state of Tamil Nadu we have only 10 to 12 child psychologists.
3. Despite the mandate of the MHA 2017 to have a separate ward for children in distress, there is not a single specific ward for children in government hospitals.

All of this impacts child development and participation of children.

Key Findings



Chapter 2



Adults with Disabilities

Highlights

The section is based on the inputs from persons with disabilities and their families during the FGDs and further inputs from the expert group members. Most of the persons with disabilities, particularly those with high support needs, are not working and belong to low- and middle-income groups with incomes ranging between Rs. 20,000 to Rs. 60,000 per month.

Cost to the families

3 to 6 times more than the family income (For families having the highest income in the range of low- and middle-income families mentioned above) for persons with low support requirements **and 2 to 10 times** more for persons with high support requirements.

Mostly persons with complex medical conditions have the highest range of costs due to the required health care.

Proportion of categories of goods and services required

Human assistance consumes the major proportion of goods and services irrespective of the level of support and particularly high among those with high support requirements.

This is followed **by assistive devices** people with physical impairments, multiple disabilities, complex medical conditions, deaf blind people

The cost of **health-related products and services, therapeutic services** are identified to be high among people with high support requirements particularly among people multiple disabilities, specific learning disabilities and people with intellectual impairment.

Medical costs are highest among persons with complex medical conditions

Transportation is yet another cost that cuts across persons with disabilities and high among persons with physical impairments and persons with multiple disabilities compared to other groups of persons with disabilities.

Government's efforts in ensuring goods and services

0 to 30% of the goods and services required. Highest (30% approximately) coverage for persons with physical and visual impairments.

Government of Tamil Nadu covers **20 to 30% of the WHO list** of priority assistive devices.

Cost incurred by families

Families take a lot of responsibility in **ensuring** the goods and services that are required by their children and by absorbing the cost of services like child care and personal assistants that **is not available or affordable**.

A large proportion of goods and services required are **either not accessible or affordable**.

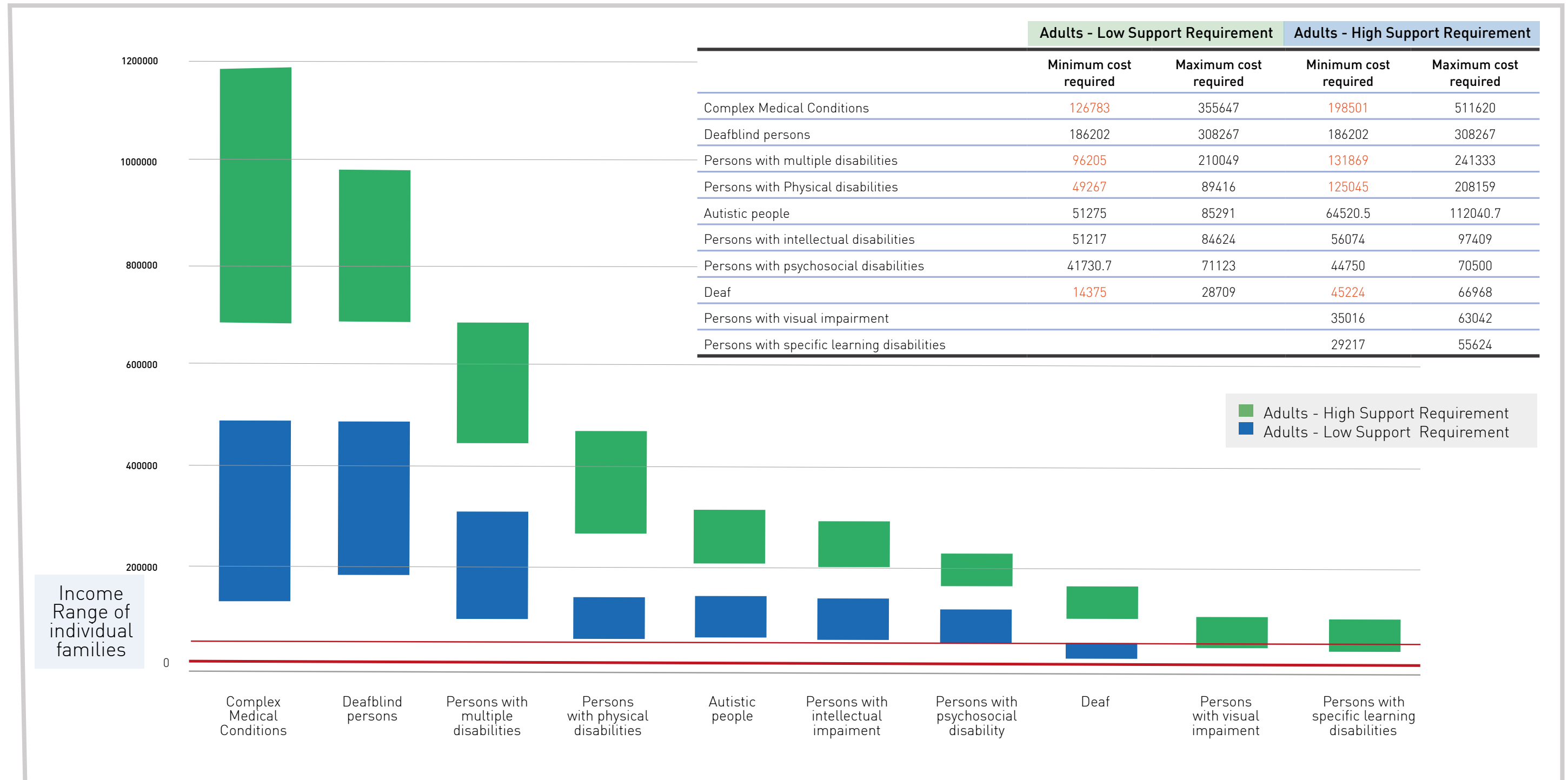
Range of costs of goods and services required by the diversity of persons with disabilities for full and effective participation

Figure 2.1 explains the cost of goods and services required by adults with disabilities to participate in activities across various domains of life, such as home and family, education, employment, leisure and community decision making processes.

1. Considerable cost differences could be observed between people with low support and high support requirements across all the constituencies of persons with disabilities.
2. The range of costs is between Rs. 1,26,783 – Rs. 3,55,647 and Rs. 14,375 – Rs. 28,709 for persons with disabilities with low support requirements and between Rs. 1,98,501 – Rs. 5,11,620 and Rs. 29,217 – Rs. 55,624 for those with high support requirements.
3. The range of costs is the highest among persons with complex medical conditions with both low and high support requirements.
4. The highest difference in the range of costs between persons with high support and low support requirements could be observed among persons with intellectual impairments.

Cost of goods and services varies based on the nature of impairment and the level of participation. Highest cost observed among persons with complex medical conditions followed by deafblind people.

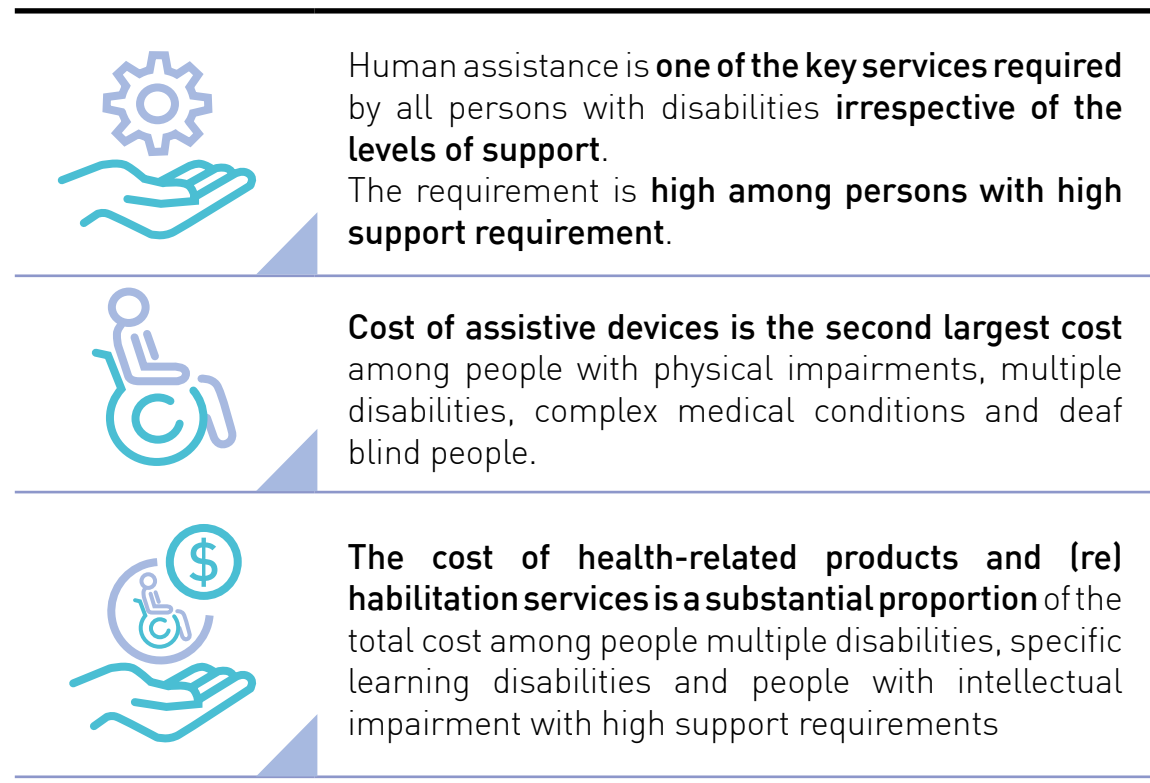
Figure 2.1: Range of cost of goods and services required



“Child care cost, cost of accessing different soft wares for participating in work and community life, managing our finances increases our living expenses though we identify ourselves as persons with low support requirements. However, the cost varies depending on our participation levels.”

As shared by a person with specific learning disability during the FGD

Figure 2.2 highlight the categories of goods and services required for participating and performing diverse activities across various domains of life.



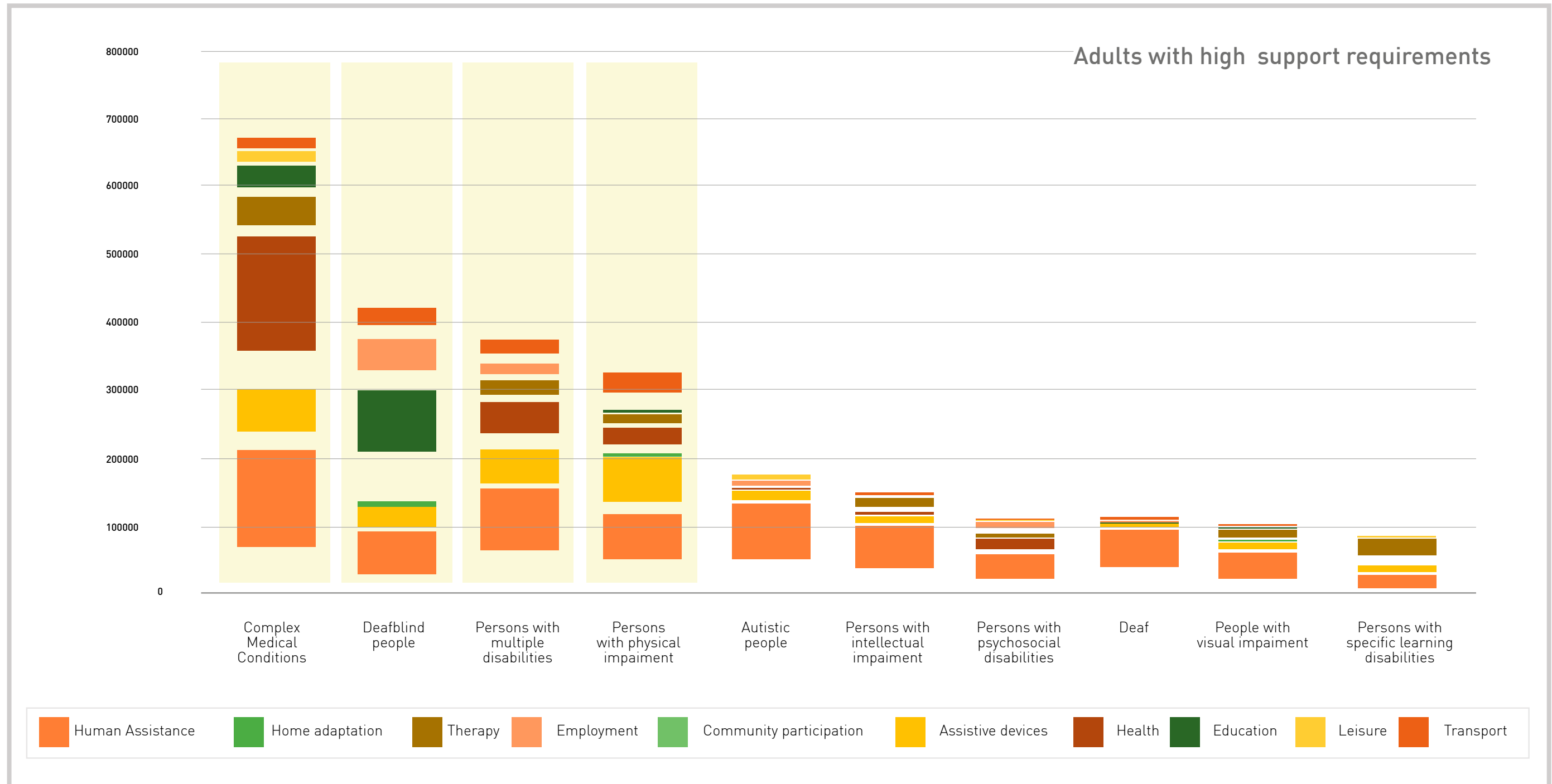
Persons with disabilities also require home modifications/adaptations for effective participation. However, the cost is high among people with low support requirements compared to people with high support needs experiencing extensive restriction in participation.

“Accessible housing is a major issue. It costs Rs. 10,000 to Rs. 15,000 in addition to hire a house in the ground floor with a reasonably accessible toilet. Jobs are available only in the cities. Considering the exorbitant housing and transport cost, I feel it is worth to stay in my village and do whatever I can for a little money.”

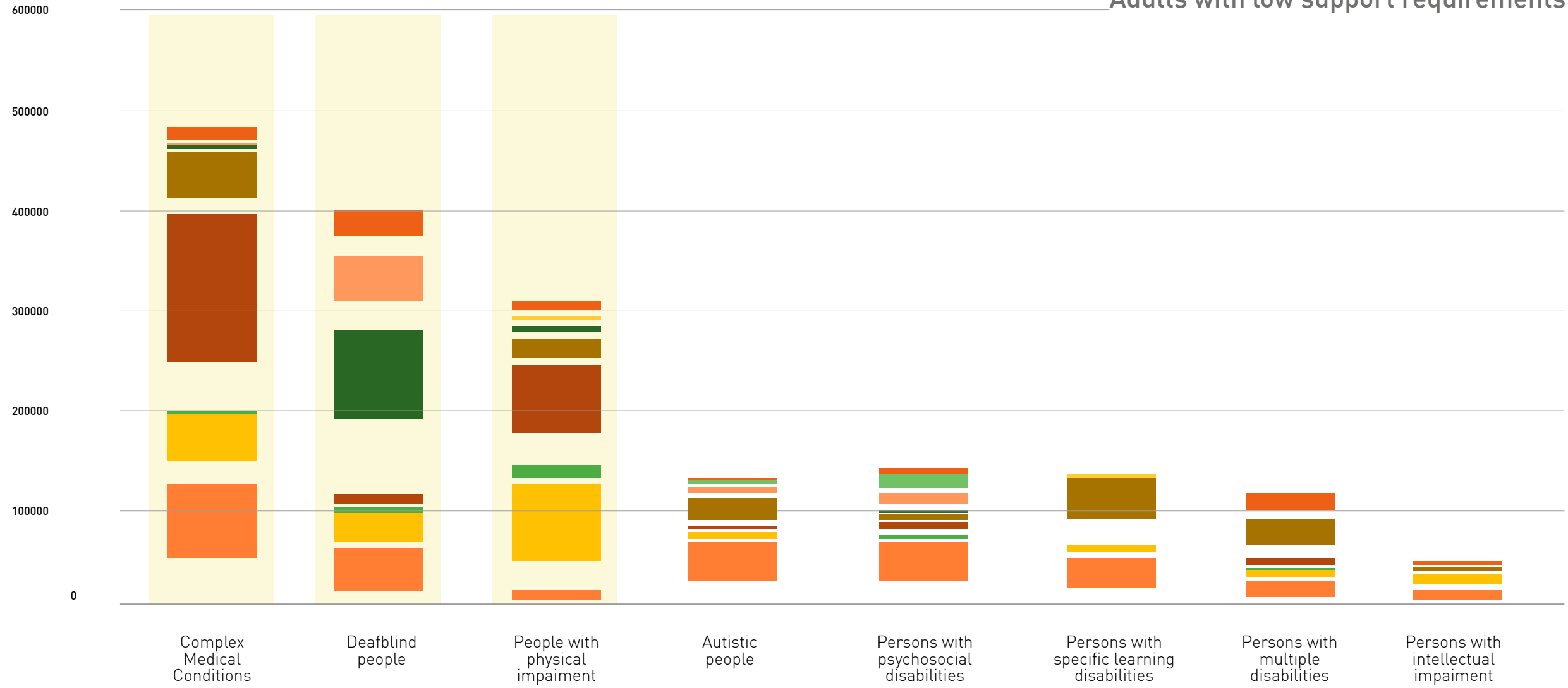
As shared by Kamaraj, a person with physical disability, during the FGD
This sentiment was shared by many individuals across different FGDs conducted for this purpose.

Categories of support requirements and the range of cost vary based on the nature and the degree of impairment, level of participation and the barriers experienced by persons with disabilities

Figure 2.2: Categories of goods and services required



Adults with low support requirements



■ Human Assistance
 ■ Home adaptation
 ■ Therapy
 ■ Employment
 ■ Community participation
 ■ Assistive devices
 ■ Health
 ■ Education
 ■ Leisure
 ■ Transport



“Persons with multiple disabilities and physical disabilities with high support needs in **rural areas** are often stuck at home without any services.

They do not have access to the required products and devices for effective participation.

Their lives remain stagnated once they attain adulthood.

Few parents are exploring income generation activities and skill training services but could not locate one that is accessible for them”.

As observed by the researcher during the FGD interactions

Government’s efforts in ensuring access to goods and services required by adults with disabilities

Measures adopted by the government include implementation of programs such as assistive devices and cash transfer.

Assistive devices

Supply of assistive devices

This program supplies 23 types of devices, such as different types of wheelchairs, tricycles, retrofitted scooters, crutches, orthoses, hearing aids, goggles with filters, Braille watches, magnifiers, Braille readers, augmentative and alternative communication (AAC) devices and canes.

The total cost of this program is Rs. 54.7 crore. This cost is approximately 5% of the overall allocation to DWDA. The per capita coverage is Rs. 464.06.

Choice-based system of assistive device

This pilot program of the government of Tamil Nadu aims to supply products based on the choices of individuals with disabilities. Currently this program covers only five types of mobility equipment, like tricycles and wheelchairs.

The cost of wheelchairs supplied through this program ranges from **Rs. 8000 to Rs. 105000**. Any customisation beyond this limit is borne by the individuals.

	Government’s range Rs.	Expert’s Recommendation
Gap	8000 to Rs. 1,05,000	Rs. 50,000 to Rs. 7,00,000




“We do not know if this program will be scaled up. Currently we are only piloting this program.

We have almost reached a saturation phase in the provision of assistive devices for persons with disabilities. We are implementing the assistive devices program since 1993.

People also procure devices through ADIP schemes of the Union Government and also through civil society.

As shared by a Key Informant interviewed for the purpose of the study




“We generally do not access the government Orthotic aid programs due to **the usual delay of 1.5 to 3 months from the date of application till the supply of device.**

The delay impacts our mobility and our day-to-day functioning. Therefore, we generally procure our devices from the CSOs engaged in the manufacture of such assistive devices or buy from a private supplier.

This actually involves huge cost of travel and accommodation since the suppliers are available only in the cities and not in our villages.”

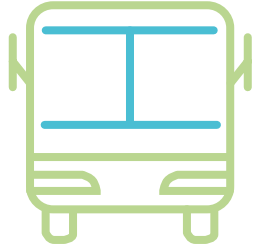
As shared by Hema and Kamaraj during the FGD conducted for the purpose of this study.

Pension



The benefit under the pension scheme is t Rs. 1500/ month. All persons with benchmark disabilities can access this scheme.

Transport allowance / concessions



Provided in few government buses to travel from their place of residence to their place of work or training centres or medical treatment. Persons with visual impairments can avail to travel within a radius of 100kms without any condition in urban areas.

Cash Transfer

Maintenance Allowance



This is a cash transfer program with a benefit of Rs. 2,000 per month for persons with high support requirements.

persons with disabilities accessing this program access programs such as assistive devices but no other programs related to education, employment and skill development. The underlying assumption being incapacity to work.

The benefit under both the programs mentioned above covers only one third of the basic international poverty line. Majority of persons with disabilities rely in these cash transfers for their living due to lack of work and employment. The benefit is the same irrespective of the nature of impairment and the level of support required by the diversity of persons with disabilities.

Table 2.1: Goods and services provided by the government in comparison to actual needs and the WHO list of priority assistive devices¹

Persons with disabilities	Ratio of goods required to what is supplied by the government – Adults	Ratio of services required to what is supplied by the Government - Adults
Persons with Complex Medical Conditions	Covers one out of the 16 required goods (6.2% of the required goods)	Covers one out the 13 services required
Deafblind persons	Covers 2 out of the 10 goods required (20% coverage)	Covers one out of the 8 services required
Persons with Multiple Disabilities	Covers 2 out of the 16 goods required (12.5% coverage of the required goods and 10.5% coverage of WHO list)	8/1Covers one out of the 8 services required
Persons with physical disabilities	Covers 8 out of the 19 goods required (42.1% coverage of the goods required and the WHO list)	2/0 Service required 2, Coverage - 0
Autistic people	Goods required -6 , Coverage - Nothing	7/0 Service required -7, Coverage - 0
Persons with Intellectual Impairments	Goods required -2, Coverage - Nothing	7/1Service required -7, Coverage -1
Persons with Psychosocial disabilities	Goods required 2 , Coverage - Nothing	7/0 Service required – 7, Coverage - 0
Persons with visual impairment	Covers 3 out of the 11 goods required (27. 2% coverage of the required goods and the WHO list)	4/1Covers one out of the 4 services required
Deaf	Covers 2 out of the 9 goods required (22.2% of the required goods and 33.3% of the WHO list)	2/1Covers one out of the two services required
Persons with specific learning disabilities	Goods required -10, Coverage - Nothing	6/0 Services required -6, Coverage - 0

¹ https://apps.who.int/iris/bitstream/handle/10665/207694/WHO_EMP_PHI_2016.01_eng.pdf

Except for a few constituencies of people with complex medical conditions who have support for health care, there is a lack of focus on the provision of services and compensation for services accessed by persons with disabilities. These services include personal assistants, care support, hospitalisation and emergency care, counselling, alternative therapies, etc.

“Most of the mobility equipments supplied by the government such as the wheelchair are not functional, are difficult to carry and involves much higher cost of transport for the person using those wheelchairs.”

As shared by participants with physical disability during the FGDs

Cost to families in procuring the goods and services; availability, accessibility and affordability of the required goods and services

Figures 2.3 & 2.4 highlight that

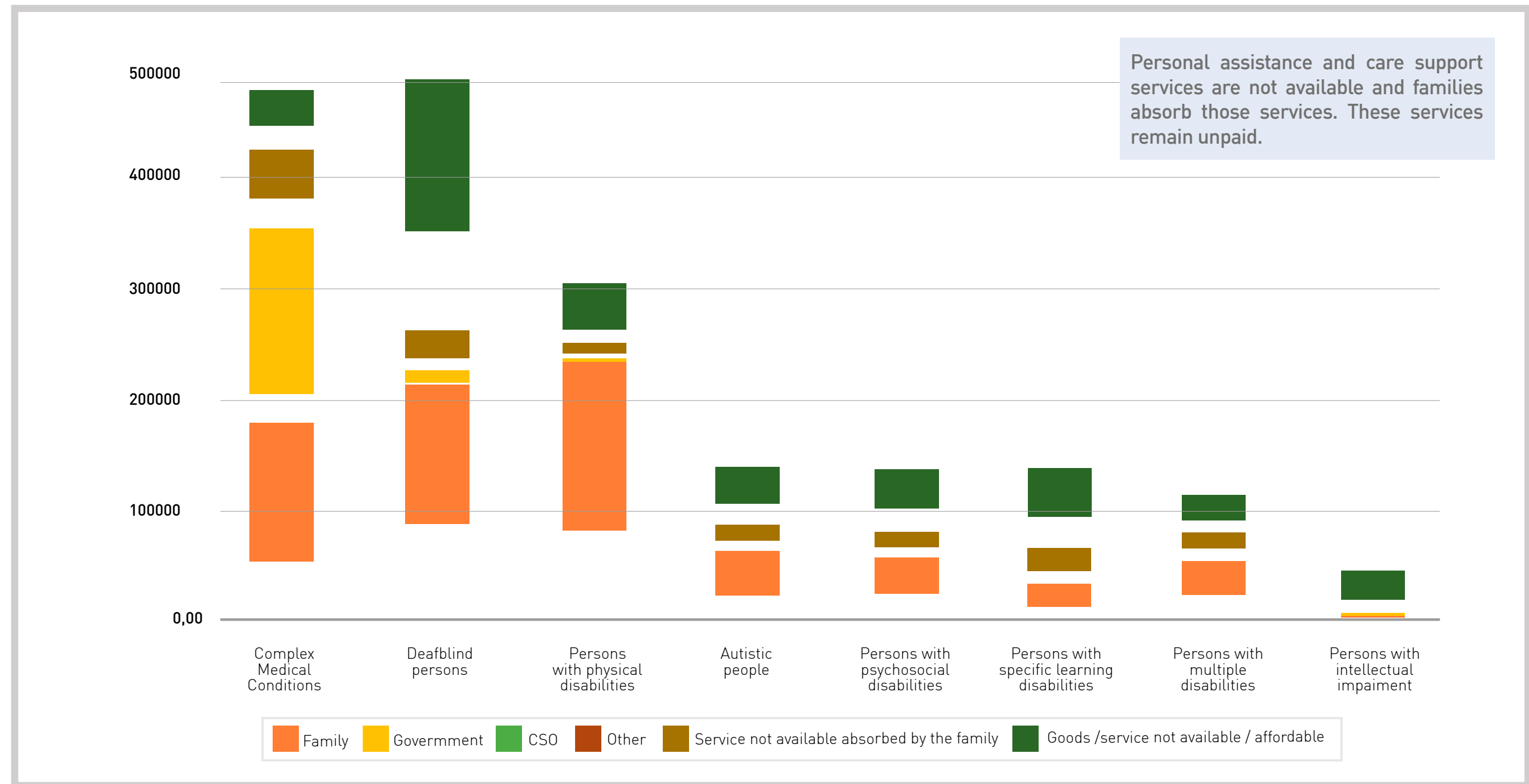
1. Persons with disabilities and their families shoulder almost 70 to 80% of the cost of the goods and services required irrespective of the level of support. The higher the level of support, the higher the cost to the families.
2. The government's compensation covers between 0.1% to 8% of the overall costs incurred by persons high support needs (highest for people with complex medical conditions and the lowest for deafblind people and persons with psychosocial disabilities).

Key Observations from FGDs

- Families bear the majority of costs related to personal care support and health care for persons with multiple sclerosis and parkinsonism.
- Personal assistant services and other forms of support services such as nursing, child care services, services of job coaches, tactile interpreters, sign interpreters, etc. are not available.
- Families usually provide physical support to help persons with disabilities perform day-to-day activities.

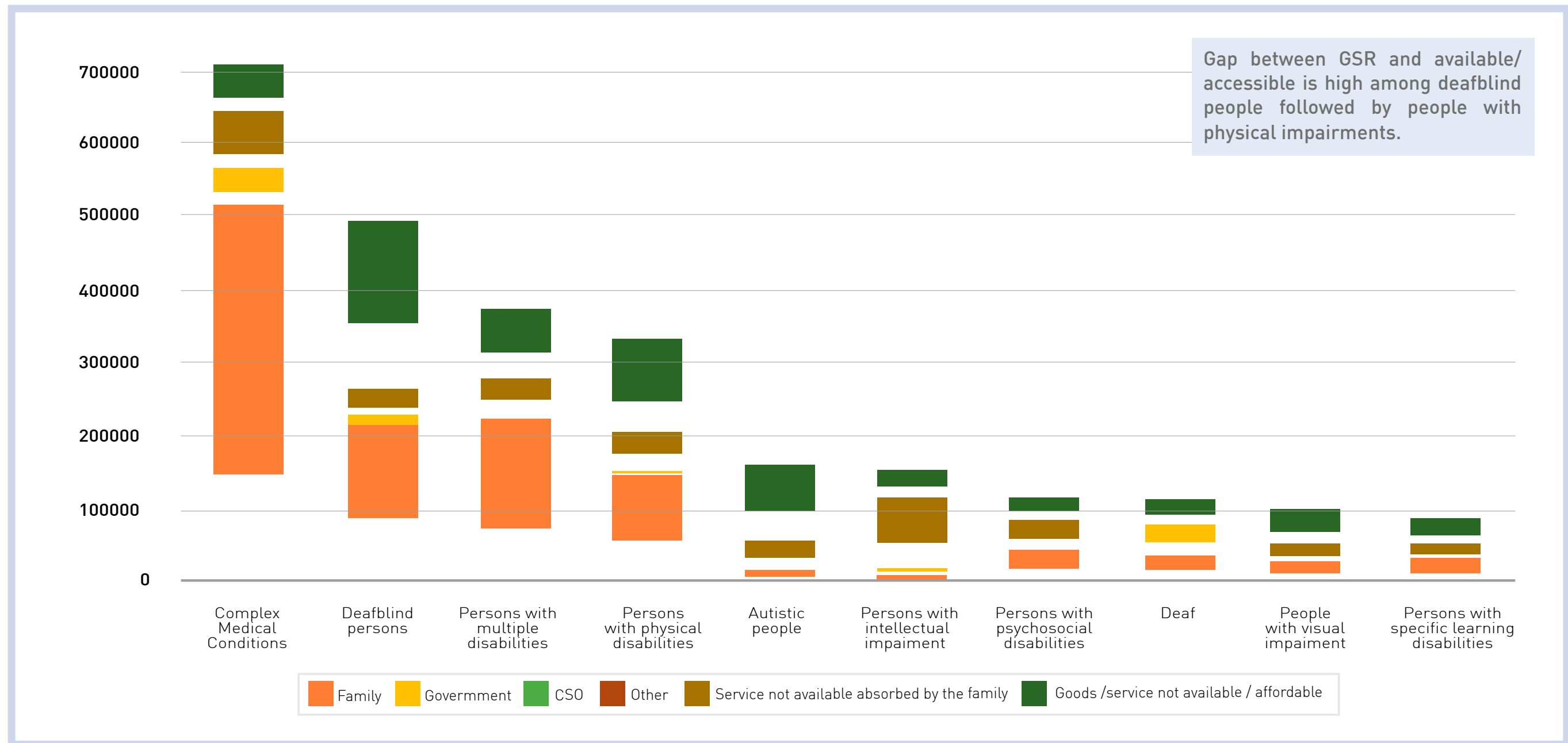
Persons with disabilities and their families procure majority of the goods and services required out of pocket.



Figure 2.3 Cost to the families - Adults with low support requirements



Cost to families increases for persons with high support requirements and wide gap between goods and services required but not available could be observed.

Figure 2.4 Cost to families / individuals with disabilities - Adults with high support requirements



	<p>Both my children have muscular dystrophy. My elder son passed away few years back and my younger son is 18 years old.</p> <p>I am his primary support person. I also take care of the family. My husband is the only earning member.</p> <p>I support my son in all his daily routine and sometimes support his rare outing plans.</p> <p>My son needs skill training, exposure to latest developments in computer-based work. I hope this will help him to engage in a gainful employment.</p> <p>After attending this discussion, I feel if my son has a PA, he will be able to participate in all activities better. Probably I am limiting his opportunities since my time is shared between too many activities. We do not have any leisure time activity either due to the support required and other logistic issues.</p> <p style="text-align: right;">As shared by a parent during one of FGDs</p>
	<p>The government provides powered wheelchair for us. Apart from the regular powered wheelchair I need a sports wheelchair since I am a basketball player.</p> <p>I have to import a second-hand wheelchair from other countries. I need sports cushion, gloves and other products that support my participation in sports. But these are expensive and mostly not available.</p> <p>This limits my participation in the sport and my performance.</p> <p style="text-align: right;">As shared by a participant in the FGD for people with physical disabilities</p>

	<p>Mostly people with psychosocial disability with high support requirements may not want to participate in daily life activities or work.</p> <p>They may want to remain with themselves so the cost could be on services such rehabilitation, health and care support to some extent. These services are limited to cities and not so much in rural areas.</p> <p>However, the range of support required by people with low support requirements range from educational support, peer support in jobs, leisure and socialisation and some forms of yoga, meditation and so on. All of them would involve cost. None of this is available due to stigma.</p> <p style="text-align: right;">As shared by Punitha Suresh, experiential expert, expert group member</p>
	<p>Most deafblind people face immense difficulty as they lost their vision or hearing later in life.</p> <p>It could be observed that all the men had support from the women in their lives - their wives or mother Learning about available solutions and learning how to use technology to assist access mostly happened through friends or family (based on a survey).</p> <p>Women faced more barriers to go out, meeting friends, purchasing solutions according to their need.</p> <p>I reached out to 7 men and 3 women for the purpose of this study. All of them spoke of depending on family members and friends for access in pretty much all areas of life.</p> <p>Interpreters do not have exposure and expertise in tactile interpretation. Caregivers (RCI training) have no knowledge of this either.</p>

There are **no training programs and no recognition of the unique nature of the roles of being either a tactile interpreter or an access provider.**

Losing vision when you have grown up deaf and losing hearing when you have grown up blind present tremendous challenges as the second sense is lost later in life when learning is harder and the sense that is lost is the one most relied on for years.

Training programs (the few that exist) are geared to children. **The person may have no idea of any access strategies available for deafblindness.** Many choose to “manage” until they are totally deafblind and go to a hospital to get a disability card so that they get travel concessions.

They are mostly unaware of any other available concessions as unfortunately are **most govt officials who should be helping by sharing this information.**

Most of the schemes are for those with certificates stating blind. If not they do not have access to many of the products such as tactile reader, canes etc., supplied by the government.

As shared by Dr. Namita Jacob, Rehab Expert and Expert group Member for this study



Conclusion & Recommendations

“Once size does not fit all”

Government schemes should address the diversity of needs

Conclusion

The results of this study yielded several strong conclusions:

- ✳ All persons with disabilities, irrespective of their age or the nature of their impairments, require a range of goods and services for full and effective participation in personal and social life.
- ✳ The goods and services required may vary from person to person depending upon the nature and extent of their impairments, the level of support required, the level of participation, the nature of the activity and the barriers they experience.
- ✳ The majority of the cost of procuring goods and services are borne by the family.
- ✳ People in rural areas lack information about the range of goods and services that could lead to participation. Their expectations of available goods and services were limited to the information received through the CSOs and organisations of people with disabilities (OPDs) working in their area. Most often this information pertains to more familiar rehabilitation services and assistive devices.
- ✳ The gap between goods and services required and currently used by individuals with disabilities is high across all constituencies.
- ✳ The government's program contributes less than 3 to 4% of the total cost per month required by the individual for procuring goods and services for participation, except for persons with complex medical conditions (particularly people with blood disorders). In addition, not all persons with disabilities are benefiting from these programs.

- ✳ Government programs such as cash transfers and those providing assistive devices take a one-size-fits-all approach and do not account for the diversity of persons with disabilities.
- ✳ The disability assessment and certification process takes a medical approach and does not seek and document information about the diversity of needs of persons with disabilities.
- ✳ We lack research and data on the goods and services required by persons with disabilities to meaningfully inform policies and programs.
- ✳ A huge gap exists between the WHO list of assistive devices and the government programs that provide assistive devices.
- ✳ Persons with psychosocial disabilities, specific learning disabilities and deafblind people do not seem to benefit from the existing programs.
- ✳ The specific needs of women and girls with disabilities are not considered in the design of government schemes and programs.
- ✳ The intensity of intersectional marginalisation is high among women and girls with disabilities.

Recommendations

<p>Shift the disability assessment and certification process from a medical approach to a bio-social approach.</p>	<p>The current medical approach to assessments does not provide information about the goods and services required by the diversity of persons with disabilities in their current environment.</p> <p>This approach limits budgetary allocation and planning for ensuring the availability, accessibility and affordability of the range of goods and services required by persons with disabilities across their life cycle.</p> <p>Moreover, to improve the implementation of assessments, persons with disabilities should be able to access this process as close to their own community as possible.</p>
<p>Initiate surveys to understand the goods and services required by the diversity of persons with disabilities.</p>	<p>Along with the move towards a social approach, assessments to identify people's difficulties in functioning should include needs assessments/surveys that determine the goods and services necessary, at a personal level, for full participation. This will assist in program planning and with case management.</p>
<p>Develop and implement (re)habilitation services at the community level.</p>	<p>Most people in rural areas do not have a range of rehabilitation programs that cater to the diversity of needs, such as occupational therapy, physiotherapy, speech therapy, mobility orientation and sign language interpretation services.</p> <p>"We had to go to city once or twice a week for accessing occupational therapy for my child. It costs around Rs. 1000 per trip. We used to take the service 4 to 5 times a month, whereas we need [it] at least twice a week. Currently we do not have adequate income due to Covid even to do what we have been doing earlier. It will be useful if we have community level interventions."</p> <p style="text-align: right;">As shared by a parent during the FGD conducted in Tiruvallur</p>
<p>Initiate programs ensuring personal assistants and care services, with specific focus on child care and persons with high support needs.</p>	<p>Almost all persons with disabilities, irrespective of the level of support in their current environment, expressed the need for personal assistant services. However, the existing care givers allowance is very limited in its coverage and benefit.</p> <p>Persons with high support needs require intense support in order to participate in most of the activities of life. With the lack of government programs, family members are currently the primary support for persons with disabilities to do the basic activities of life such as taking a bath, eating, accessing medical care, etc. This also implies that the family loses the income of the primary care giver and their services remain unpaid.</p> <p>To address the economic costs to family and to ensure adequate and appropriate support services, the government should establish a policy for human assistance. This should include a range of programs that allows individuals with disabilities to choose the type of support and hours of services required. For example: personal assistants for care service, mobility assistants, travel assistance, orientation support, etc. The cost of the service can be covered either through an increased allowance or by direct provision of the service.</p>

<p>Ensure adequacy and innovation in the procurement and supply of assistive devices.</p>	<p>The existing government programs cover only 20% of the goods required by the diversity of persons with disabilities and the WHO list of assistive devices.</p>
<p>Expand universal health care to cater to disability specific health care needs and services, such as assistive devices, training, rehabilitation and support services for health care.</p>	<p>The government health insurance program should be expanded to cover all the disability specific health-related costs. Currently, the state health insurance does not address specific health care services required by persons with disabilities, particularly those with complex medical conditions, such as:</p> <div style="background-color: #e1f5fe; padding: 10px; margin: 10px 0;"> <ol style="list-style-type: none"> 1. Medication 2. Care and treatment 3. Products and services needed to prevent secondary impairments and other disability specific needs such as rehabilitation, procurement of assistive devices, etc. </div> <p>Further, hospitalisation of persons with haemophilia and thalassaemia is not covered.</p>
<p>Initiate awareness and sensitisation programs at the community level to inform persons with disabilities and their families about the range of goods and services that could facilitate participation of persons with disabilities.</p>	<p>People in rural areas are often not aware of the availability, innovations and applications of goods and services that could facilitate full and effective participation of persons with disabilities.</p> <p>“Museum of Possibilities”, one of the recent initiatives of the government of Tamil Nadu in partnership with CSO, is a best practice that could be scaled up across all districts/sub-districts to raise awareness about the difference that goods and services could bring in ensuring community living and participation of persons with disabilities.</p>
<p>Disability specific cash transfer programs should ensure universal coverage and adequate benefit.</p>	<p>The benefit has to be designed to ensure income security, compensating for the extra cost of disability across the person’s life cycle. Further, cash transfer programs across sectors must adopt a layered approach.</p>

Full and effective involvement of all persons with disabilities in planning and implementation of programs and policies.

The government of Tamil Nadu currently has committees and boards with representation from organisations of persons with disabilities (OPDs) for planning the implementation of RPDA 2016 and for implementing a few programs under the welfare board.

However, there is no process to:

- a. Train the members on the needs of the diversity of persons with disabilities
- b. Disseminate information to a wider audience of persons with disabilities
- c. Ensure a bottom-up consultative process to effective policy formulation and implementation
- d. Ensure social audit and accountability

The representation is also very limited in including the voices of women and girls with disabilities, and lacks specific representation of children with disabilities.

Annexure 1

Detailed components of goods and services and their costs across the diversity of persons with disabilities

Annexure 1.1 Persons with Multiple Disabilities



As per the RPDA 2016², the term “multiple disabilities” refers to persons with more than one of the specified disabilities mentioned in the schedule of specified disabilities of the Act. The schedule includes deafblind persons under this category of persons with disabilities³. However, for the purposes of this report and based on expert advice, deafblind people are considered as a separate group.

Nearly 7.8% of the population of persons with disabilities in the state are persons with multiple disabilities, as per the Census 2011.⁴

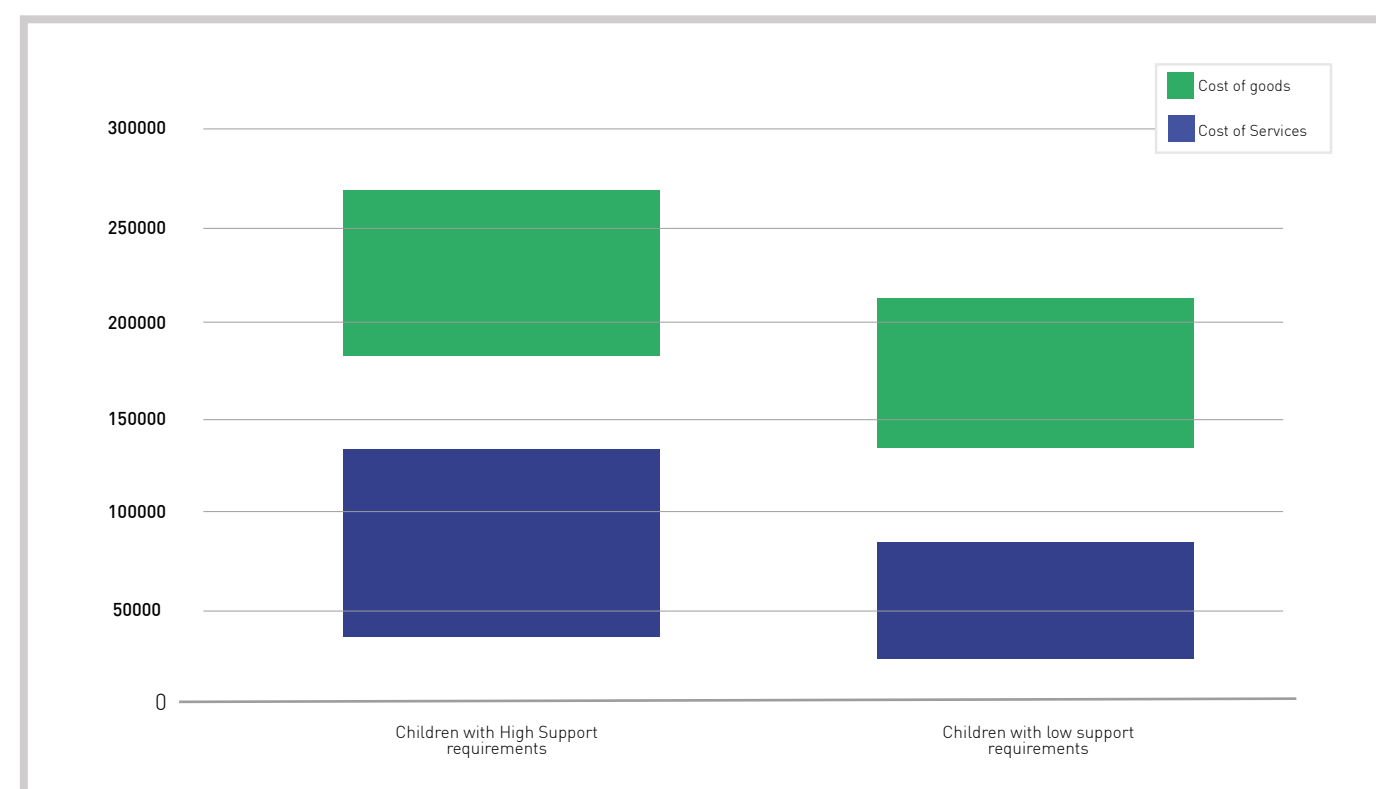
The NSSO survey 2018 does not provide details about the goods and services required by persons with multiple disabilities, nor does it provide any information about the participation levels of persons with disabilities in education, the labour market and other domains of life.

This calls for a need to understand the goods and services required, the range of costs of those goods and services, the out-of-pocket expenses for the families, the prioritisation of government programs, and the gaps between what is used and what is required for full and effective participation.

Children with multiple disabilities

Figure 1.1.1 shows the range of costs of goods and services required by children with multiple disabilities, based on information provided by FGD participants and the research conducted by the expert group members.

Fig 1.1.1: Range of cost of goods and services required by children with multiple disabilities in INR



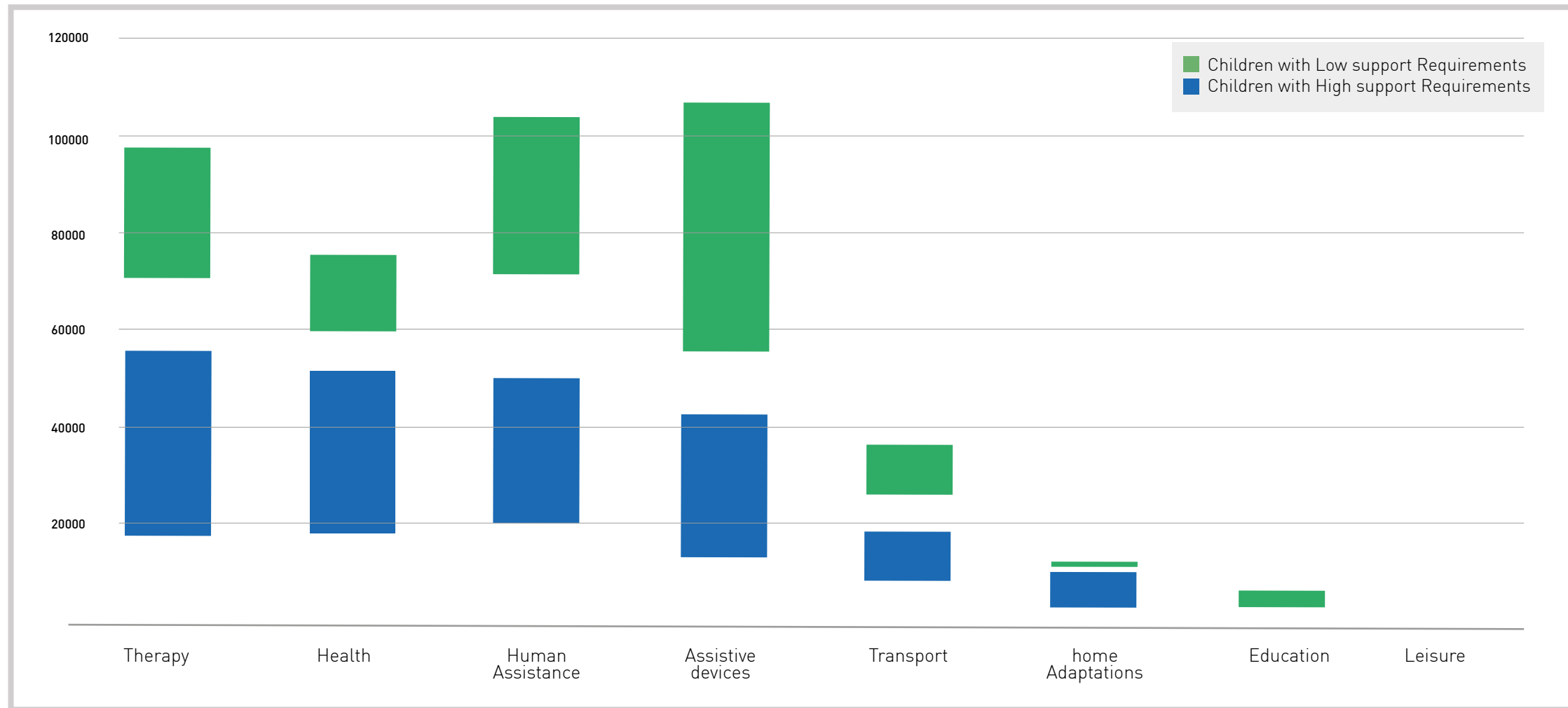
² RPDA 2016

³ ibid

⁴ Census 2011

Figure 1.1.2 shows the break-up of the range of goods and services required by children with multiple disabilities and their range of costs.

Fig 1.1.2 Break up of goods and services required and their cost in INR - Children with multiple disabilities



The cost of therapy, health and human assistance is high among children with high support requirements. Among those with low support requirements, the costs of assistive devices is observed to be the highest, followed by human assistance.

Families in rural areas are at a particular disadvantage due to the lack of rehabilitation and health services within the community. They have to travel to the district headquarters for accessing the services offered by the government. This involves cost of travel for the entire family to support the child, in addition to the cost of care support offered by the members of the family, which is not compensated.

Further, the families are not exposed to the range of assistive devices that could support their child's participation within and outside their homes. In particular, assistive devices (such as wheelchairs) that are supplied by the government are not designed to the needs of children.

As shared by families during the FGDs

Families of children with disabilities undertake responsibility to ensure the children receive services like therapy, health care, child care and the required goods and assistive devices.

Children with high support requirements receive a maintenance grant from the government.

Most families expressed that they rarely go out and that they spend very little time on leisure activities due to exorbitant transport cost and the support required. Families also expressed the need for adapted toys, play equipment, and coaching for different forms of indoor and outdoor games.

Table 1.1.1 Types and costs of products and services required by children with multiple disabilities – high support requirements

Category	Sub Category	Monthly	Once in 6 months	Once in a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Care giver - full time	20000-30000					
Assistive devices	Updated Communication Device						
	Neck Collar	100-500					
	Customized wheelchair				50000-700000		
	KAFO			15000-30000			
	Shoulder Belt		3000-5000				
	Braille Print			3000-5000			
	Braille Stylus & Slate			1000-1500			

Hand Gaiter		1000-3000
Automatic Brush		1500-2000
Specific Shower / Hand Shower		100-1000
Liquid Soap	200-500	
Adapted Spoon		1000-1500
Spectacles		1000-10000
Sipper	100-500	
Walker		2000-5000
Communication Chart	100-500	
Communication Device		35000-100000
Technology enabled glasses that announces people, obstacles		40000-50000
Chest Belt		3000-10000
Magnifier		5000-20000
Hearing Aid		40000-50000
Prosthetic leg		25000-100000
Portable Ramp		15000-25000
Switch adapted toys		5000--15000
Home adaptations		
Toilet Seat		2000-2500
Bathing Stool		500-5000
Cooling bed		3000-15000
hand rails		5000-15000

	Western Closet		
	Custom Made garments		
	Universal remote for appliances at home		10000-15000
	Switch compatible power outlets		5000-20000
	Rounded edges walls and doors		3000-5000
	Hoist		45000-100000
Health	Hygiene products	1000-1500	
	Diapers	3000-5000	
	Seizure Medication	3000-5000	
	Disability health care	3000-5000	
	UTI infection related treatment	500-1000	
	General Health	500-1000	
	Bipap Machine		30000-78000
	Bipap Mask	5800-7000	
	Portable Battery Back up for Bi-pap	500-1000	
	UPS		20000
	UPS service	1000-	
	Gastrostomy PEG method		30000-50000
	PEG Button	8000	
	PEG tube	1000-10000	
	Ryles tube	1000-10000	

	Baclofen pump		300000
	Implantation of Baclofen Pump		40000
	Vision Care	500-750	
	Juvenile cataract surgery		10000 to 35000
Therapy	Physiotherapy	5000-10000	
	Occupational Therapy	5000-10000	
	Speech and Language Therapy	5000-10000	
	Counselling	1000-5000	
	Feeding specialist	1500-3000	
Transportation		8000-10000	

Table 1.1.2: Types and costs of products and services required by children with multiple disabilities – low support requirements

Category	Sub Category	Monthly	Once in 6 months	Once in a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	care giver	20000-30000					
	Scribe	1000-3000					
	A sign language teacher						
	A braille teacher						
Assistive devices	Electrical tooth brush			1500-2000			
	portable toilet						
	Adapted spoon			1000-1500			

Custom made furniture		5000-10000
cup with double handle	500-1000	
Glasses	1000-10000	
Ramp		30000-50000
Portable ramp		5000-15000
Mobile		10000-20000
Alexa	1000-3000	
Accessibility apps	10000-15000	
computer		50000-75000
Switch		
Talking watch	5000-10000	
Tab		25000-35000
Wheel chair		50000-700000
Adapted pen	500-1000	
Adapted plate		1000-1500
Scooter Board		5000-10000
Liquid soap dispenser		
Brush for bathing		
Voice Output Communication Device		35000-100000
Adapted Board Games		
Home modification		
Railings in bathroom		5000-15000
Western toilet		5000-15000

	Hose	100-500	
Health	Hospital visit	500-1000	
	Dentist/ oral care	1500-3000	
	Neurologist	500-1000	
	counselling	1500-3000	
	dietitian	1500-3000	
	pulmonologist	500-1000	
	ophthalmologist	500-1000	
	medication	3000-5000	
	Gynaecologist	500-1000	
	Dermatologist	1000-1500	
	Baclofen pump	3000-5000	
	Implantation of Baclofen Pump	100-500	
	Therapy	OT	3000-5000
PT		5000-10000	
Speech therapy		3000-5000	
Vision therapy		3000-5000	
Chest therapy		3000-5000	
Education		adapted work sheets	1500-2000
	big font books	1500-3000	
	recorder		1500-3000
	Auditory books	3000-5000	

TLM for math	3000-5000
Braille & Stylus	1500-3000
Slant Board	800-1200
Lesson AAC Boards	200-300
Transportation	8000-10000

Not all children with multiple disabilities require all of the goods and services listed in tables 1.1.1 and 1.1. However, these are a representation of a range of goods and services required by the diversity of children with multiple disabilities to be able to participate in different activities both within and outside their homes. The majority of the cost required for participation of children with multiple disabilities is borne by the families.

Figures 1.1.3 and 1.1.4 highlight the costs to the family and the costs of goods and services that are either not available or accessible for children with multiple disabilities.

Figure 1.1.3: Cost of goods and services to families and cost of goods and services required but not available - Children with high support requirement

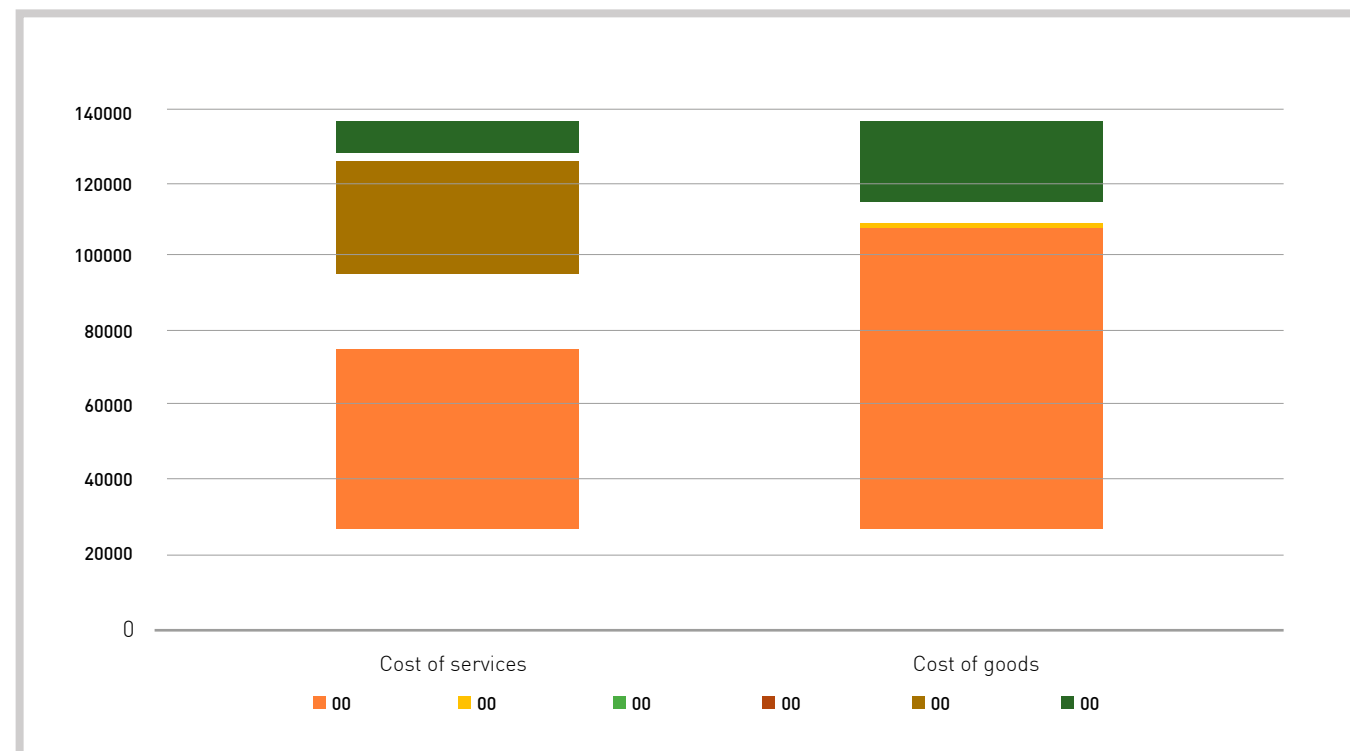
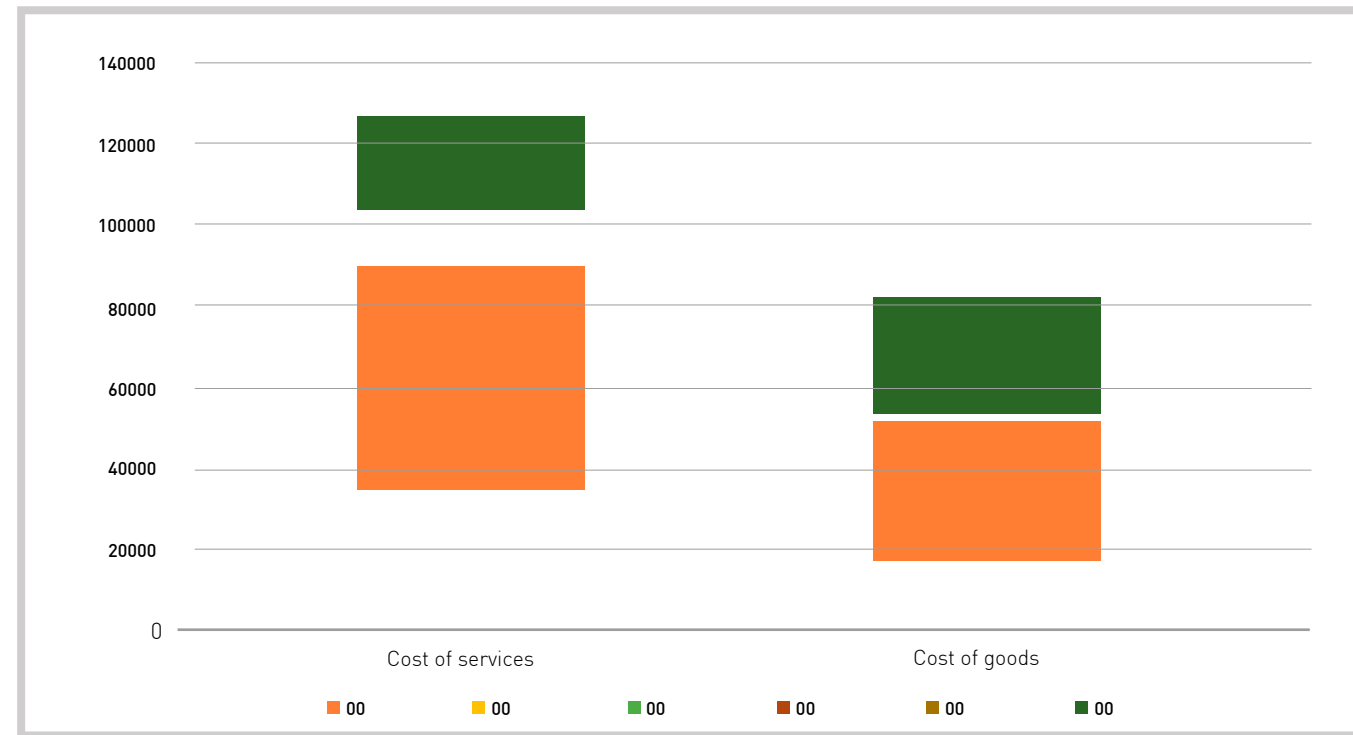


Figure 1.1.4: Cost of goods and services to families and cost of goods and services required but not available-Children with Low support requirement



The cost of goods and services that are required but not available is high irrespective of the level of impairment. In particular, services such as occupational therapy, speech therapy, counselling and other forms of alternative therapeutic services are not available as per the requirement in urban areas, and they are rarely available in rural areas.

The stories of children with disabilities explain the various needs in depth depending upon their extent of impairment and the range of support they require.



Story of Jannath

(person with visual impairment and spinal cord injuries)

Jannath is a 13-year-old girl who uses a wheelchair for mobility. She lives with her parents and has a younger sibling who is 6 years old. Her father is working as an electrician and is the only earning member of the family. Their monthly income ranges between Rs. 19000 to 20000 per month.

Jannath is studying in Little Flower Convent, a school for children with visual impairment. The school takes care of education-related expenses. The family lives in the city because of the services that are available there for Jannath.

Jannath requires the following goods and services for her participation:

- ▲ 1. Care support services for self-care, education and for accessing health care
- ▲ 2. Transportation for accessing school and health care
- ▲ 3. Assistive devices
- ▲ 4. Education
- ▲ 5. Health care

Jannath's mother is her primary care giver. Jannath needs assistance for at least eight hours a day, including during school hours. Jannath receives the maintenance grant of Rs. 2000 per month as social protection from the state government (as shown in below adjusted for service).

Costs for Jannath

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Human assistance	Care giver	21000				
Transportation	Auto	6500				

Assistive devices	wheelchair		8000
	Audio recording devices		6000 (twice a year)
	Vision Aid		50000
Education	Note books	1000	
	Braille Stylus and Slate		10800 (thrice a year)
Health Care	Diaper	3800	
	UTI related care		5000(twice a year)

Total Cost / Who Provides / Availability

Category	Sub- Category	Goods monthly	Services monthly	Family	Government	CSO	Cost required	Cost incurred
Human Assistance	Care support		21000				21000	Service NA
Assistive devices	wheelchair	222				100%	222	
	Audio recording device	500					500	Goods not purchased yet
	Vision Aid	1389					1389	Goods NA
Education	Note Book	1000					1000	1000
	Braille Stylus & slate	900					900	900
Transportation			6500				6500	6500
Health care	Diaper	3800					3800	3800
	UTI related care		416				416	416
Total monthly cost		6811	27916				35727	12616

Share of Costs

Nature of Expense	Family	Government	CSO	Service Not Available absorbed by the family member	Goods Not affordable & accessible	Total
Goods	5700	2000	222	19000	1889	28811
Service	6916					6916
Total	12616	2000	222	19000	1889	35727
Percentage	35.3	5.6	0.6	53.2	5.3	100

Adults with multiple disabilities

The range of total costs of goods and services required by adults with multiple disabilities is shown in Figure 1.1.5:

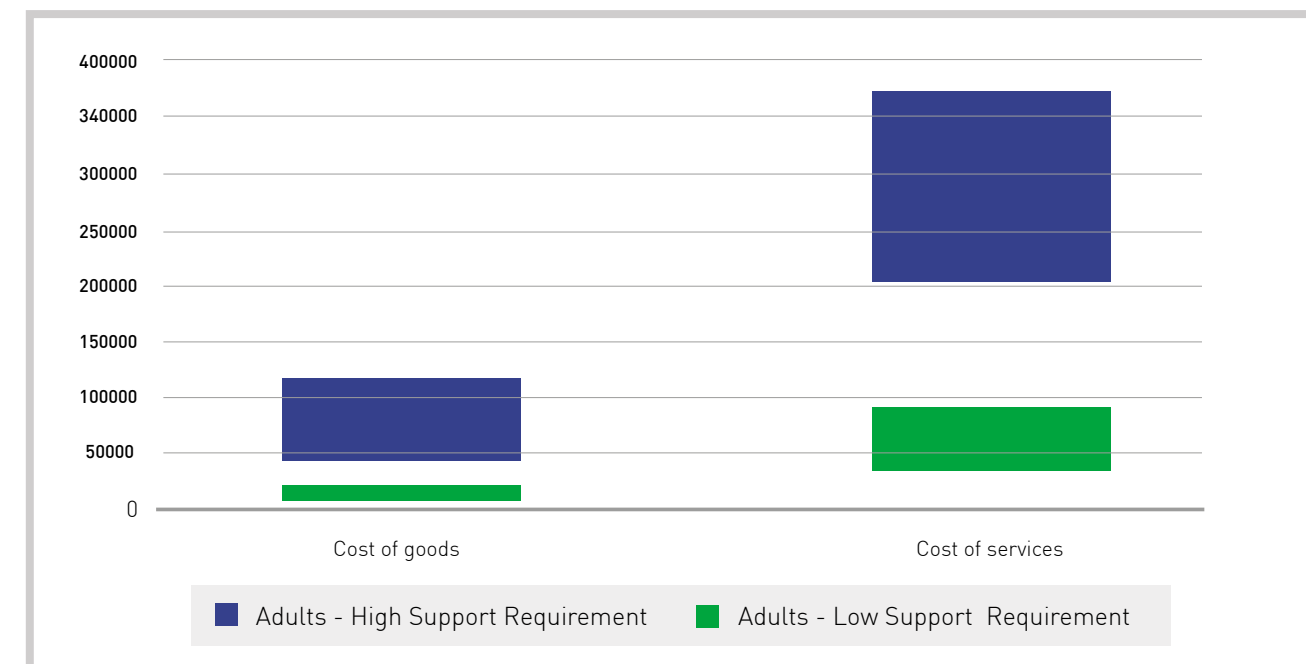
▶ Adults with high support requirements:

- * Rs. 112416 to Rs. 168042 per month for services
- * Rs. 19453 to Rs. 73291 per month on goods

▶ Adults with low support requirements:

- * Rs. 33792 to Rs. 56500 per month on services
- * Rs. 7938.7 to Rs. 14623 per month on goods

Fig 1.1.5 Range of Cost of goods and services required by adults with multiple disabilities in INR



The stories of Sriram and Sunder Ram (persons with high support requirements) and Adhieswar Ram (a person with low support requirements) highlight the range of goods and services and the diversity of those needs. This also highlights that one size doesn't fit all.



Story of Sriram and Sunder Ram

(persons with multiple disabilities, high support requirements)

iblings Sunder Ram and Sriram, both aged 36 years, run their own leaf cup production unit and a gift shop called Twin Twigs. They experience multiple disabilities and use wheelchairs for mobility. They live with their parents; their personal assistant (PA), Karthik, who is also a partner in their business; and their two pet dogs.

Sunder Ram and Sriram earn money for their day-to-day expenses. However, for disability specific costs they rely on their parents. They receive the maintenance grant of Rs. 2000 each from the state government.

Both Sunder Ram and Sriram love to travel and want to have more leisure time. However, due to the cost of transport they restrict their leisure trips to only once a week.

They require the following goods and services:

- ▲ 1. Personal assistance
- ▲ 2. Wheelchair both for their shop and at home. Sunder Ram requires a therapeutic Otto bock wheel chair, whereas Sriram is comfortable in his wheelchair that costs around Rs. 25000. However, he expressed that he needs a PA throughout the day.
- ▲ 3. Communication facilitator – plain language
- ▲ 4. Transportation
- ▲ 5. Support for financial decisions
- ▲ 6. Home and manufacturing unit adaptations and modifications

Costs for Sriram

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Human assistance	Personal Assistant (24 hours a day)	25000				
	Cook	7000				
Assistive devices	Ottobock wheelchair				150000	

Costs for Sunder Ram

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Human assistance	Personal Assistant (24 hours a day)	25000				
Assistive devices	Therapeutic Ottobock wheelchair				10.00.000	
Common expenses for both Sundar and Sriram						
Transportation	Petro for car	2000				
Employment	Maintenance of adaptation to the machines		80000			
	Procuring accessible machine					10,00,000
Home modifications	Bathroom adaptation					100000

Total Cost / Who Provides / Availability

Category	Sub- Category	Goods monthly	Services monthly	Family	Government	Cost required	Cost incurred
Human Assistance	PA		50000	92%	8%	50000	50000
	Cook		7000			7000	Service NA
Assistive devices	Wheelchair	20833		50%		20833	10416.7
Transportation			2000	100%		2000	2000
Employment	Machine maintenance	6666.7		100%		6666.7	6666.7
	Adaptation to the machine	4000		100%		4000	4000
Total		31499.7	59000			90499.7	73083.4

Share of Costs

Nature of Expense	Family	Government	CSO	Service Not Available absorbed by the family member	Goods Not affordable & accessible	Total
Goods	21083.4				10416.3	31499.7
Service	48000	4000		7000		59000
Total	69083.4	4000		7000	10416.3	90499.7
Percentage	76.33	4.41		7.73	11.51	100



Story of Adhieshwar Ram

(adult with multiple disabilities, low support requirements)

Adhieshwar Ram is a person with cerebral palsy, low vision and specific learning disabilities. He is 27 years old and lives with his mother in Chennai. They have migrated from Coimbatore, a city in one of the western districts of Tamil Nadu.

Adhieshwar has a diploma in visual communication and is currently looking for a job.

Their current monthly income is Rs. 24000, which includes the salary of Adhieshwar’s mother and the support from their extended family members and relatives.

Adhieshwar requires the following support:

- ▲ 1. Services of a personal assistant for travel, reading and writing
- ▲ 2. Support for making his food
- ▲ 3. Assistive devices
- ▲ 4. Health care for seizure and dietary food
- ▲ 5. Transportation

Adhieshwar is not accessing the pension program because of the procedures involved and the lack of support in accessing the benefit.

Costs for Adhieshwar Ram

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Human assistance	Personal Assistant for few hours a day	18750				
Transportation	Auto	3000				
Assistive devices	Spectacles		18000			

	Digital watch		3000
Health Care	Blood test		750
	Medicine (Seizure, Ayurvedic medicines for skin related issues due to medication)	11500	
	Scan & EEG		5000
	Consultation		6000
	Nutrition	1600	

Total Cost / Who Provides / Availability

Category	Sub- Category	Goods monthly	Services monthly	Family	Government	CSO	Cost required	Cost incurred
Human Assistance	Personal Assistant for few hours a day		18750				18750	NA
Assistive devices	Specs	1500		100%			1500	1500
	Digital watch	250		100%			250	250
Transportation	Auto		3000	100%			5000	3000
Health care	Blood test		63	100%			63	63
	Medicine (Seizure, Ayurvedic medicines for skin related issues due to medication)	11500		100%			11500	11500
	Scan & EEG		417	100%			417	417
	Consultation		500	100%			500	500
	Nutrition	1600		100%			1600	1600
Total monthly cost		14850	22730				39580	18830

Share of Costs

Nature of Expense	Family	Government	CSO	Service Not Available absorbed by the family member	Goods/ SERVICES Not affordable & accessible	Total
Goods	14850					14850
Service	3980			18750	2000	24730
Total	18830			18750	2000	39580
Percentage	48%			48%	5%	

In both stories, the individuals and their families expressed that although almost all of the required goods are available, they could not afford them.

Customisation of regular use products to suit the individual requirements and maintenance services for assistive devices has been a cause of concern for most of the individuals with disabilities.

The absence of personal assistant services, the cost of which is usually absorbed by the family members, limits the participation of individuals with disabilities.

Figure 1.1.6 highlights the range of goods and services required to perform day-to-day activities, and those required specifically in the context of education, employment, leisure and sport activities.

fig 1.1.6 Break up of goods and services required by adults with multiple disabilities and their costs in INR

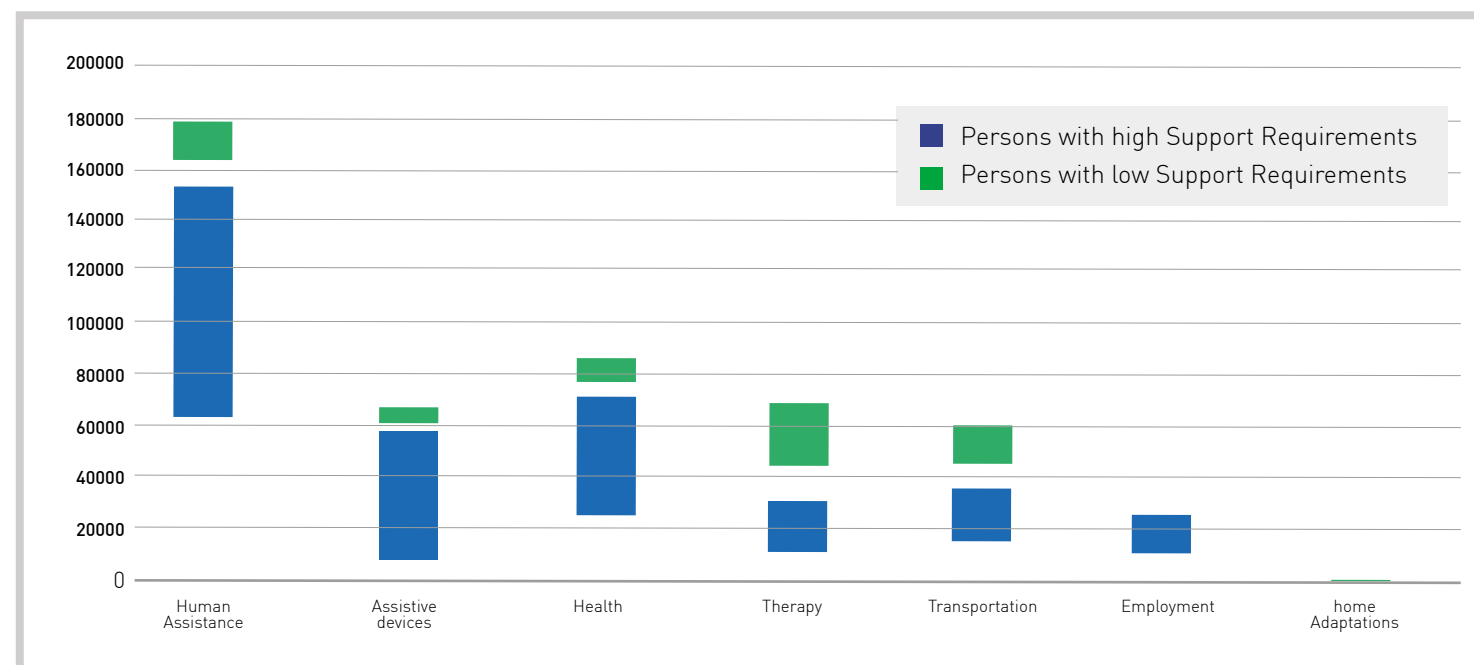


Table 1.1.3: Types and costs of products and services required by adults with multiple disabilities – high support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a Year	Once in 2 or 3 years	Once in 5 Years	Once in a life time
Human Assistance	PA	25000-30000					
	Home health nurse	15000-25000					
	Scribe	3000-5000					
	Sign Language interpreter	5000-10000					
	Executive assistant at work place	15000-20000					
Assistive devices	Customised Wheelchair					50000-700000	
	voice output device						
	Alexa		1000-3000				
	Orthotic Aids					15000-30000	
	urine bottle		100-500				
	Remote			5000-15000			
	Switches						
	water bed			3000-5000			
	Custom made furniture					5000-15000	
	Glasses			1000-10000			
	Adapted pen	100-500					
	Portable Ramp				5000-15000		
	Arch Shoes			500-1000			

	Adapted spoon	1000-1500
	Heavy Plate	500-1000
	Smart phone	15000-30000
	Laptop	50000-75000
	Switch compatible power outlets	5000-20000
	Switch compatible electronic gadgets	20000-50000
	Refreshable Braille display	45000-200000
	Magnifier	5000-50000
	Adapted Board Games	
Transportation		15000-20000
Health	Hospital visit	1000-1500
	corrective surgery	50000-100000
	neurologist/ seizure	1000-1500
	Physicians	500-1000
	counselling	3000-5000
	weight management	3000-5000
	Hospitalisation\	50000-100000
	Emergency care	100000-150000
	Medications	5000-10000
	Bipap Machine	500-1000
	Bipap Mask	500-1000
	Portable Battery Backup for Bipap	500-1000

	UPS	100-500
	UPS service	100-500
	Gastrostomy PEG method	500-1000
	PEG Button	1000-1500
	PEG tube	100-1500
	Ryles tube	100-500
	Baclofen pump	3000-5000
	Implantation of Baclofen Pump	100-500
Therapy	Physio therapy	5000-10000
	Occupational Therapy	3000-5000
	Chest Therapy	3000-5000
Employment		
	Job Coach	10000-15000

Table 1.1.4: Types and costs of products and services required by adults with multiple disabilities – low support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a Year	Once in 2 or 3 years	Once in 5 Years	Once in a life time
Human Assistance	PA	10000-15000					
Assistive devices	High Quality hand functioning splint				1250-3000		
	Walker				2000-5000		
	Adapted Foot wear			1500-3000			

	quality hearing aid		45000-65000
	Spectacles	1000-10000	
	Smart Phone		15000-30000
	Grab Bar		5000-15000
	Water jet/ bidet		3000-5000
	Brush	1000-1500	
	Device for Soap	100-500	
	Hand Shower	100-500	
	Adapted Tumblers	2500-3500	
	Adapted Water Bottle	150-500	
Home adaptation	Western Closet		5000-15000
Transportation		10000-15000	
Health	Seizure Medicine	3000-5000	
	Specific Food	1500-3000	
	General Health issues	500-1000	
	UTI	1000-1500	
	Cardiac Issues		1500-3000
Therapy	Physiotherapy	3000-5000	
	Gym	5000-10000	
	Swimming	5000-10000	

Services such as personal assistants, sign language interpreters and job coaches are not available, though required by most of the individuals with high support requirements. Family members usually absorb the job of personal assistants to some extent.

The lack of availability of services denies a person from participating in all activities of life and restricts them to the bare minimum of maintaining their personal care and hygiene.

Health care services such as counselling, occupational therapy and other activities for a healthy life like swimming, gym, etc., are not affordable for people in urban areas and are not available for people in rural areas.

Figures 1.1.7 & 1.1.8 highlight the share of costs borne by the individual and families and the costs of goods and services not available / affordable for those who require them.

Figure 1.1.7: Costs of goods and services incurred per month, costs of goods and services required but not available - Adults with high support requirements

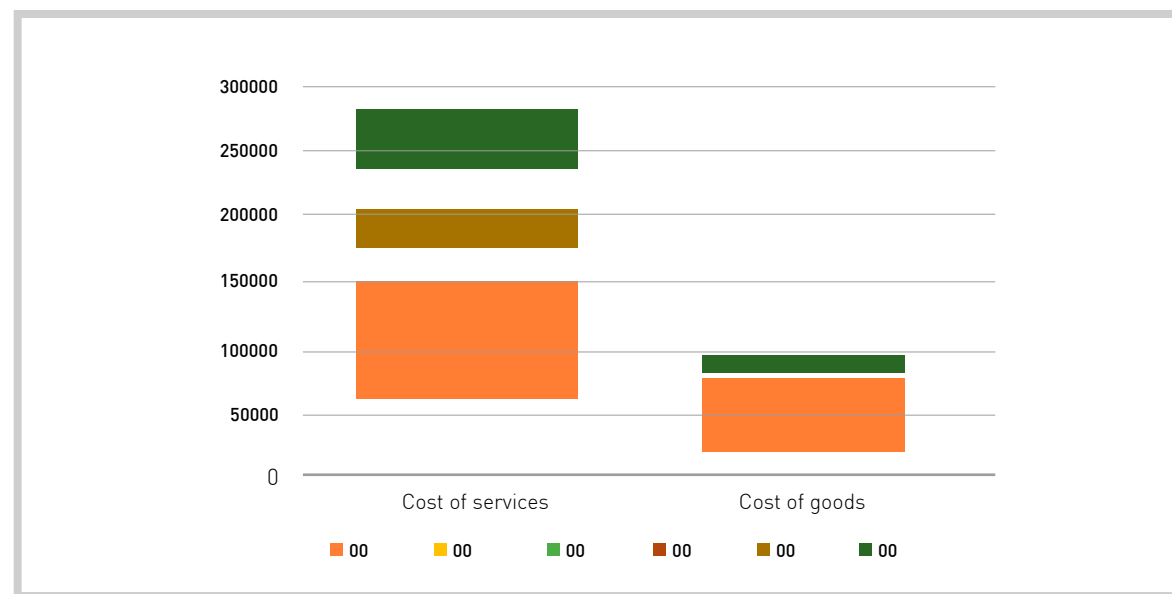
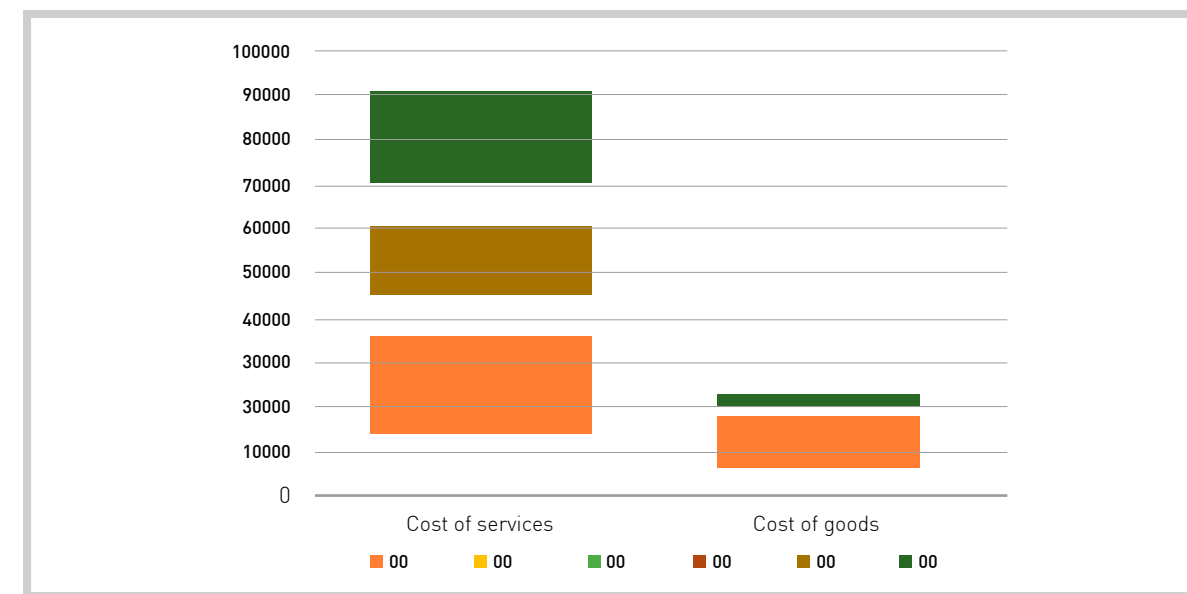


Figure 1.1.8: Costs of goods and services incurred per month, costs of goods and services required but not available - Adults with low support requirements



Most of participants in the FGDs access the government pension of Rs. 1500 per month. However, this is observed to be too little to support both:

- a. the huge monthly cost incurred or required by the individual for full and effective participation.
- b. basic income for the individual, given that almost all of the individuals and family members present in the FGDs expressed a lack of engagement in any income-generating activity.

Annexure 1.2 Persons with Intellectual Impairment

8.5% of the population of persons with disabilities in the state are persons with intellectual impairment.⁵

Nearly 45% of children ages 5 to 19 years with intellectual impairment have reported not attending any educational institutions.⁶

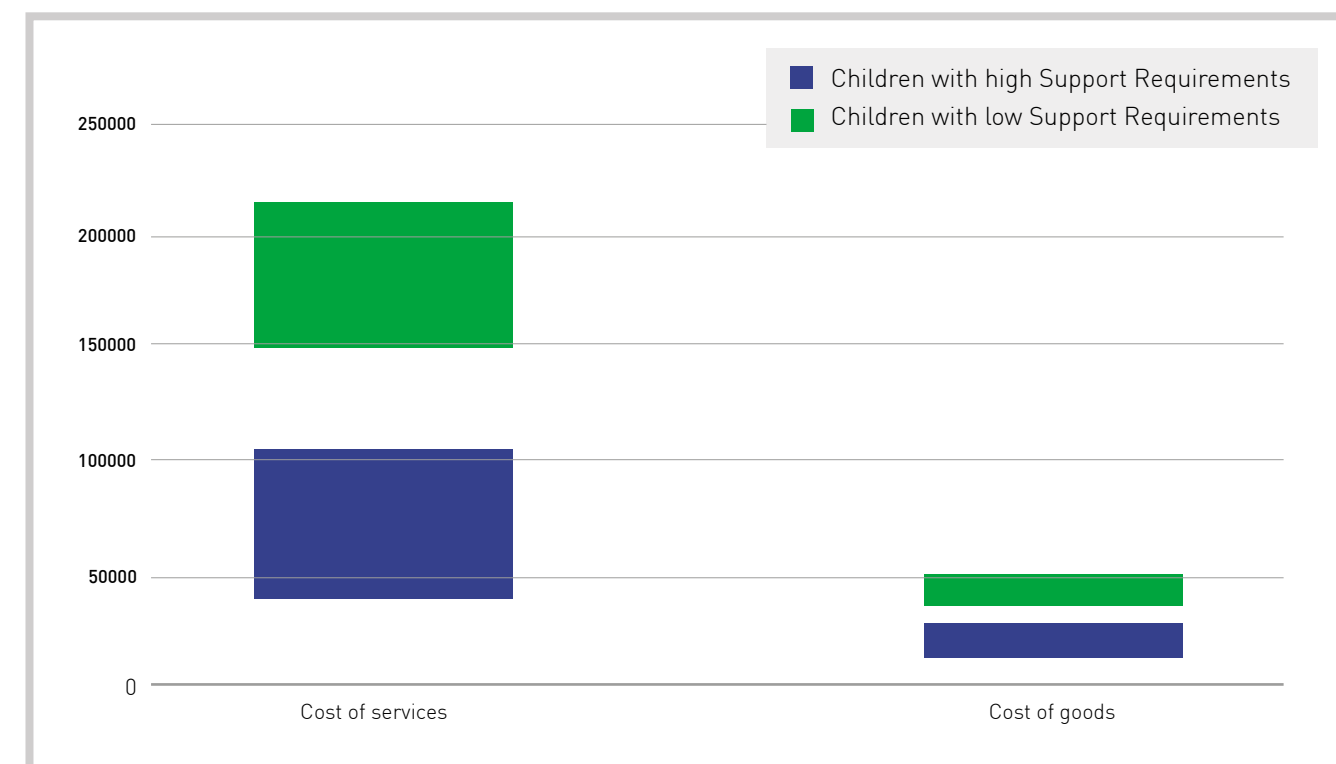
Nearly 69% of persons with intellectual impairment form part of the non-worker population.⁷

The key government programs that benefit persons with intellectual impairment include the maintenance grant of Rs. 1500 per month and the travel allowance to access health or rehabilitation centres.

The following sections highlight the range of goods and services required by persons with intellectual disabilities to participate across activities of life.

Children with intellectual impairment

Fig 1.2.1 Range of cost of goods and services required by children with intellectual impairment in INR



“My son is 19 years old. I am concerned about his future when I cannot support him or when I am no more. He supports me in the day to day activity like fetching water, house hold work etc., but he does not have any work or income that could sustain him and he needs support in decision making. There is no job in the neighbourhood. The specific training initiatives so far as has not resulted in any gainful employment.”



As shared by Ms. Malathi, parent of a person with intellectual impairment, during the FGD

⁵ Census 2011

⁶ Census 2011

⁷ ibid

Fig 1.2.2 Break up of goods and services required by children with intellectual impairments and their costs per month in INR

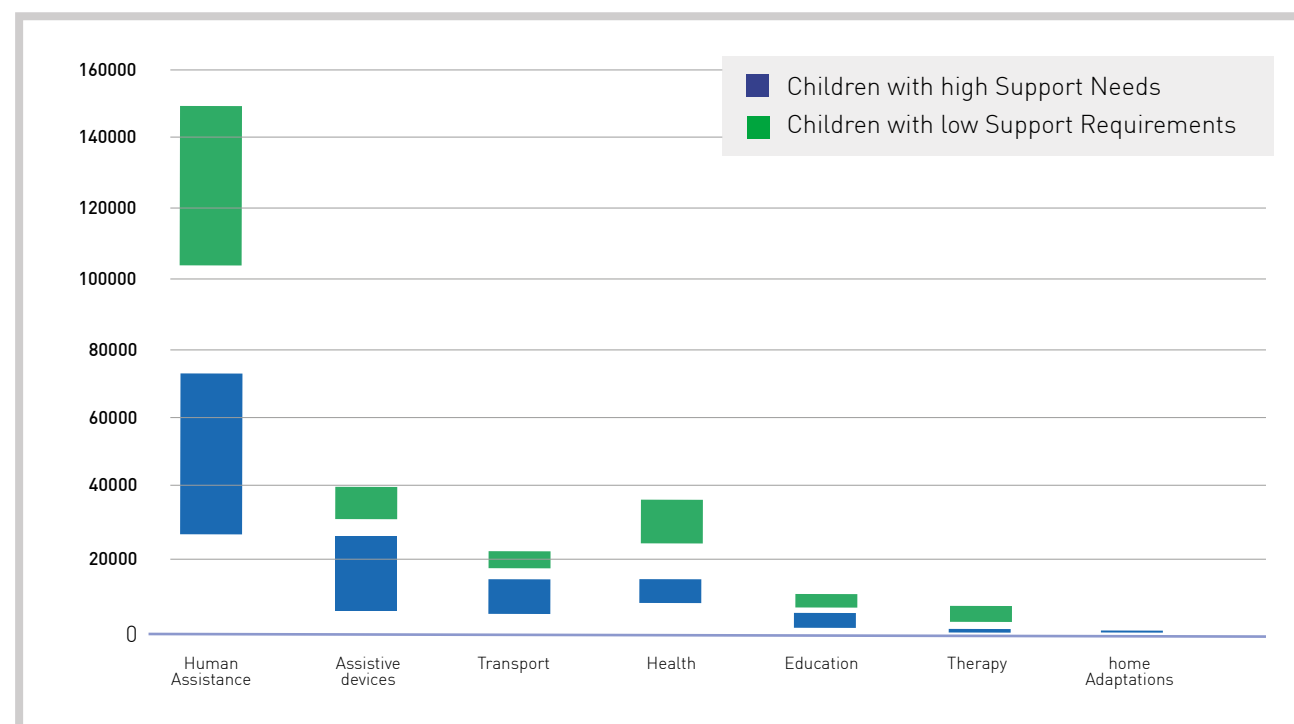


Table 1.2.1: Types and costs of products and services required by children with intellectual impairment – high support requirements

Category	Sub Category	Monthly	Once in 6 months	Once in a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Care giver	15000-25000					
	Personal Coach	3000-5000					
	Play Coach	10000-15000					
Assistive devices	Smart phone				15000-25000		
	Computer				50000-100000		
	Smart Tv				50000-100000		

Electrical Tooth Brush		500-1000	
Walking Stick	100-500		
Anti Slippery Mat	100-500		
Health Faucet		100-500	
Single Lever Tap		100-500	
Measuring Cups & Glasses		100-500	
Double handle sipper		100-500	
Towel Stand			500-1000
Soap Dispenser		100-500	
Tooth Paste Dispenser		100-500	
Rollator			
Internet and Wi-Fi	500-1000		
pen drive		100-500	
adapted dress		100-500	
adapted plate		1000-3000	
adapted spoon		1000-3000	
customised furniture			1000-3000
bathing chair			3000-5000
Shoes with Velcro		500-1000	
Diaper	3000-5000		

home modifications	Bathroom grab bars						1000-3000
	Western closet						5000-10000
Transportation							5000-10000
Education	TLM						1000-3000
	Plain Language Books						500-1000
Health	General consultations with specialists						500-1000
	Lab Tests						3000-5000
	Hospitalisation and ICU						above 50000
	Surgical Intervention						3 to 500000
Therapy	Sensory Integration therapy						500-1000

Table 1.2.2: Types and costs of products and services required by children with intellectual impairment – low support requirements

Category	Sub-Category	Monthly cost	Once in 6 months	Once a year	Once in 2 to 3 years	Once in 5 years	Once in a life time
Human Assistance	Care giver	10000-15000					
	Extracurricular coaching	10000-15000					
	Play Coach	10000-15000					
Assistive devices	Smart Phone				15000-25000		
	Computer				50000-100000		
	Smart Tv				50000-100000		
	Electrical Toothbrush			500-1000			

Education	TLM	1000-3000		
	Plain Language Books	500-1000		
Health	doctor consultation	500-1000		
	therapy pt &ot	500-1000		
	counselling	500-1000		
	sensory integration therapy	500-1000		
	alternative therapy/yoga	500-1000		
	medical emergencies		25000-50000	
	hospitalisation		above 50000	
	diagnosis /lab testing	1000-3000		
	Surgical Intervention			3 to 500000
	Transportation		3000-5000	

The majority of the costs are borne by the family, irrespective of their income levels and where they live. Families expressed that they had to move to cities to explore services for their child with disability, which has both impacted their support system and also increased the cost of living due to the high cost of rent, electricity and other costs in cities. Most families expressed that they had to shift houses once a year due to the pressure from the neighbourhood, and the cost of doing so adds to their family's cost of living.

Figures 1.2.3 & 1.2.4 explains the cost of goods and services incurred by the family and the gap between goods and services required but not available for persons with disabilities.

Figure 1.2.3: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - Children with high support requirements

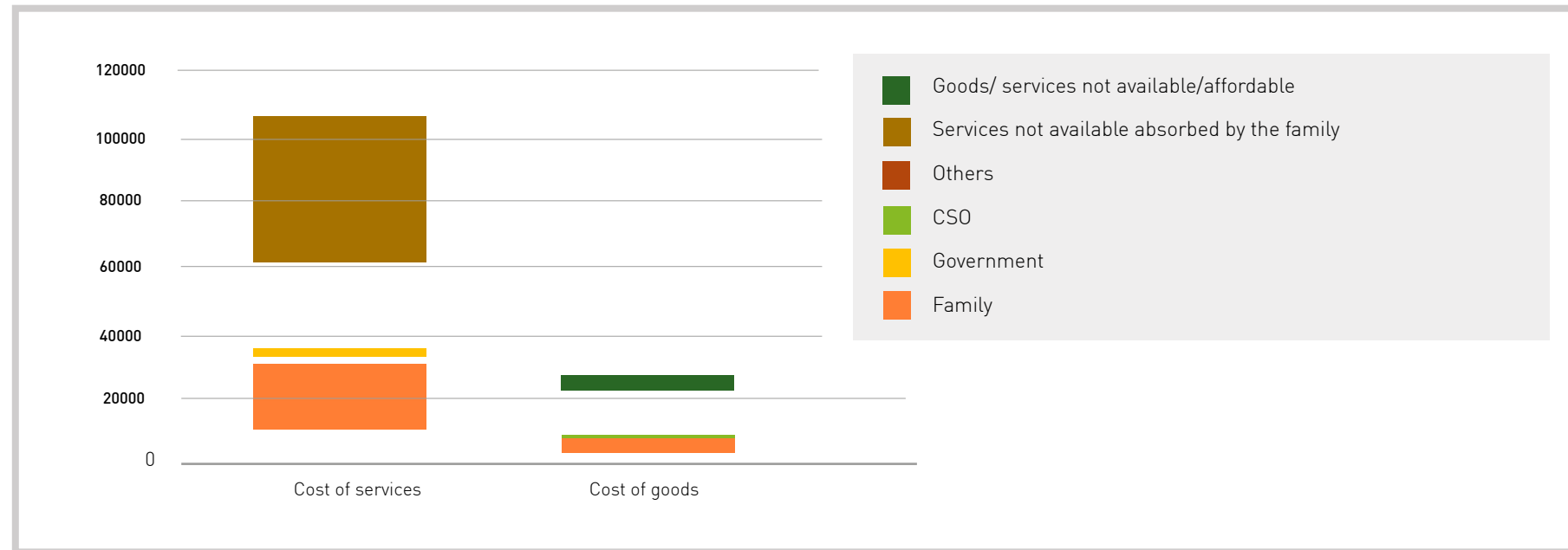
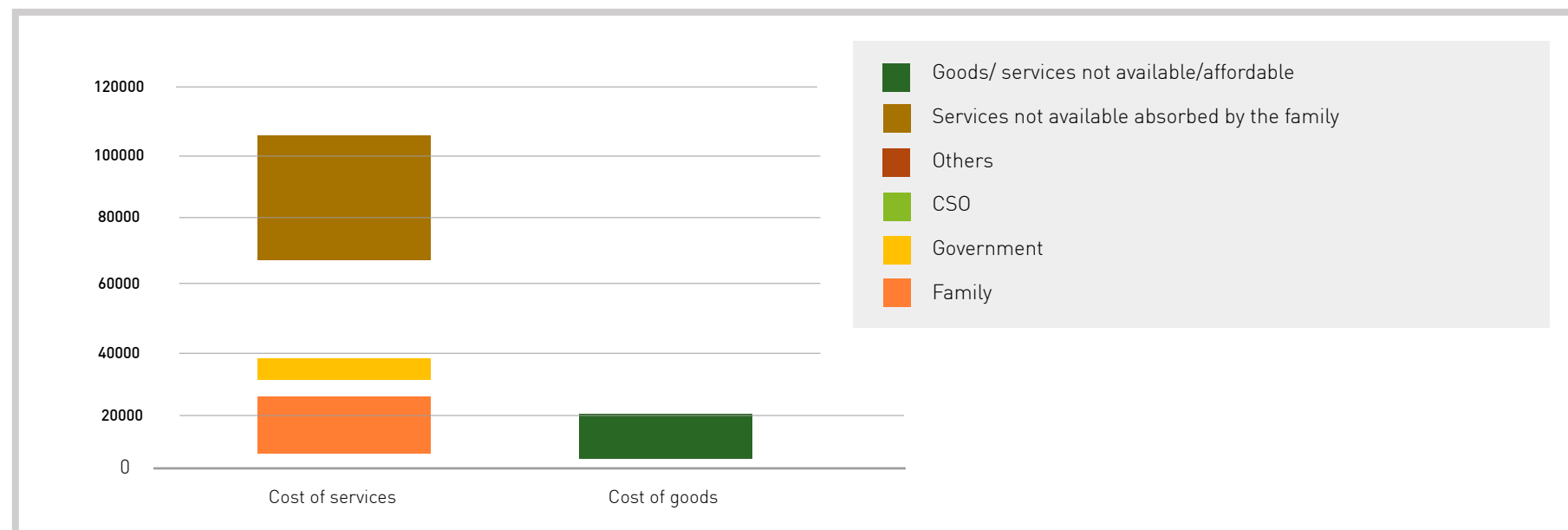


Figure 1.2.4: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - Children with low support requirements



Story of Ponni

(adult with intellectual impairment, high support requirements)

This story explains the gap between what is required and what is available.

Ponni is a 35-year-old person who lives in Chennai with her parents and two siblings. One of her siblings has a similar condition as Ponni.

Her mother is the only earning member of their family, and their father is addicted to alcohol and can only take up temporary jobs. Their family income is between Rs. 20,000 to 25,000 per month.

Ponni needs the following support for participation:

- ▲ 1. Care support services – personal assistant services
- ▲ 2. Transportation
- ▲ 3. Employment

Ponni's mother is her primary support person, and she also accesses the services of an organisation for persons with disabilities and undergoes skill development training. She receives the maintenance grant from the government of Rs. 2000 / month.

Costs for Ponni

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Human assistance	PA for self-care	15000				
	Travel Support	10000				
	PA at work	15000				
Transportation	Public Transport	550				

Total Cost / Who Provides / Availability

Category	Sub- Category	Goods monthly	Services monthly	Family	Government	CSO	Cost required	Cost incurred
Human Assistance	Self- care		15000		13.33%		15000	Service NA
	Travel Support		10000				10000	-DO-
	PA at Work		15000				15000	-DO-
Transportation	Public Transport		550		100%		550	550
Total			40550				40550	550

Share of Costs

Nature of Expense	Family	Government	CSO	Service Not Available absorbed by the family member	Goods Not affordable & accessible	Total
Service		2550		38000		40550
Total		2550		38000		40550
Percentage		6.3		93.7		100

Figure 1.2.5 highlights the overall cost incurred by families of persons with intellectual impairments. Irrespective of the level of impairment, the cost of services required occupies the highest proportion, and this cost unsurprisingly is high among persons with high support requirements.

Fig 1.2.5: Range of costs of goods and services required by adults with intellectual impairment per month in INR

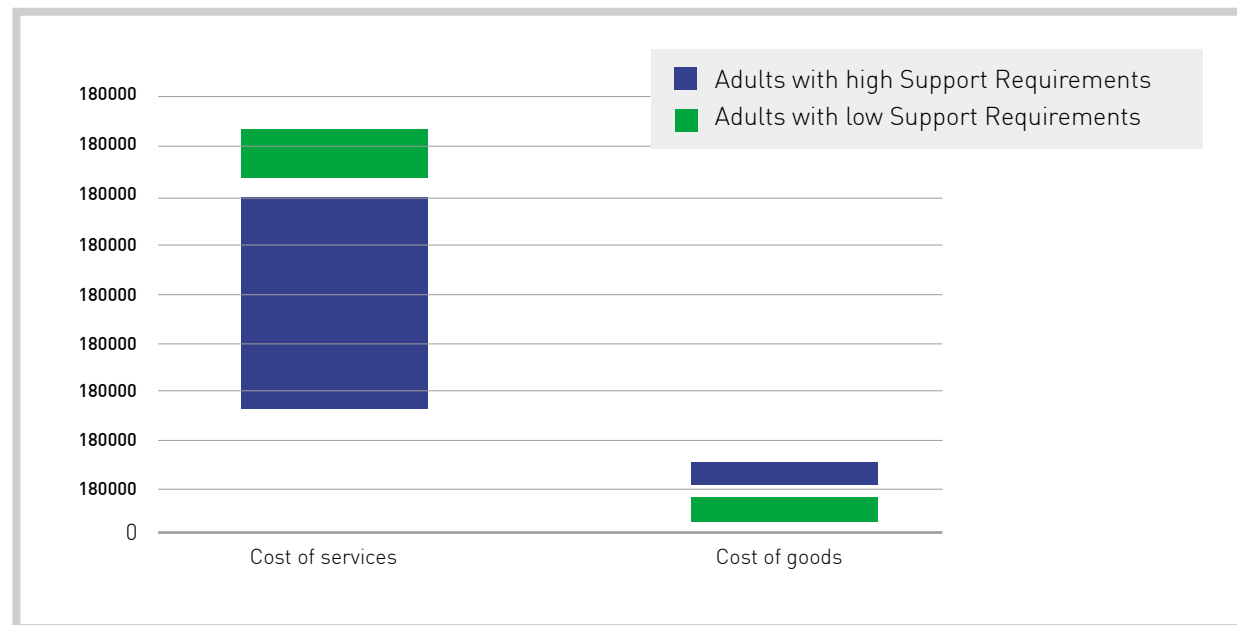
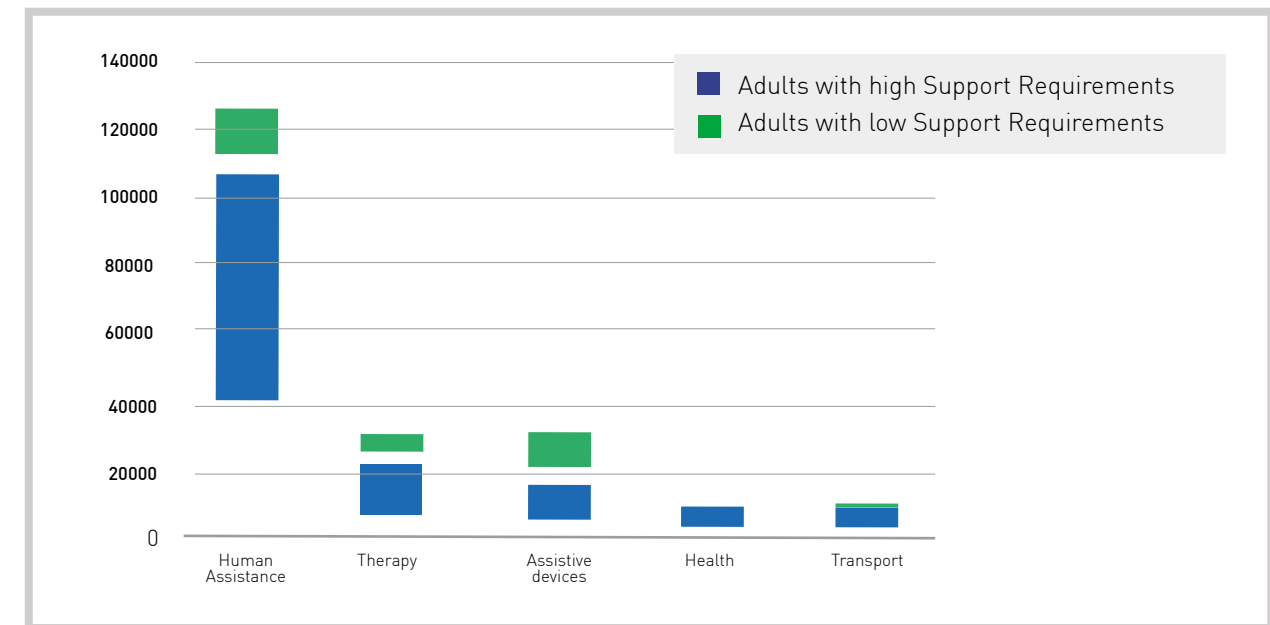


Fig 1.2.6 Break up of goods and services required by adults with intellectual impairment and their costs per month in INR



The break-up of the costs includes the cost of human assistance, therapy, health, transportation and assistive devices. The range of each of these costs is presented in Figure 1.2.6.

“I like to play football and tennis. I used to play with my father during evenings or weekends. Watch TV and sometimes go to beach. I like to travel but we do not generally travel.”

As shared by the participants during the FGD
(It has to be noted that most of the participants were youth representatives.)

Most people with high support requirements require a PA for performing activities in almost all domains of life. The other costs include health and therapeutic services. Usually, people use public transport for accessing services, which is free for the individual and their support person.

People with low support requirements use assistive devices such as smart phones for communicating, adapted tools for skill training and for performing their jobs.

Tables 1.2.3 & 1.2.4 present the break-up of goods and services required for performing various activities.

Table 1.2.3: Types and costs of products and services required by adults with intellectual impairment – high support requirements

Categories	Sub-Categories	Monthly Costs	Once in 6 months	Once a year	Once in 2 to 3 Years	Once in 5 Years	Once in a life time
Human Assistance	PA	15000-25000					
	Plain language communication facilitator	1000-3000					
	Supported decision	1000-3000					
	Access consultant			1000-3000			
	Job Coach	10000-15000					
	Child Care	10000-15000					
Assistive devices	Alexa				3000-5000		
	Timer			500-1000			
	Digital Clock			500-1000			
	Wi-Fi and internet	500-1000					
	Smart TV				50000-100000		
	Smart Phone				50000-100000		
Transportation		3000-5000					
Health	General consultation			1000-3000			
	Counselling	3000-5000					
Therapy	Physio therapy	1000-3000					
	Occupational Therapy	1000-3000					

Alternative therapy 3000-5000

Sensory 1000-3000

Table 1.2.4: Types and costs of products and services required by adults with intellectual impairment – low support requirements

Categories	Sub-Categories	Monthly Costs	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Plain Language interpreter	1000-3000					
	Job Coach	1000-3000					
	Supported decision making	500-1000					
	Clerical assistance	3000-5000					
Assistive devices	Alexa				3000-5000		
	Timer			500-1000			
	Digital Clock			500-1000			
	Wi-Fi and internet	500-1000					
	Smart TV					50000-100000	
	Smart Phone					50000-100000	
Transport		500-1000					
Therapy	Counselling	3000-5000					

Figures 1.2.7 & 1.2.8 highlight the costs to the family and the gap between goods and services required but not available / affordable.

Figure 1.2.7: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - Adult with high support requirements

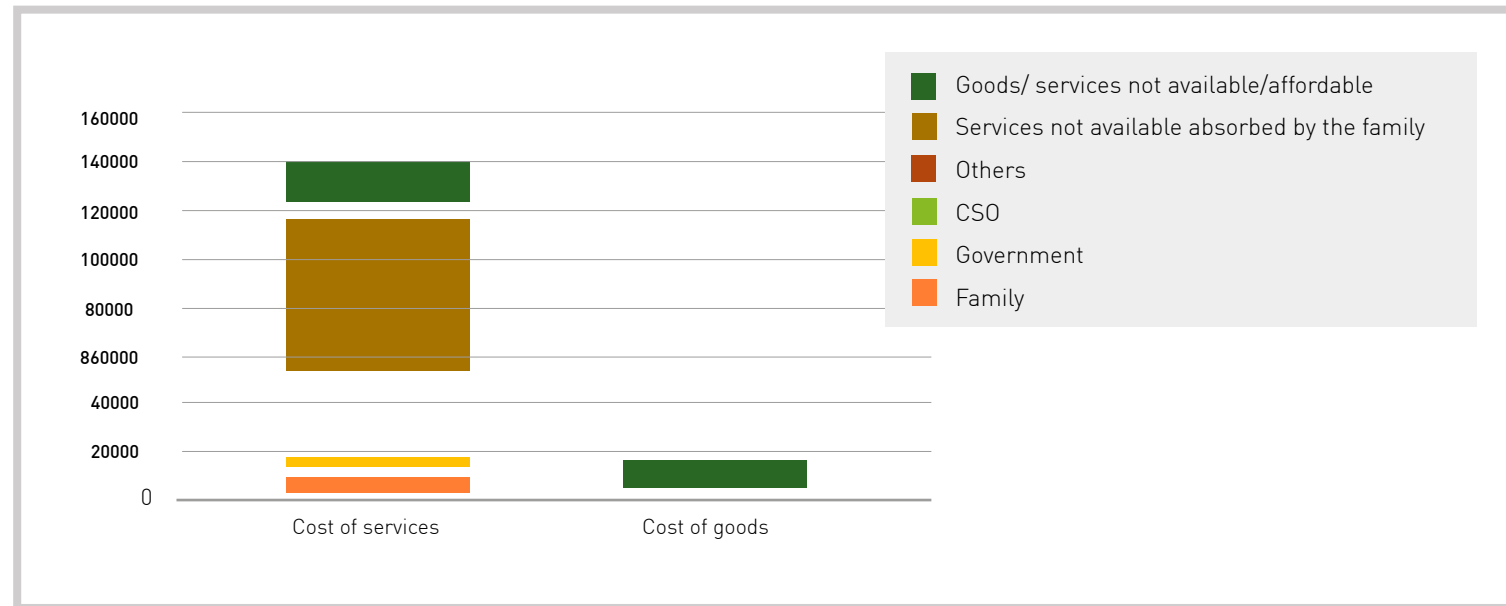
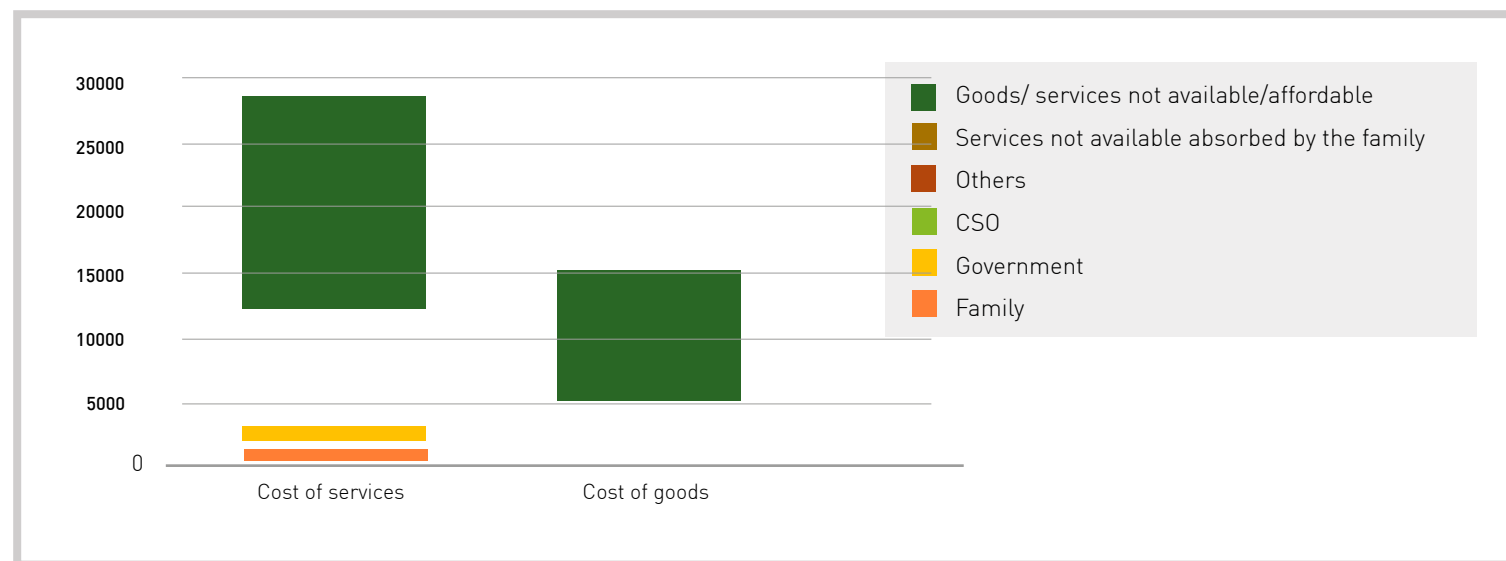


Figure 1.2.8: Costs of goods and services incurred by the family per month and goods services required but not available / affordable - Adult with low support requirements



Annexure 1.3 Persons with Complex Medical Conditions

Persons with complex neurological conditions (such as multiple sclerosis and parkinsonism) or blood disorders (such as haemophilia and thalassemia) are covered under this category of persons with complex medical conditions.

There is no census data available for this population, since persons with the specified conditions are covered under the RPDA 2016 and not the earlier Act. The NSSO does not report about people with complex medical conditions.

“

“In Tamil Nadu there are approximately 100000 people with thalassemia among them adults constitute not more than 3000 to 5000 people since survival rate beyond 18 years of age among people with thalassemia is very low.”

As shared by Mumtaz, a lawyer, experiential expert, participant in the FGD

“The approximate number of people living with haemophilia in the state based on our work is 2455. Out of this 660 are children with disabilities and we do not have age proof for about 396 people. The rest are adults with disabilities. But these days we hear that some people access the medication directly from the government hospital. This will be a small number, which we do not have data.”

As shared by Ambica, Haemophilia Association and expert group member

”

“

“There 306 registered members with the Multiple Sclerosis Society of India (MSSI), Chennai Chapter. Mostly neurologist[s] refer people to the society. However, many people hesitate to identify themselves and so they do not register with us as members. There is no registry with the health system about persons with multiple sclerosis. Only ICMR has initiated the registry.”

As shared by Smitha Sadasivan, member of MSSI and expert group member

There are approximately 10 million people living with Parkinson’s disease globally, and this number is expected to double by 2040. In India, there are about 1 million people diagnosed with this disease. The incidence rate is around 50-100 per 100,000 people in states like Tamil Nadu. Men are slightly more likely to develop Parkinson’s than women, and the disease is most commonly diagnosed in people over the age of 60. However, in recent times, the disease is on the rise even in the younger age groups.⁸

”

⁸ “Exhibition featuring paintings of Parkinsons patients held at Rela Hospital” - April 21st 2023 - <https://www.relainstitute.com/media/exhibition-featuring-paintings-of-parkinsons-patients-held-at-rela-hospital/> - accessed on 17.05.2023

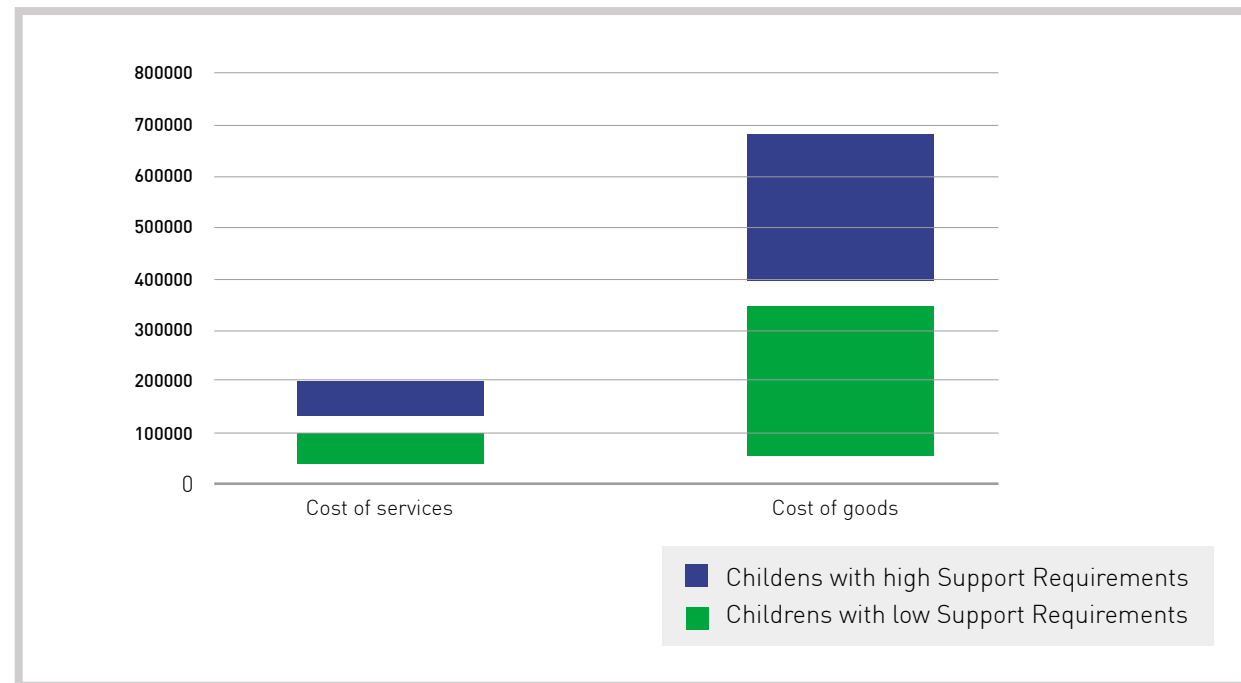
Children with disabilities

This section covers children with haemophilia and thalassemia, since families of children with multiple sclerosis often do not wish to disclose their identities.

Hospitalisation, blood transfusion and medications are the major costs to the families. Most of the costs related to transfusion and medications are covered by the government health insurance program. However, hospitalisation expenses are high and not covered by the insurance, so this has been an out-of-pocket expense for the families.

Figure 1.3.1 highlights the total costs of goods and services incurred by families of children with complex medical conditions, irrespective of the level of support requirements.

Fig 1.3.1 Range of costs of goods and services required by children with complex medical conditions per month in INR



“

“It has to be noted that for children with haemophilia the health care needs such as medication and treatment during bleed is required. People can go without it for [months] together. Sometimes it happens often. We cannot predict.”

As shared by Ambica, expert group member

”

Story of Alia and Alisha Fathima

(children with high support needs, complex medical condition – thalassemia)

This story highlights the situation of children with thalassemia.

Alia (age 15 years) and Alisha (age 11 years) have thalassemia. They live with their parents in Mathur, an outer part of Chennai. Their father is the only earning member and is working as a driver with a monthly income of Rs. 18,000 to 20,000 (INR).

Both of them need the following services:

- ▲ 1. Care support
- ▲ 2. Transportation
- ▲ 3. Health care

Their mother is the primary care giver and supports them with their psychological needs, education and health care. The mother was working earlier and had to leave the job to care for their children.

Costs for Alia Fatima

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Human assistance	Care giver	15000				
Transportation		3600				
Health Care	Blood transfusion	20000				
	Medicines	7500				
	General health care	1000				
	Blood test	1000				

Costs for Alisha Fatima

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Human assistance	Care giver	15000				
Transportation		1000				
Health Care	Blood transfusion					
	Medicines	3000				
	General health care	1000				
	Doctor's fees	800				

Total Cost / Who Provides / Availability

Category	Sub- Category	Goods monthly	Services monthly	Family	Government	Cost required	Cost incurred
Human Assistance	Care support person		30000	100%		30000	Service NA
Transportation	Auto charges		4600	100%		4600	4600
Health care	Medicines	10500		76%	24%	10500	10500
	Blood transfusion		20000		100%	20000	20000
	Doctor's charges		800	100%		800	800
	Blood test		1000	100%		1000	1000
	General Health care		2000	100%		2000	2000
Total monthly cost						68900	38900

Share of Costs

Nature of Expense	Family	Government	Service Not Available absorbed by the family member	Total
Goods	8000	2500	30000	40500
Service	8400	20000		28400
Total	16400	22500	30000	68900
Percentage	23.80	32.66	43.54	100

Figure 1.3.2 shows the disaggregation of costs of goods and services required across domains and activities. Health care is the highest cost, irrespective of the level of support required. This is followed by services such as personal assistants and therapeutic needs.

Fig 1.3.2 Break up of goods and services required by children with complex medical conditions and their costs per month in INR

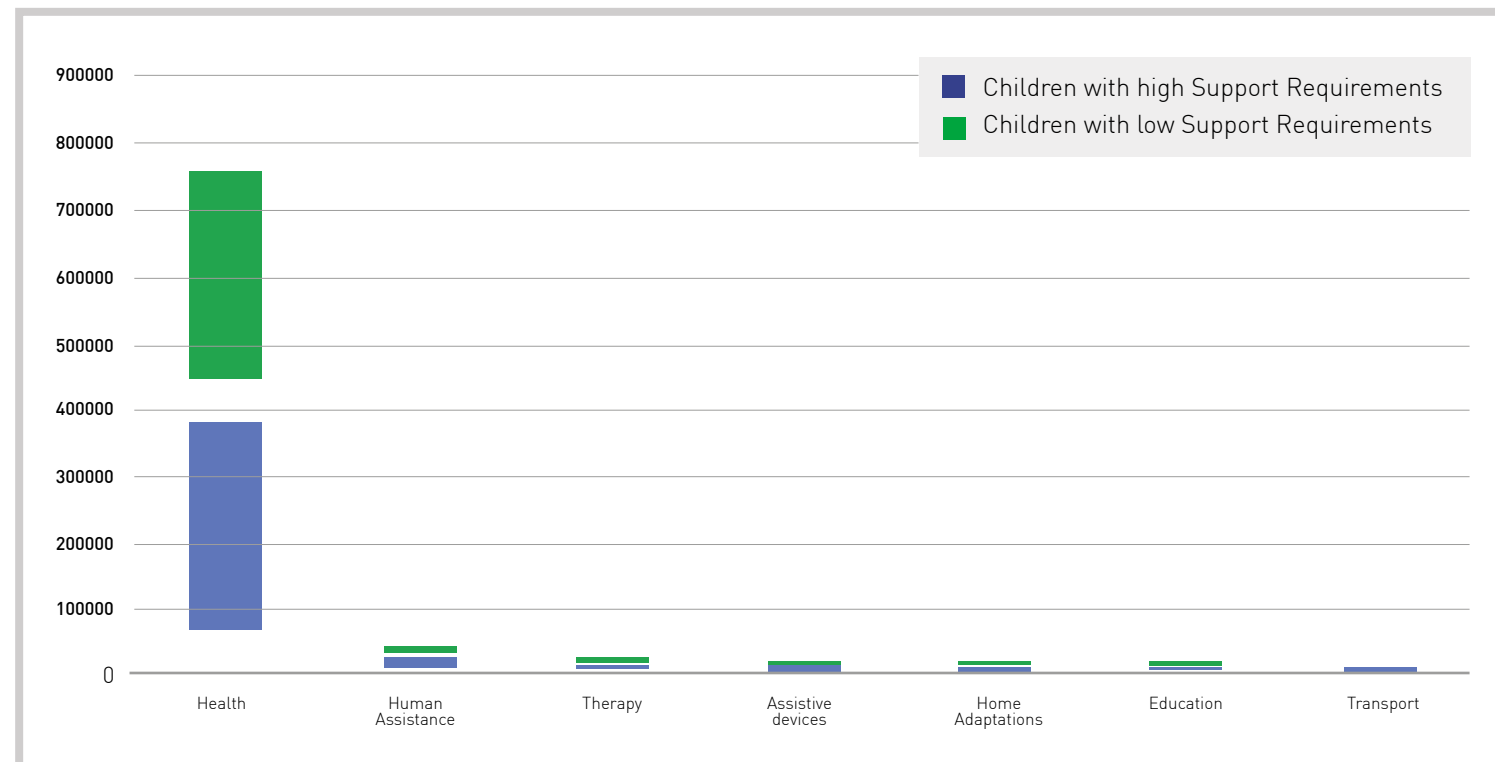


Table 1.3.1: Types and costs of products and services required by children with complex medical conditions – low support requirements

Category	Sub-Category	Monthly costs	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Care giver	6000-10000					
Assistive Devices	Crepe bandage	100-300					
	Shoulder sling			300-500			
	Knee cap	167-667					
	Soft & Arch Shoes		6000-10000				
	Ankle cap	200-333					
	Ice-gel bag			200-500			
	Gel ball		400-500				
	Soft bed / mattress & pillow					10000-30000	
	hot /			150-600			
	cold water bag			150-400			
	Wheel chair				7000-25000		
	Sound Amplifier				5000-10000		
Health	Medicines	40000-280000					
	MRI			2500-15000			
	CT Scan		500-5000				
	Transfusion	15000-30000					
	Syringe, needles etc.,	8000					
	inhibitor screening		4500-6500				

	Vein Finder		2000-17000
	Hospital admission	18500-25000	
	Thal Pump (portable)		30000-50000
	Thal Pump Battery		3000-5000
	Regular Check Up	500-1000	
Therapy	Physio therapy	2000-5000	
	Counselling	1000-3000	
Education	Recorded Lessons	3000-5000	
	adapted pen , pencil	200-500	
Home Modification			
	Bathroom modification		15000-35000
	Rooms & walls with foam NA		50000-100000

Table 1.3.2: Types and costs of products and services required by children with complex medical conditions – high support requirements

Category	Sub-Category	Monthly costs	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Care giver (Fly)	6000-10000					
	Scribe - Government			1250-2500			
	Extra Coaching	2000-2500					
Assistive Device							
	Crepe bandage	100-300					
	Shoulder sling			300-500			
	Knee cap	167-667					

	Soft & Arch Shoes	6000-10000	
	Ankle cap	200-333	
	Ice-gel bag		200-500
	Gel ball	400-500	
	Soft bed / mattress & pillow		10000-30000
	hot /		150-600
	cold water bag		150-400
	Wheel chair		7000-25000
	Walker		1500-2000
	Cane Walker		1500-5000
	Crutch		1050-1300
	adapted pen , pencil	200-500	
	accessible table and chair		10000-20000
Health	Medicines	40000-280000	
	MRI - (Government)		2500-15000
	CT Scan	500-5000	
	Transfusion	15000-30000	
Govt	Syringe, needles etc.,	8000	
	inhibitor screening	4500-6500	
	Vein Finder		2000-17000
	Hospital admission	18500-25000	

	Thal Pump (portable)		30000-50000
	Thal Pump Battery		3000-5000
	Regular Check Up	500-1000	
Therapy	Physio therapy	2000-5000	
	Counselling	1000-3000	
Transportation		2000-5000	
Education	Recorded Lessons	3000-5000	
Home Modification			
	Bathroom modification		15000-35000
	Rooms & walls with foam		50000-100000

Figures 1.3.3 & 1.3.4 highlight the costs to the family and the costs of goods required but not available/accessible/affordable by the families.

Figure 1.3.3: Costs of goods and services incurred by the family per month goods and services required but not available / affordable-children with High support requirements

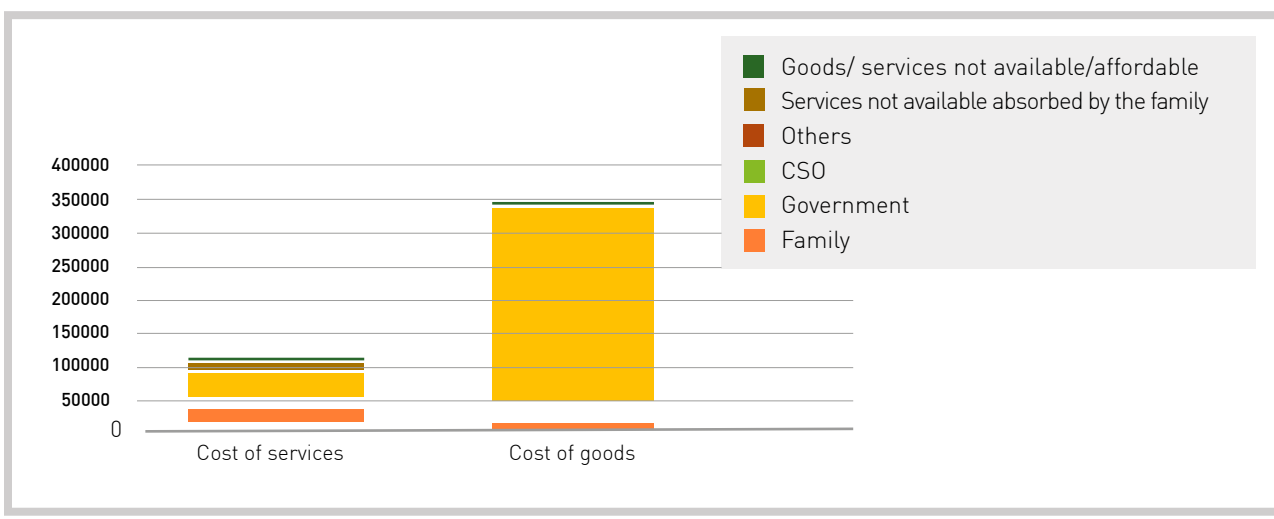
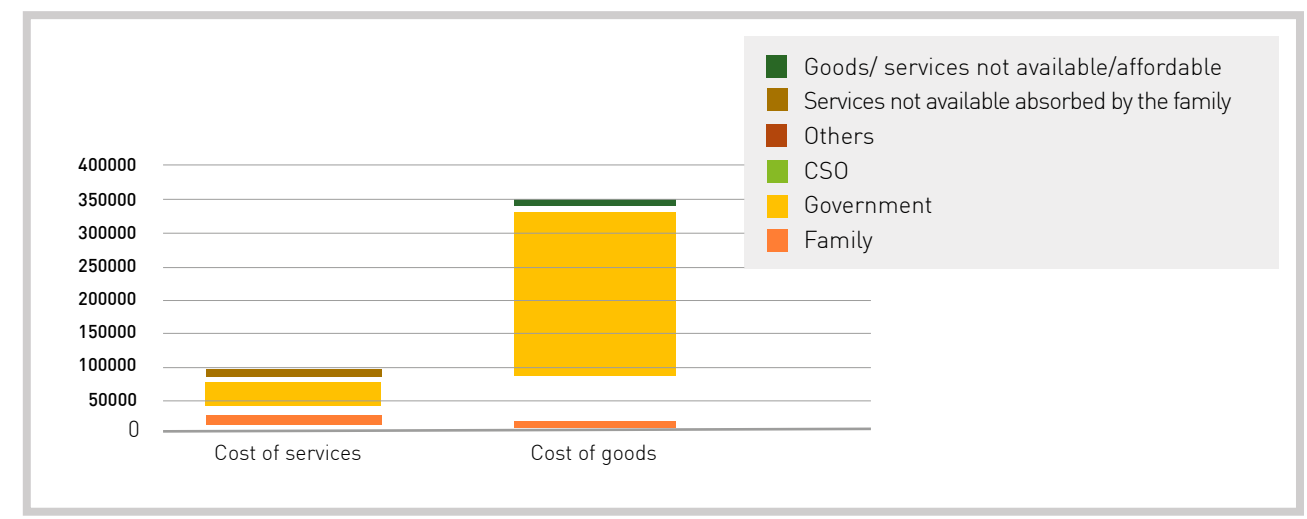


Figure 1.3.4: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable-children with Low support requirements

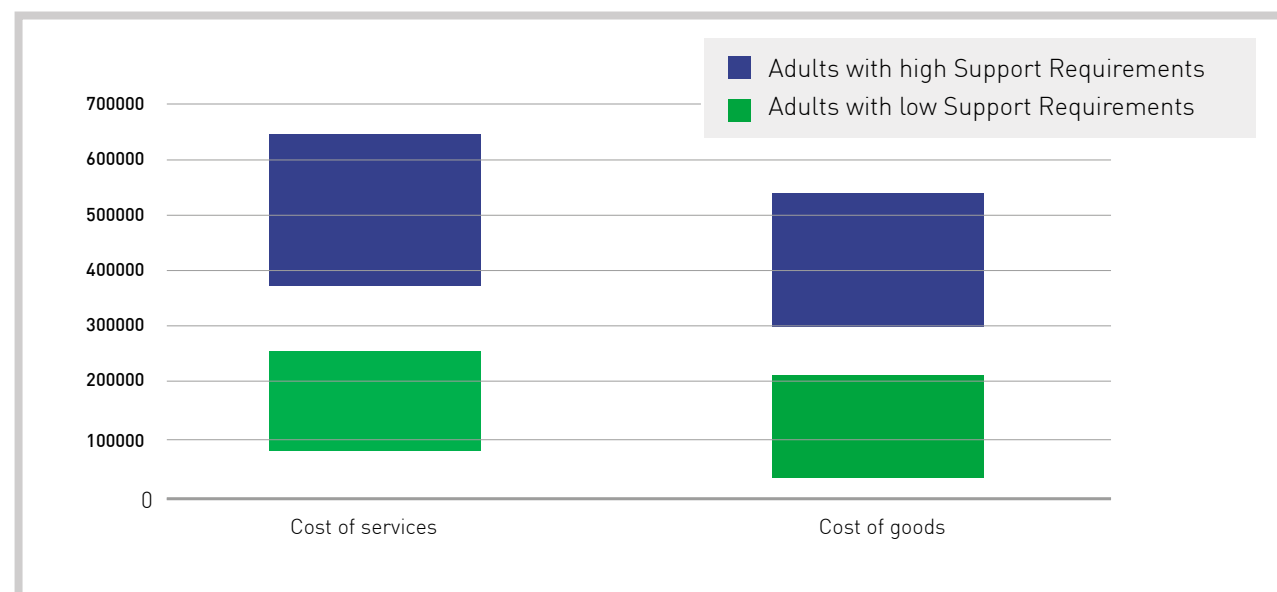


Adults with Disabilities

Unsurprisingly, the costs of goods and services required by adults with complex medical conditions are higher than the costs for children. The income levels of the participants range between Rs. 20000 to Rs. 50000 per month. Some of the participants had to stop working due to their conditions.

Figure 1.3.5 explains the range of costs of goods and services required per month for adults' full and effective participation.

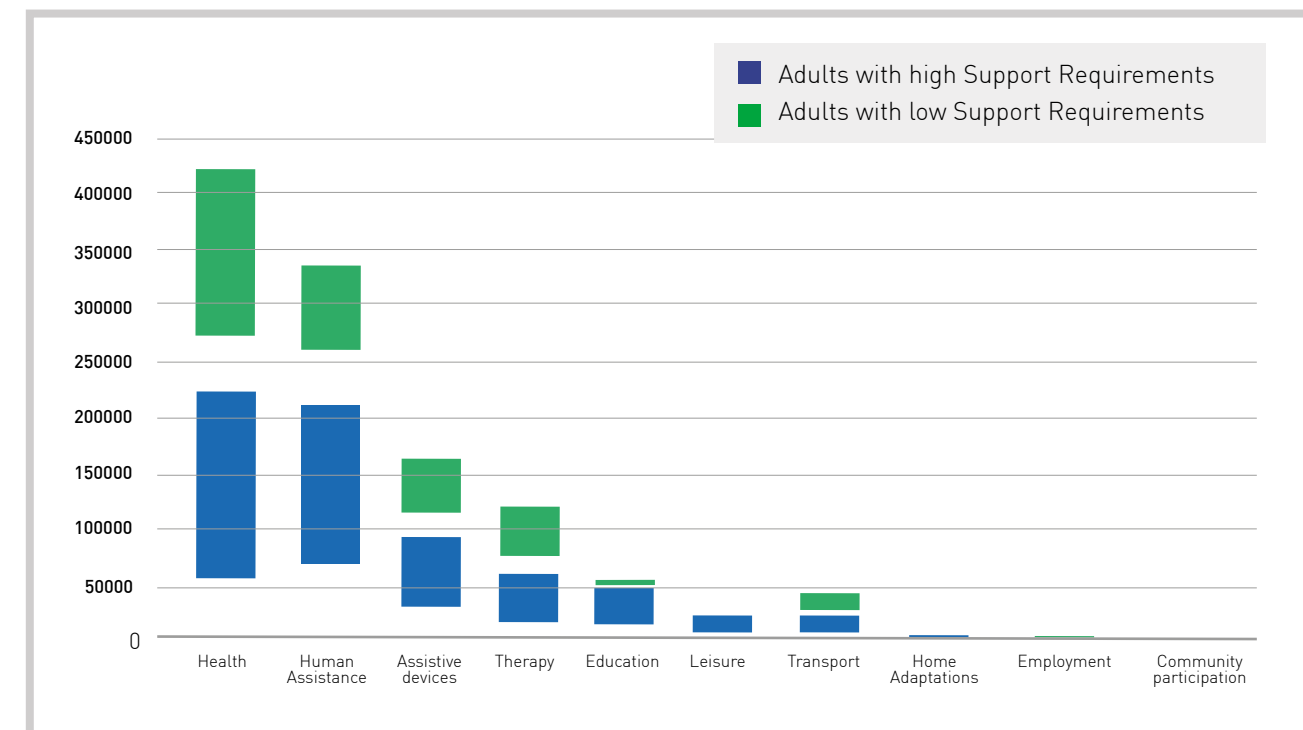
Fig 1.3.5 Range of costs of goods and services required by adults with complex medical conditions per month in INR



Irrespective of the level of support required, the cost of services occupies the highest proportion of cost per month for families and individuals with complex medical conditions.

The break-up of cost of goods and services required is highlighted in Figure 1.3.6:

Fig 1.3.6 Break up of goods and services required by adults with complex medical conditions and their costs per month in INR



Health care is the highest proportion of cost followed by human assistance, assistive devices, and therapy irrespective of the level of support needs.

The following tables provide detailed lists of goods and services required across categories of costs, across domains and activities.

Table 1.3.3: Types and costs of products and services required by adults with complex medical conditions – high support requirements

Category	Sub-Category	Monthly Costs	Once in 6 months	Once a Year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	PA	15000-50000					
	support for house hold work and cooking	5000-12000					
	Academic support person	10000-30000					
	Scribe	3000-5000					
	Reader assistant	3000-5000					
	Paramedic services	500-2000					
	Job Coach	5000-10000					
	nursing assistant	25000-30000					
Transportation		5000-15000					
Assistive devices	Sound Amplifier				5000-10000		
	Crepe bandage	100-300					
	Shoulder sling			300-500			
	Knee cap	167-667					
	Soft & Arch Shoes		6000-10000				
	Ankle cap	200-333					
	Ice-gel bag			200-500			
	Gel ball		400-500				

Soft bed / mattress & pillow		10000-30000
air / water bed		2500-5000
hot /	150-600	
cold water bag	150-400	
Wheel chair (customised)		14000-25000
battery operated wheelchair		55000-155000
recliner		2500-20000
Pace Maker		
Thal Pump (portable)		30000-50000
Thal Pump Battery		3000-5000
Glucose monitoring Device		
Crutch	750-5000	
oxygen monitor		
communication device		30000-50000
magnifier	10000-12000	
smart phone (less SAR value/ light weight)		20000-50000
rolator - PA		4500-9000
neck brace	1000-2000	
hip brace	500-2000	
body / spine brace / jackets	1000-14000	
room heater	3000-5000	

air conditioner		40000-60000
bed pan	100-250	
diaper	3000-6500	
urine bottle	33-167	
western closet		10000-15000
commode wheel chair		10000-50000
staircase lift		250000-350000
Stair case lift maintenance		10000-20000
Standing Frame/ walker		4000-7000
Suction pump for excretion	2000-10000	
silicon catheter		
urine bag		
customised / acupressure foot wear		5000-10000
Hospital cot- high calibre / cot with wheels		55000-85000
rubber sheet	333-667	
therapy table		15000-25000
mask every 4 - 5 hours	300-500	
standing wc		15000-150000
Woollen cloths		2000-10000
Micro wave		4000 - 18000
Jump suits		2000-10000

	adapted clothing	2000-10000	
	hose / throat suction pump		5000-14000
	Calling bell portable		1000-1500
	Railing		2000-10000
	Bathroom modification		15000-30000
	bathing chair -		2000-5000
	stool for leg support		500-1000
	Tissue paper	200-500	
	Portable Ramp		10000-20000
	Low tech charts	200-500	
	Cushion	1000-5000	
	Eye Gaze (Environmental access device		500000-100000
	iPad		50000-100000
Education	Recorded lessons	333-3333	
	Extra coaching	5000-10000	
	Light weight computer		35000-80000
	adapted pen , pencil	200-500	
	Large Print	1000-3000	
Therapy	Spasm & Pain management	2000-5000	
	light relaxing therapy	2000-10000	

	Physiotherapy	2000-10000	
	Bladder management		
	Counselling	1000-3000	
	Occupational Therapy	2000-5000	
	Hydrotherapy	4000-6000	
	Yoga	2000-5000	
Leisure	Easy Board Games		
	Extra cost for accessible stay	5000-15000	
Health	Medicines	10000-100000	
	General Meds	10000	
	MRI -		15000-30000
	CT Scan		500-5000
	Transfusion	15000-30000	
	Syringe, needles etc.,	8000	
	Hospital admission		25000-100000
	Nutrition	500-1000	
	Thermometer & BP machine		2500-6000
	Weighing scale		2000-3500
	Portable oxygen cylinder		
	Bi Pap machine		35000-75000
	Bipap mask		
	Bi Bap battery		

DBS for Parkinsons	
Consultation with dietician	1000-2000
Consult with Orthopaedist	1000-2000
consult with gastroenterologist	1000-2000
consult with urologist	1000-2000
consult with dermatologist	1000-2000
consult with neuro ophthalmologist	1000-2000
consult with ENT	1000-2000
consult with pomologist / cardiologist	1000-2000

Table 1.3.4: Types and costs of products and services required by adults with complex medical conditions – low support requirements

Category	Sub-Category	Once a month	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	PA	10000-15000					
	Nursing support	2000-5000					
	Cooking & house maintenance	5000-10000					
	Scribe	3000-5000					
	Reader	3000-5000					
	Executive assistant	15000-20000					
	Child Care	10000-15000					

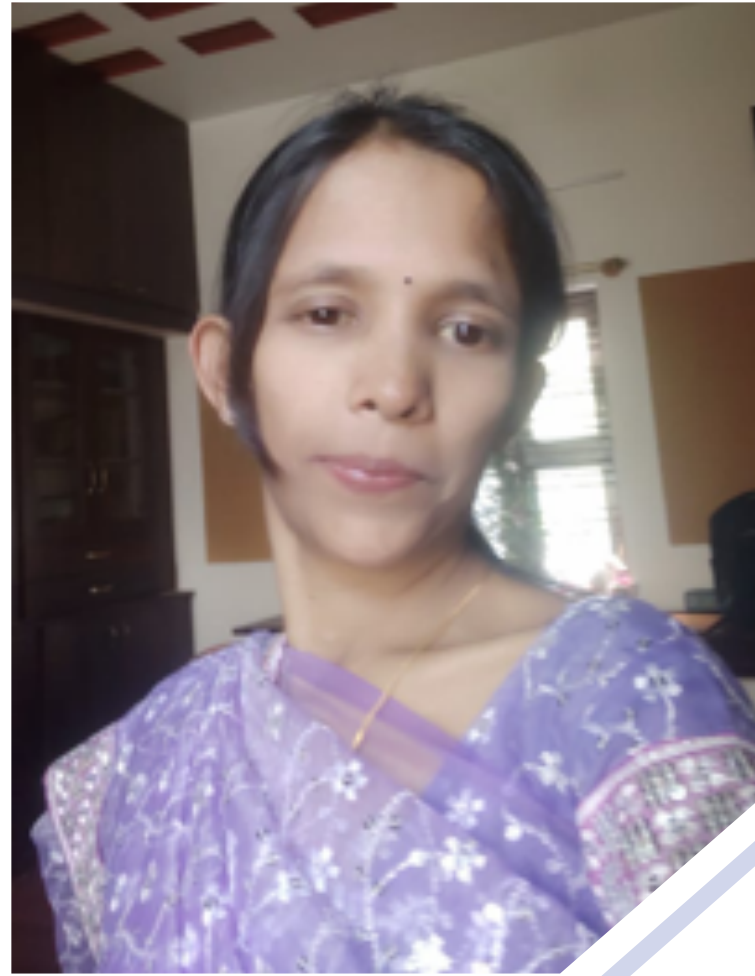
Transportation		5000-15000	
Assistive device	Sound Amplifier		5000-10000
	Crepe bandage	100-300	
	Shoulder sling		300-500
	Knee cap	167-667	
	Soft & Arch Shoes		6000-10000
	Ankle cap	200-333	
	Ice-gel bag		200-500
	Gel ball	400-500	
	Soft bed / mattress & pillow		10000-30000
	air / water bed		2500-5000
	hot /		150-600
	Cold water bag		150-400
	Wheel chair (custom-ised)		7000-25000
	Pace Maker		
	Thal Pump (portable)		30000-50000
	Thal Pump Battery		3000-5000
	Glucose monitoring Device		
	Crutch		750-5000
	oxygen monitor		

	communication device		30000-50000
	magnifier	10000-12000	
	smart phone (less SAR value/ light weight)		20000-50000
	rolator - PA		4500-9000
	room heater	3000-5000	
	air conditioner		40000-60000
	bed pan	100-250	
	diaper	3000-6500	
	urine bottle	33-167	
	Railing		2000-10000
	Bathroom modification		15000-30000
	Eye Gaze (Environmental access device)		500000-100000
	iPad		50000-100000
Education	Light weight computer		35000-80000
	adapted pen, pencil	200-500	
	Adapted learning material	10000-12000	
Employment	accessible table and chair		10000-20000
Health	Medicines	10000-100000	
	General Meds	10000	
	MRI -		15000-30000
	CT Scan		500-5000

	Transfusion	15000-30000
	Syringe, needles etc,	8000
	inhibitor screening	4500-6500
	Vein Finder	2000-17000
	Hospital admission	25000-100000
	Dental	
	ENT	
	Osteo	
Therapy	Spasm & Pain management	2000-5000
	light relaxing therapy	2000-10000
	Physiotherapy	2000-10000
	Bladder management	
	Counselling	1000-3000
	Hydrotherapy	4000-6000
	Occupational Therapy	2000-5000
	Yoga	2000-5000
	nutrition	500-1000

It has to be noted that not all persons with complex medical conditions require all of the goods mentioned in the tables above. However, most services are found to be required by many of participants of the FGD.

The stories of Mumtaz and Maheswari highlight the diversity of needs.



Story of Mumtaz

(adult with thalassemia)

36-year-old Mumtaz is a person with thalassemia. She is a lawyer practicing from Chennai for the last one year. She is from Thirupathur, a rural district of Tamil Nadu. She is a single mother mostly supported by her parents. She earns up to Rs. 30000 / month.

Mumtaz needs blood transfusion twice a month. Unlike others, she cannot avail the government insurance since her condition requires transfusion after diluting the blood cells. A facility for this is not available in Tamil Nadu, and she has to travel to Bangalore for this care. Mumtaz has to support her child financially. She does not receive any support from the child's father. She had to divorce as her disability was not accepted and was challenged by her partner.

Mumtaz needs the following goods and services:

- ▲ 1. Human assistance for household activities like cooking, cleaning, washing, etc.
- ▲ 2. Child care services
- ▲ 3. PA at work for typing, writing and for handling books/papers while moving around
- ▲ 4. Health care services
- ▲ 5. Assistive devices

Costs for Mumtaz

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Human Assistance	House hold Support	6000				
	Child care	10000				
	PA at work	5000				
	Work buddy	8000				

Transportation		10000
Assistive devices	Smart Phone	20000
	Lap top	50000
Health care	Blood	5000
	Blood filter	1000
	Medicine	10000

Total Cost / Who Provides / Availability

Category	Sub- Category	Goods monthly	Services monthly	Family	Government	CSO	Cost required	Cost incurred
Human Assistance	Household work		6000				6000	Service NA
	Child care		10000				10000	Service NA
	PA at work		5000				5000	Service NA
	Work buddy		8000	100%			8000	8000
Transportation			10000				10000	10000
Assistive device	Smart phone	833.33		100%			833.33	833.33
	Laptop	833.33		100%			833.33	833.33
Health Care	Blood	5000		100%			5000	5000
	Blood Filter	1000		100%			1000	1000
	Medicine	10000		100%			10000	10000
Toral		17666.7	39000				56666.7	35666.7

Share of Costs

Nature of Expense	Family	Government	CSO	Service Not Available absorbed by the family member	Goods Not affordable & accessible	Total
Goods	17666.7					17666.7
Service	18000			21000		39000
Total	35666.7			21000		56666.7
Percentage	62.9			37.1		100

Mumtaz requires a work buddy, since there could be a hearing for the clients on the days she goes for blood transfusion. Also due to her condition she often feels sick, which can impact her work.

Story of Maheshwari

(adult with multiple sclerosis)

Maheshwari, 57, is a home science graduate with a specialization in textile and family relations. She was working for a garment export house from 1994 to 2005, but could not continue this work due to poor eyesight. Since 2005 she has been doing social service.

Maheshwari has two brothers. The elder one is an ex-Air Force officer and stays in Chennai. The younger one is a research scientist and stays in Tennessee, USA. She has one daughter who is married with 2 kids. Both her parents have passed away. She got divorced 25 years back, and her ex-husband passed away seven years ago. Maheshwari has no contact with her ex-husband's family.

Maheshwari realized that she is a person with disability at the age of 13, and was diagnosed with MS when she was in her 30s. When the doctors confirmed she has MS, she did not know the real gravity of situation. There was a fear at the back of her mind, as she was the breadwinner and had to take care of her young child as a single parent. She always had a positive attitude towards life, which helped her to manage life.

Her monthly income is Rs. 10800 and she does not get any support from the government. Maheshwari has extra costs due to the need for a ground floor house, which costs at least Rs, 8000 in addition. Maheshwari is supported by her daughter and extended family members. Her other costs due to her disability include:

- ▲ 1. Cost of cook
- ▲ 2. Cost of domestic help
- ▲ 3. Cost of accessing health services such as consultation and transportation

All these costs add up to Rs. 8225 per month, in addition to her house rent and other household expenses. Her medication needs are taken care of by the MSSl since she is a member of the association.

“I am a dental surgeon, but I had to stop my work as a surgeon due my condition, Parkinson's. I had changed my profession and now I am full time artist without much income. I need the support of a cook, domestic help, travel assistant apart from my health care needs. All of these expenses are taken care by my family. In future I might need communication devices since I might have speech impairment, which I have not explored so far.”

As shared by a person with early Parkinson's, participant in the FGD

From these different stories, we can understand that families and the individuals have taken responsibility to procure the majority of goods and services required.

Figures 1.3.7 & 1.3.8 explains the range of costs to the family and the range of goods and services required but not available.

Figure 1.3.7: Costs of goods and services to families per month and goods and services required but not available / affordable-Adults with high support requirements

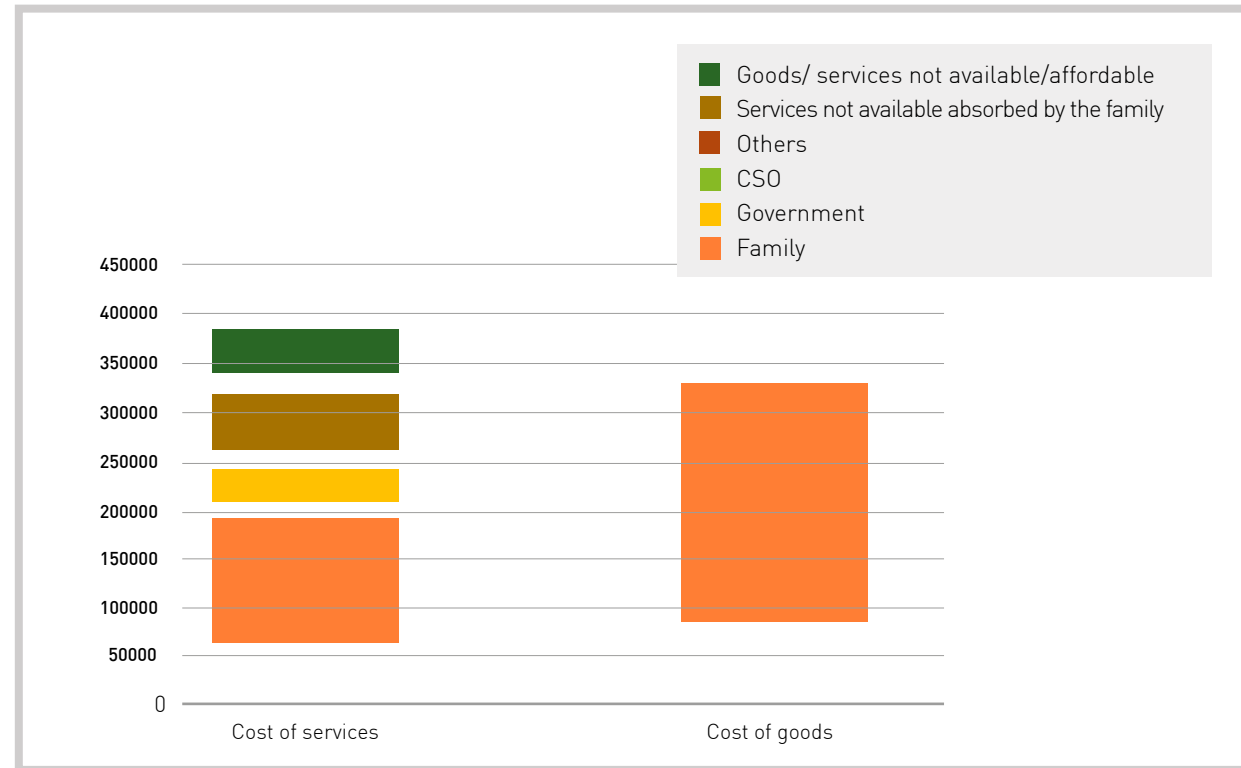


Figure 1.3.8: Costs of goods and to families per month and goods and services required but not available / affordable-Adults with low support requirements



Annexure 1.4 Deaf

The key government programs for this disability include schools for deaf children, cochlear implant for children with hearing impairment, hearing aids, smart phones for deaf adults and skill training programs. Deaf people can also access the disability pension implemented by the revenue department of the government of Tamil Nadu.

There is huge gap in the availability of sign language interpreters for effective participation of deaf individuals. There is not much effort on the part of the government to train and recruit a pool of interpreters. Mostly deaf people rely on video relay services, which is expensive.

Though the government provides for cochlear implant, maintenance and services are not taken care of. Families report that they spend between Rs. 50000 to 100000 per year to replace parts and batteries of the machine.⁹ There is also an ongoing debate on the effectiveness of cochlear implants in terms of allowing full and effective participation across all domains of life. There is a lack of effort on the part of the government to ensure multimodal communication. Technology upgradation is another cause of concern for families with children using cochlear implant.¹⁰

Deaf Children

The total cost of goods and services incurred by families with deaf children / children with speech and hearing impairments ranges between Rs. 33499 to Rs. 57457 per month.

Figures 1.4.1 & 1.4.2 explain the range of cost for accessing goods and services required and the break-up of categories of goods and services required to perform different activities across various domains.

Figure 1.4.1: Range of costs of goods and services required per month by Deaf children

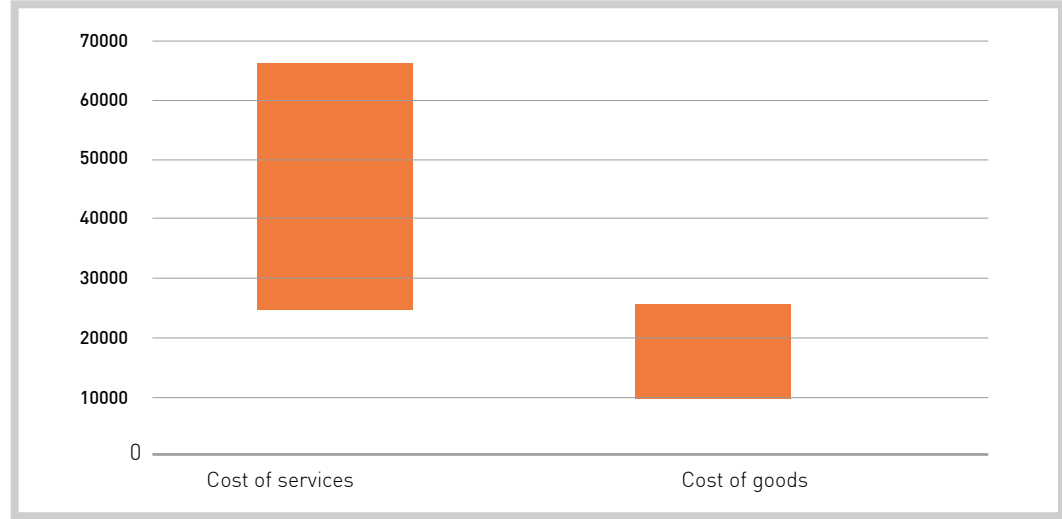
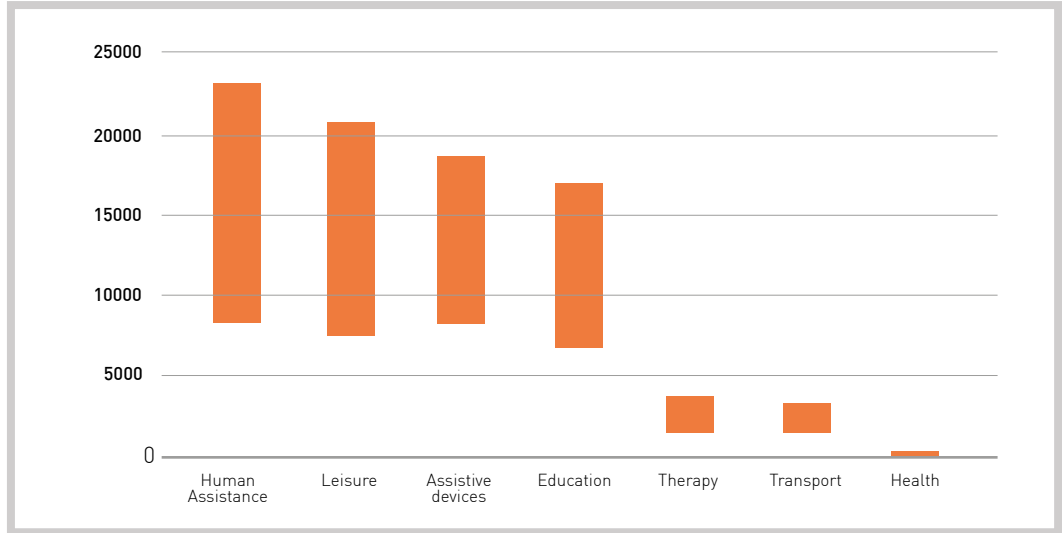


Fig 1.4.2 Break up of goods and services required by deaf children and their costs per month in INR



⁹ As shared by parents of deaf children during the FGD.

¹⁰“Who pays the price when cochlear implants go obsolete?” – By Michele Friedner, 29.03.2023 - <https://www.sapiens.org/culture/planned-obsolescence-cochlear-implants/?ref=disabilitydebrief.org> – accessed on 18.05.2023

The one-time cost of cochlear implant (Rs. 600000 – part of the government program) is not included in the graph.

Figure 1.4.3: Costs of goods and services to families per month and goods and services required but not available / affordable

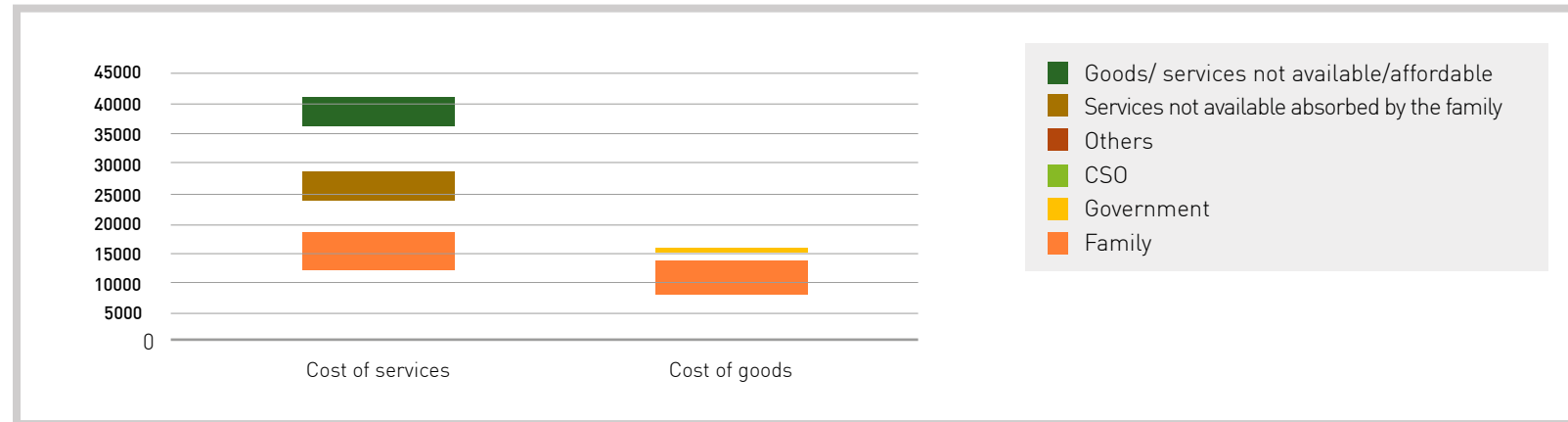


Figure 1.4.3 highlights that the majority of costs of goods and services are borne by the family. Services such as sign language training, sports coaching are not available, and teaching and learning equipment and materials are not affordable by the families, even though they are felt to be essential.

Table 1.4.1: Types and costs of products and services required by deaf children

Category	Sub Category	Monthly	Once in 6 months	Once in a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	child care	5000-10000					
	Education related support	3000-5000					
Assistive Device	Hearing aid				30000-50000		
	Cochlear Implant						600000
	Maintenance			50000-100000			
	Laptop				50000-75000		
	Smartphone				15000-25000		
Education	Sign Language	5000-7500					

	Internet	1000-1500
	Teaching learning materials	10000-15000
Transportation	Bus fare for the parent	1500-2000
Health	Ear Check up	500-1500
Therapy	Speech Therapy	1500-2500
Leisure and Sport	Yoga	3000-5000
	Foot Ball	3000-5000
	Silambam	1500-3000

Deaf adults

Figure 1.4.4: Range of costs of goods and services required per month by Deaf adults in INR

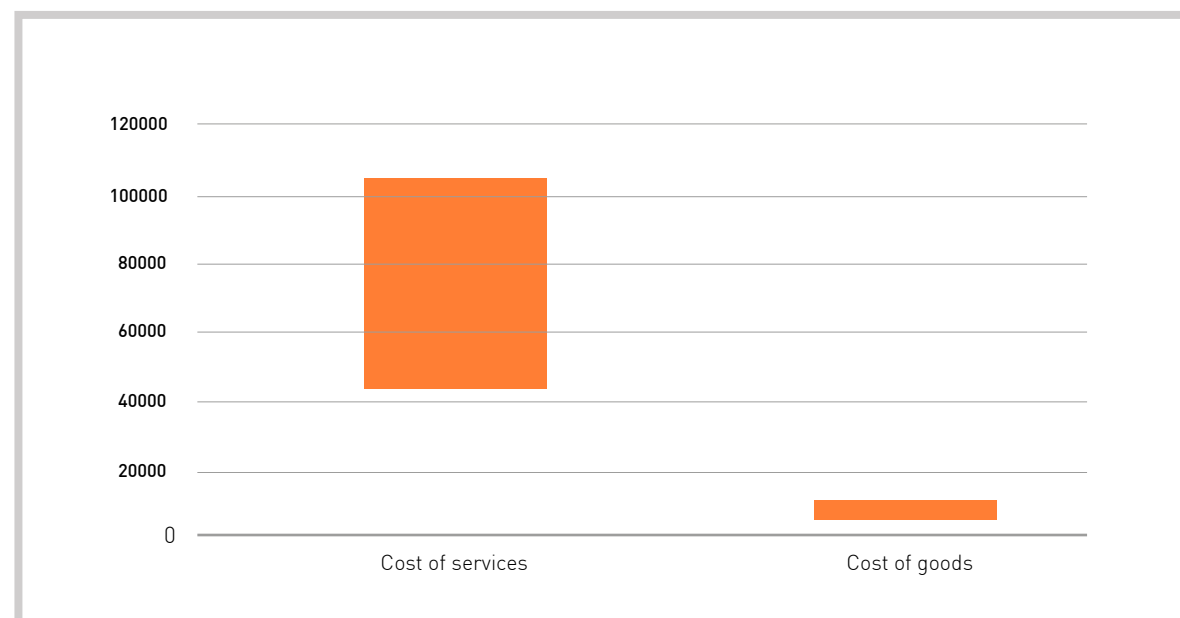
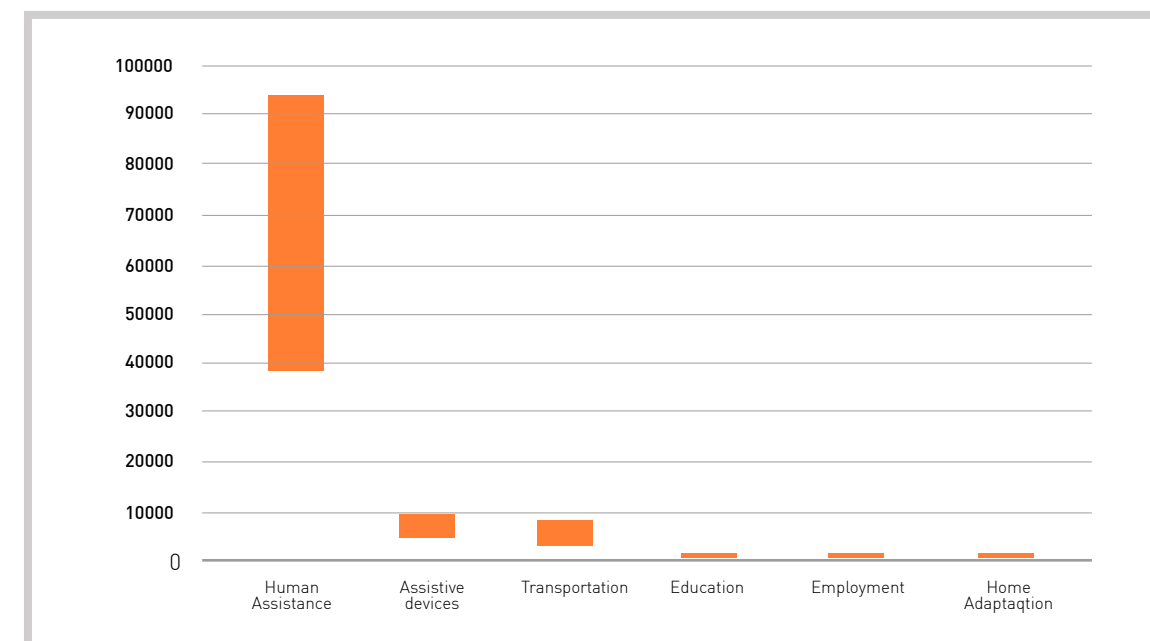
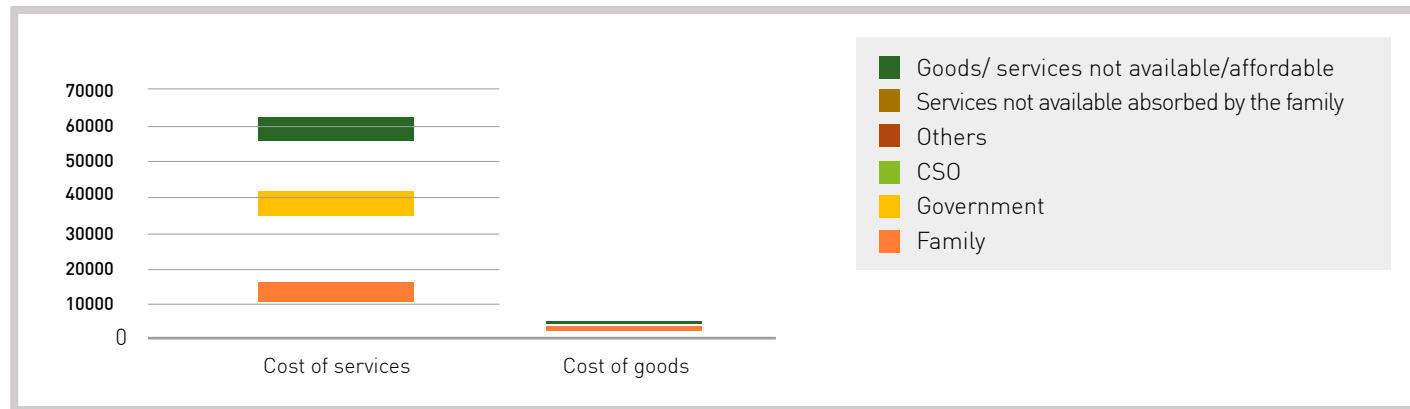


Figure 1.4.5: Break up of goods and services required by deaf adults and their costs per month in INR



The cost of services for deaf adults includes sign language interpreters, orientation support in employment, and health. In Tamil Nadu, sign language interpretation service is available only in educational institutions focusing on education for the deaf. In other contexts, people have to rely on video relay services, which is expensive. Access to sign language interpretation services is very limited in rural areas, and people generally rely on family members for relay communications. For students accessing higher education in the specified course, sign language interpretation is provided by the educational institution (government-run institution). However, this service is not available in all colleges across different courses.

Figure 1.4.6: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - Deaf adults



“People find it extremely hard to cope up in their work place, where there is no interpreter to facilitate [a] smooth flow of information across levels of management and among colleagues. Deaf people generally feel isolated in those environments.”

As shared by Kavitha, deaf person and expert group member

Table 1.4.2: Types and costs of products and services required by deaf adults

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a Year	Once in 2 or 3 years	Once in 5 years
Human Assistance	Sign Language interpretation					
	Education	15000-20000				
	Health	3000-5000				
	Employment	10000-15000				

	Leisure and community participation	10000-15000	
Assistive devices	Smart Phone		15000-30000
	Laptop		50000-75000
	Internet	1000-1500	
Education	Sign Books		1000-5000
	Sign Language dictionary		2000-3000
Transportation		3000-5000	
Home adaptation	Flashing calling bells		1399-5000
	CCTV Camera		5000-10000

Annexure 1.5 Persons with Visual Impairment

The government of Tamil Nadu has a number of schemes that benefit persons with visual impairment, such as cash assistance for scribe, canes, goggles with filters, Braille watches, smart phones, skill development and training programs, and monthly pension.

Despite the various measures adopted by the government, there is an evident gap between what is required by individuals for participation and what is provided by the government.

Children with visual impairment

The monthly cost of goods and services incurred by families of children with visual impairment ranges between Rs. 17515 to Rs. 33028.

Fig 1.5.1 Range of costs of goods and services required by children with disability

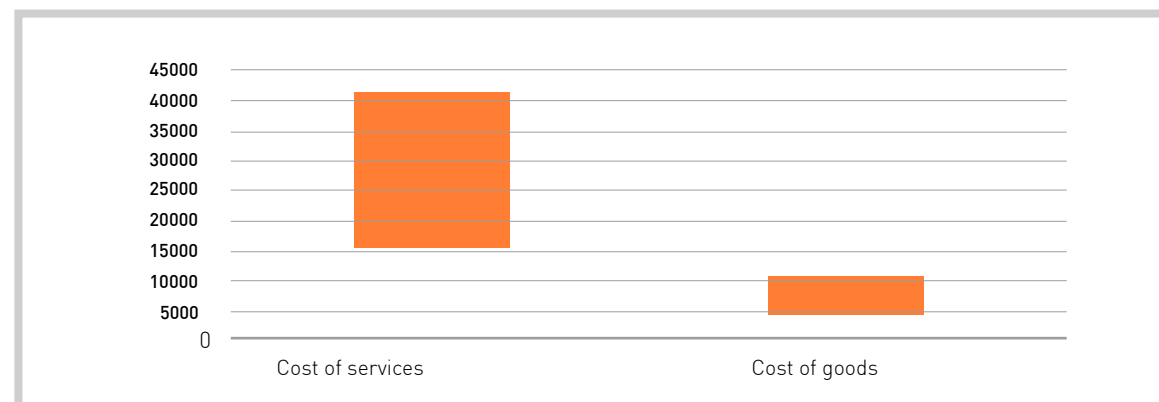


Fig 1.5.2 Break up of goods and services required by children with disability and their cost per month in INR

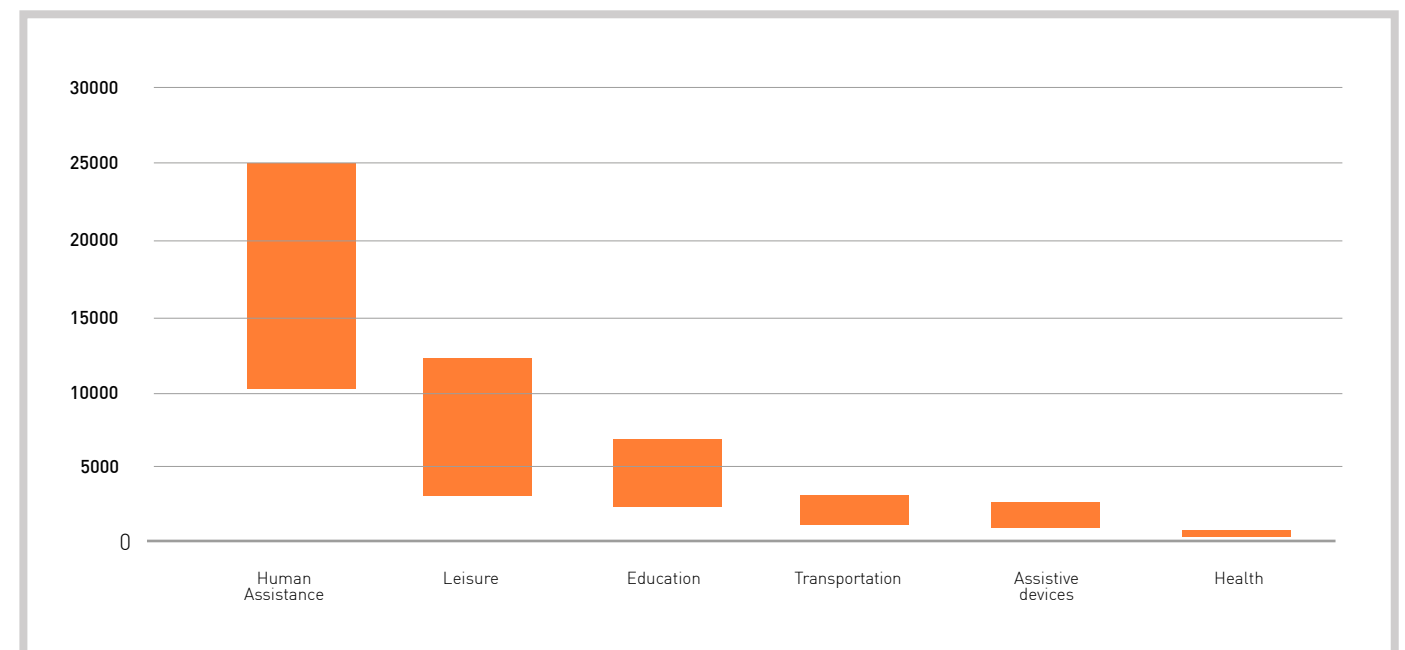


Table 1.5.1: Types and costs of products and services required by children with visual impairment

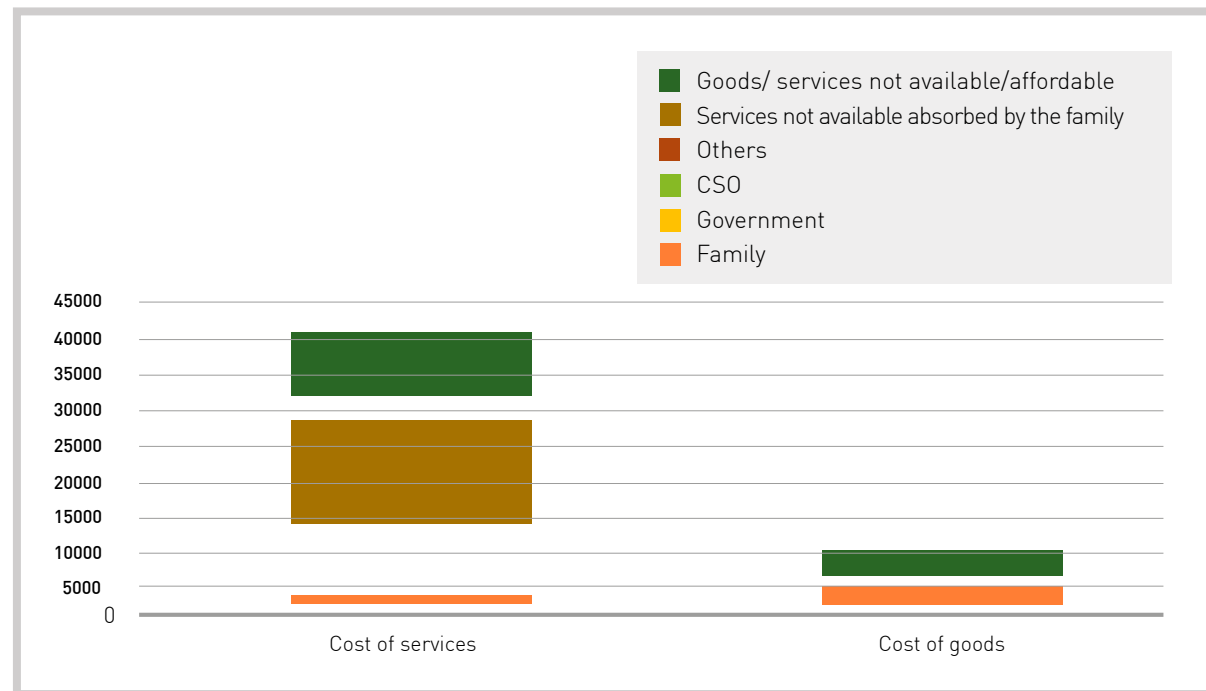
Category	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Care giver / nanny - 8 hrs	10000-15000					
Assistive devices	Cane		500-1000				
	Smart Cane		1000-3000				
	Braille Slate & Stylus				1000-3000		
	Long Note Books	500-1000					
	Recording Device			500-1000			
	Specs			1000-3000			
	Magnifier & Lens					10000-15000	
Education	Braille Guide and Books for younger kids			3000-5000			
	Lap tops				50000-100000		
Transportation	Bus fare for escorts	500-1000					
	Private transport for emergencies	500-1000					
Health	Eye Check Up			500-1000			
	Eye Drops	500-1000					
Leisure & sport	Indoor games	1000-3000					
	Additional Coaching	1000-3000					
	Instrumental Music	1000-3000					

The cost to the family and the range of goods and services required but not available are represented in Figure 1.5.3. The majority of the cost of services that are required by children is borne by their families. Almost two thirds of the goods and services required by the children are either not affordable or accessible for consumption.

“We used to be with our children during school hours since the schools do not provide support services to access toilets, during lunch hours and so on. In fact, the schools expect us to be with our children.”

As shared by parents of children with visual impairment during the FGD conducted for this purpose

Figure 1.5.3: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - Children with visual impairment



Adults with visual impairment

The total cost of goods and services for adults with visual impairment ranges between Rs. 35016 to Rs. 63042 per month, which is around 60 to 100% of the families' income.

Fig 1.5.4 Range of costs of goods and services required by adults with disabilities per month in INR

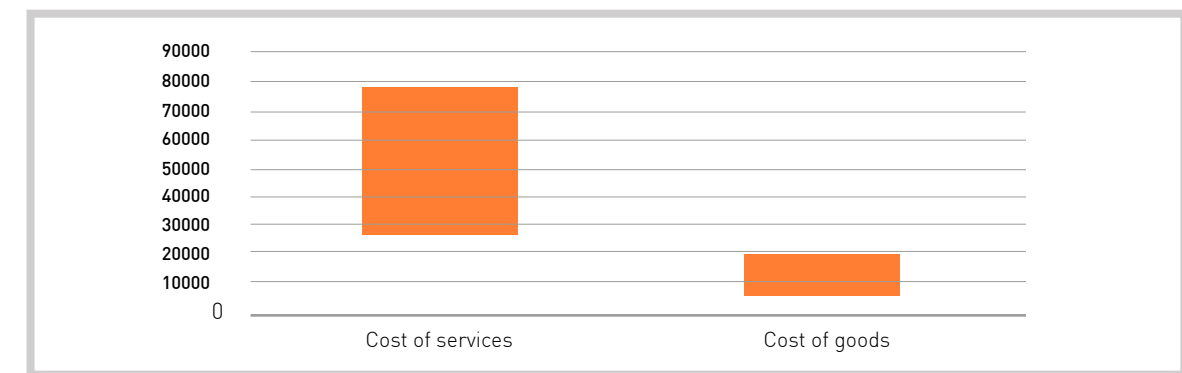


Fig 1.5.5 Break up of goods and services required by adults with disabilities and their costs per month in INR

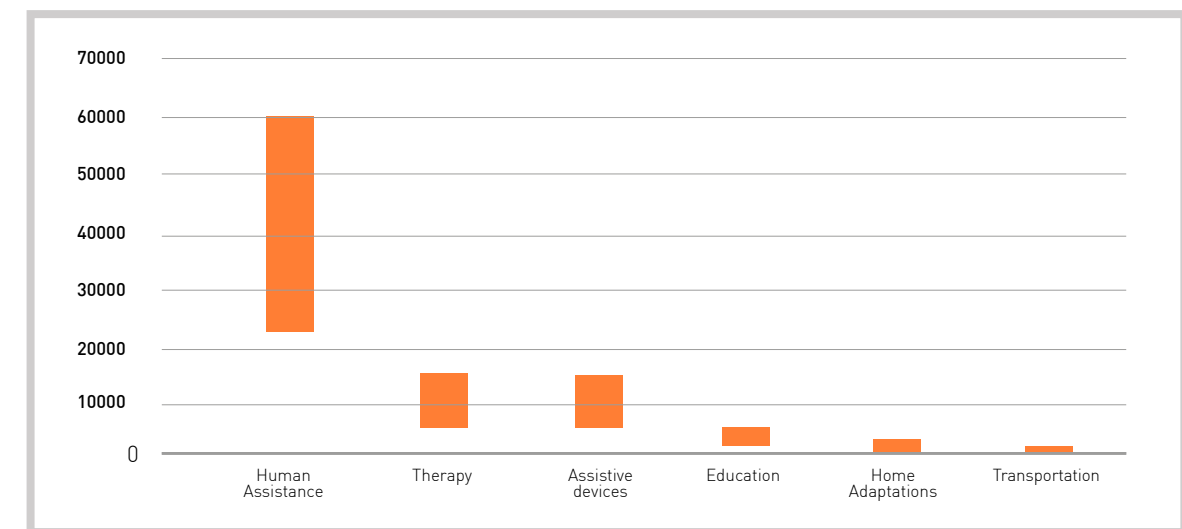


Table 1.5.2: Types and costs of products and services required by adults with visual impairment

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 Years	Once in a life time
Human Assistance	PA (few hours at least 2 hours a day)	3000-5000					
	Scribe		500-1000				
	Reader	3000-5000					
	Household support	1000-3000					
	Child care	5000-10000					
	Older person care support	10000-15000					
Assistive devices	Envision mobile application			500-1000			
	Stick		500-1000				
	Smart Phone				10000-15000		
	Braille Watch				1000-3000		
	Talking Watch		100-500				
	Mobile Speaker			500-1000			
	Smart Vision Eye Glass				25000-50000		
	Head phone			1000-3000			
	Tactile maps			3000-5000			
	Pen labeller				5000-10000		
	Alexa				5000-10000		
Education	Scanner				5000-10000		

	Reader	
	MS Office Soft Ware	5000-10000
	Science & Math educational Soft Ware	3000-5000
	Tactile learning material	5000-10000
Partially available	Orbit Digital Braille	25000-50000
	Lap top	50000-100000
	Braille books	5000-10000
Transportation		500-1000
home modifications	Audio enabled house hold devices	25000-50000
Health	Gym	5000-10000

The story of Aruna Devi and Figure 1.5.6 explain the cost to the families and the nature of goods and services that are required but not available or affordable by the individual or the families.

“Government provides cane/walking sticks. However, it takes nearly 3 to 6 months for accessing the product if we apply with the government. Mostly canes are available in big surgical shops in Chennai and not in other districts. So, I always keep one extra cane with me as it often breaks due to the terrain and the traffic in Chennai.”

As shared by Aruna Devi, a person with visual impairment, member of SFRWD (Women’s Federation Tamil Nadu)



Story of Aruna Devi

(adult with visual impairment)

Aruna Devi has a master's in social work and works with the government of Tamil Nadu. Her monthly income is Rs. 40,000. She has a daughter and they live in Chennai along with Aruna's mother.

Aruna is also a disability rights activist and is well aware of the government schemes and programs related to persons with disabilities.

Aruna requires the following support:

- ▲ 1. Transportation
- ▲ 2. Mobility assistance
- ▲ 3. Domestic help
- ▲ 4. Child care
- ▲ 5. Assistive devices such as cane, smart phone and laptop

Costs for Aruna

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Human Assistance	House hold Support	6000				
	Child care	10000				
	Mobility Assistance	5000				
Transportation		8000				

Assistive devices	Smart Phone			25000		
	Lap top				75000	
	Cane		3000			
Increased household expenses	Increased cost of regular items	4000				
Support to child	Enrolment of child in extracurricular activities	3000				

Total Cost / Who Provides / Availability

Category	Sub- Category	Goods monthly	Services monthly	Family	Government	CSO	Cost required	Cost incurred
Human Assistance	Household work		6000	100%			6000	6000
	Child care		10000				10000	Service NA
	Mobility Assistance		5000				5000	Service NA
Transportation			8000	100%			8000	8000
Assistive device	Smart phone	1042		100%			1042	1042
	Laptop	2083		100%			2083	2083
	cane	250		100%			250	250
House hold extra costs	Regular items such as fruits and vegetables	4000		100%			4000	4000
Child related	Enrolment of child in extracurricular activities		3000				3000	Cannot afford
Toral		7375	32000				39375	21375

Share of Costs

Nature of Expense	Family	Government	CSO	Service Not Available absorbed by the family member	Goods Not affordable & accessible	Total
Goods	7375					7375
Service	14000			15000	3000	32000
Total	21375			15000	3000	39375
Percentage	54			38	8	100

Figure 1.5.6 is an overview of the costs incurred by the family or the individual and the nature of goods and services required but not affordable / available. The majority of services required are not available for adults with visual impairment, such as child care, mobility assistance and orientation support in the work environment.

Figure 1.5.6: Costs of goods and services incurred by the family per month goods and services required but not available / affordable - Adults with visual impairment



Annexure 1.6 Persons with Psychosocial Disability

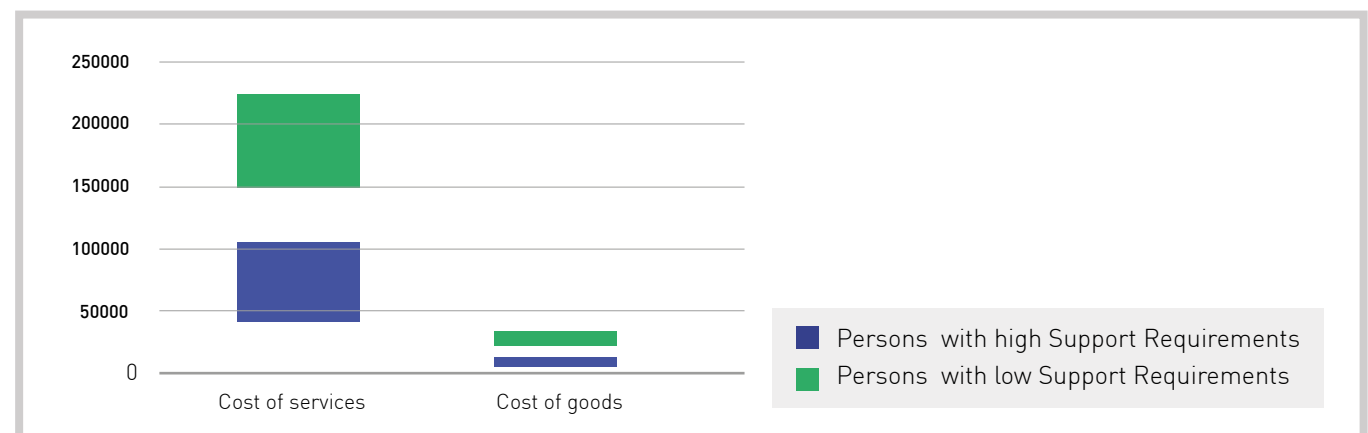
There is a lack of specific programs addressing the diversity of needs of persons with psychosocial disabilities. The government-run programs include homes or rehabilitation or rescue centers, supply of medications and review. The cash transfer program is not extended to persons with psychosocial disabilities.

The range of cost of goods and services required ranges between Rs. 44750 to Rs. 70500 for people with high support needs, and between Rs. 51275 to Rs. 85921 for those with low support requirements.

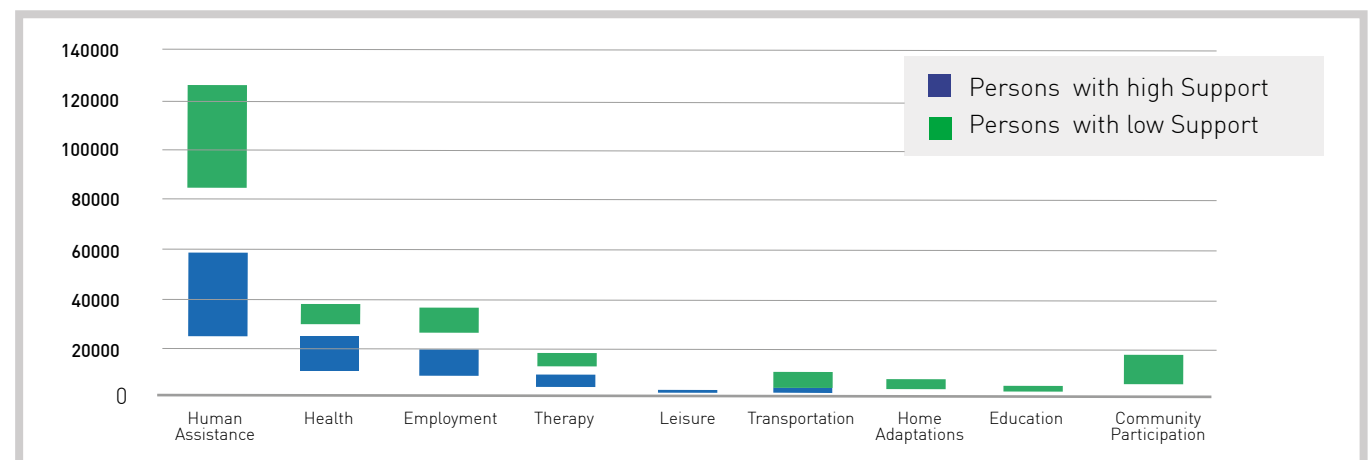
Figure 1.6.1 highlights the range of goods and services required and the range of costs. Irrespective of the level of support needed, the cost of services is higher among persons with psychosocial disability.

Fig 1.6.1 Range of costs of goods and services required by adults with psychosocial disability per month in INR

Fig 1.6.2 Break up of cost of goods and services required by adults with disability and their costs per month in INR



As shown in Figure 1.6.2, irrespective of the level of support needed, human assistance represents the highest proportion of the cost. The second highest cost for persons with



“Usually, people with low support requirements will be willing to participate and require a range of support services such as job coach, peer counselling, education related support and so on [,] contrary to people with high support requirements, where the majority of cost required will be for personal assistants, medication and other forms of rehabilitation.”

As shared by Punitha Suresh, a person with psychosocial disability, expert group member

high support requirements is health care, and community participation for people with low support requirements, followed by employment and health care.

Table 1.6.1: Types and costs of products and services required by persons with psychosocial disability – high support requirements

Category	Sub-Category	Monthly Costs	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Cook	7500-10000					
	Personal assistance	10000-15000					
Health Care	Medicines	5000-7500					
	Thyroid related medicines	100-500					
	Diagnostics	500-1000					
	Skin related issues			2000			
Therapy	Counselling	1500-3000					
	Yoga	1500-2000					
Employment	Job Coach	5000-10000					
	Counselling	7500-10000					
Leisure	Travel	350-500					
	Social gathering	800-1000					
Home modifications							

Table 1.6.2: Types and costs of products and services required by persons with psychosocial disability – low support requirements

Category	Sub-Category	Monthly Costs	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 Years	Once in a life time
Human Assistance	Cook	7500-10000					
	Personal assistance	10000-15000					
	Education Support / Guide	3000-5000					
Transportation	Private transport like taxis/ auto	2500-5000					
Education	Audio Notes	1500-2000					
Health Care	Medicines Psychiatric	5000-7500					
	General Health	100-500					
	Reproductive health care	208-291					
Therapy	Counselling	1500-3000					
	Yoga	1500-2000					
Employment	Job Coach	5000-10000					
	Counselling	7500-10000					
Leisure	Travel	350-500					
	Social gathering	800-1000					
Gardening/ Planting		1000-1500					
Home modifications	Changing paints / design	1500-2000					
Community participation	Legal services			50000-150000			

“

“In Chennai there are many NGOs reaching out to persons with psychosocial disabilities. Therefore, mostly costs of medicines are taken care of by those NGOs if the individual has access to such services. There is huge gap in availability of specific health services in rural areas and mostly the medicines available at the health care centers almost adopts a one size fits all approach without catering to the diversity of needs. People have to often travel to cities or district headquarters to access those medicines.”

”

As shared by Dr. Kotteeswara Rao, specialist working with people with psychosocial disability

The government adopts a medical approach towards persons with psychosocial disabilities without focusing on community participation, community level services and ensuring availability of a range of rehabilitation services and alternatives to medicines.

Story of Lokesh Vethathri

(adult with psychosocial disability)

I work for an NGO in Chennai. I earn Rs. 9000 per month. I am married and have a child. Both my wife and child are persons with disabilities. My child is studying 3rd standard. I have studied 12th standard and I had to drop out of college during my second year in college due to my condition.

I am 43 years old and only for the past nine years I have had a constant job. Previously I used to work for three months and leave the job. I used to be stressed out and scared all the time, and I did not engage with my co-workers.

When I started working at the NGO, I earned Rs. 2500 per month. I give my mother Rs.1000 and I spend Rs. 1000 on travel and keep Rs. 500 for smoking. Then I realised the cost involved in smoking and quit.

Currently I do not have any medical costs, and all my medication-related expenses are taken care of by the organisation with which I am working. However, we have extra costs related to the education of my child. I am managing most of it by working part-time on weekends.

If I get more money I could spend it on the educational and specific needs of my child, which is not possible at present.

We used to travel long distances and visit many temples once in 2 to 3 months. This helps me to focus and work effectively. This involves some cost but we cannot avoid this. I am not getting any benefit from the government. We are managing all expenses from my income only.

Figures 1.6.3 & 1.6.4 highlight the costs to the families and the range of goods and services required but not available / accessible.

Figure 1.6.3: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - persons with high support requirements

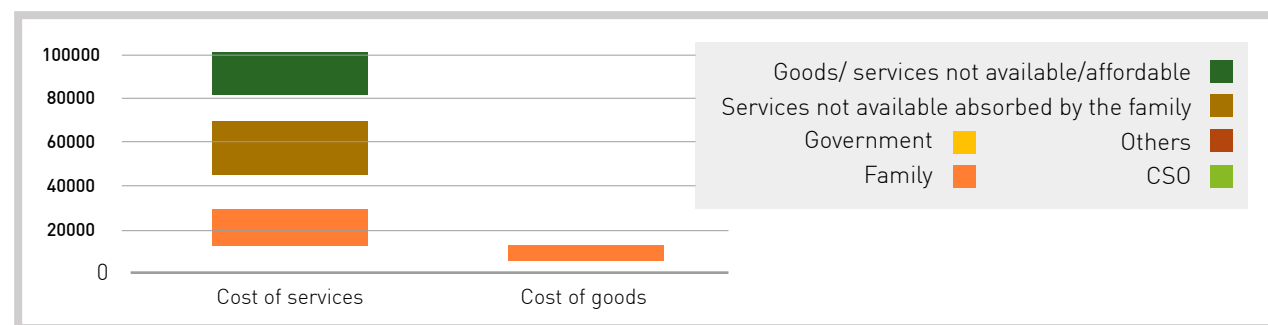
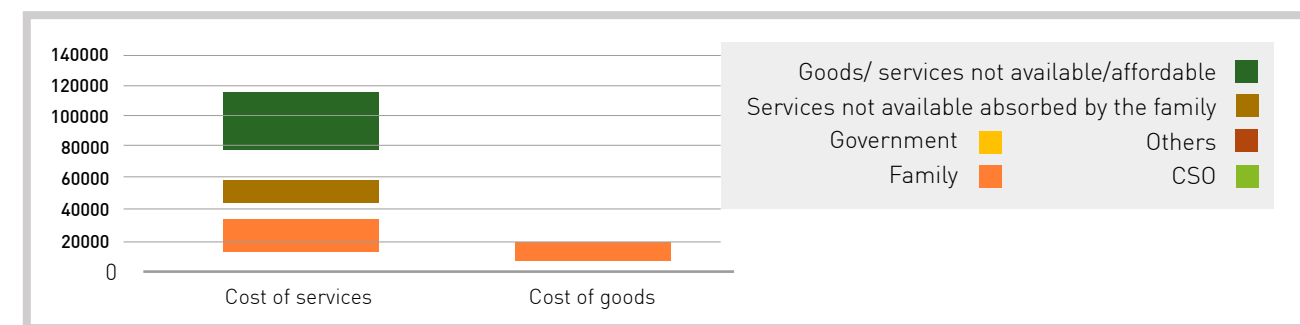


Figure 1.6.4: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - persons Low support requirements



The majority of the services required are not available for persons with psychosocial disabilities, irrespective of their level of impairment. These include PA, legal aid, tutoring and mentoring, and work place support services.

Annexure 1.7 Deafblind

Neither the Census 2011 nor the NSSO disability survey 2018 has captured specific data on deafblind persons in India, since the condition is clubbed under the category of multiple disabilities in the schedule to the RPDA 2016.¹¹

“Lack of specific data of deafblind people has resulted in lack of policies and programs that ensure participation and effective inclusion. This has also perpetuated the existing misconception of extending services for the deaf and for the blind people to persons with deafblindness. This has adversely impacted the full and effective participation of this population.”¹²

However, a survey conducted in 110 districts in 23 states across India revealed that there are 500000 deafblind people in India.¹³

A fact sheet produced by the Society for the Empowerment of the Deafblind (SEDB) India revealed that deafblind people in India lack access to general services such as education and health skill development programs, resulting in lack of employment, and also lack availability of habilitation, rehabilitation and other support services such as tactile interpretation, guide interpreter services and assistive devices.¹⁴

Children with disabilities

“We come from a rural area. My son is deafblind and we do not have any services in our village. We have to travel to Chennai to access the services of NIEDPMD. But we also need to support our child at home to practice whatever is taught here. But we do not have the necessary equipments as basic as an accessible table, chair and lighting for my child at home.”

As shared by a parent during the FGD conducted for this purpose

¹¹“How restricted are Deafblind people in India?” – A fact sheet by SEDB India

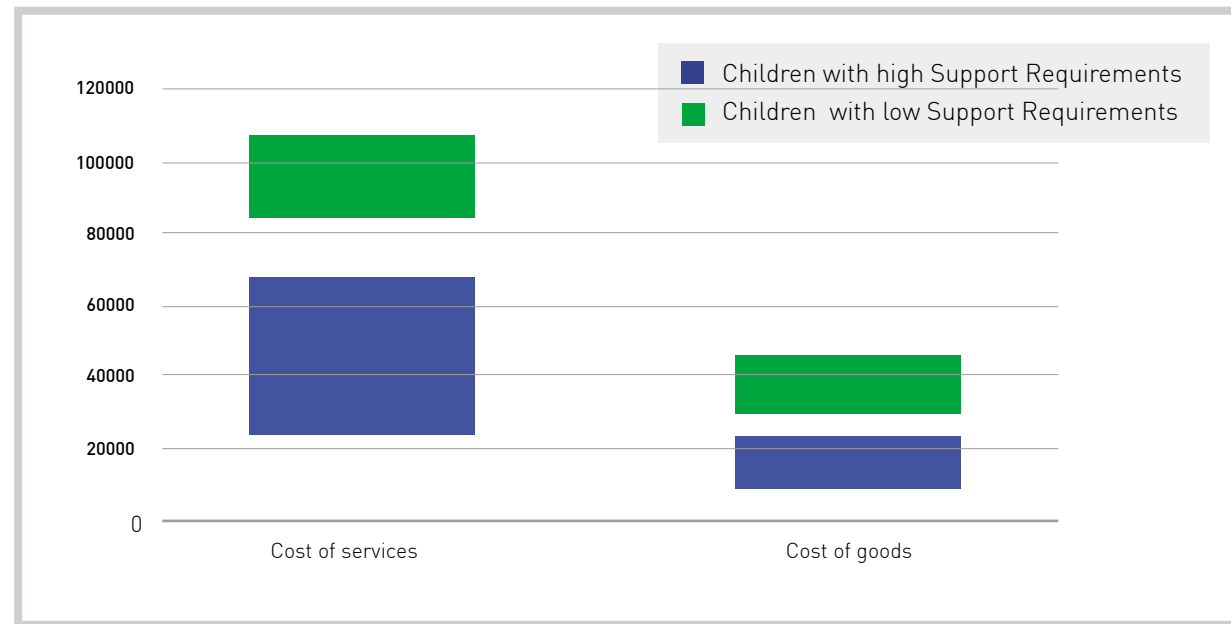
¹² ibid

¹³ “5 Lakh deafblind people across 23 states, reveals data” by Shivani Azad/TNN/Oct 30,2020 - <https://timesofindia.indiatimes.com/city/dehradun/5-lakh-deaf-blind-people-across-23-states-reveals-data/articleshow/78938535.cms> - accessed on 27.05.2023

¹⁴ “How restricted are Deafblind people in India?” – A fact sheet by SEDB India

The range and cost of goods and services required by deafblind children is explained in Figures 1.7.1.

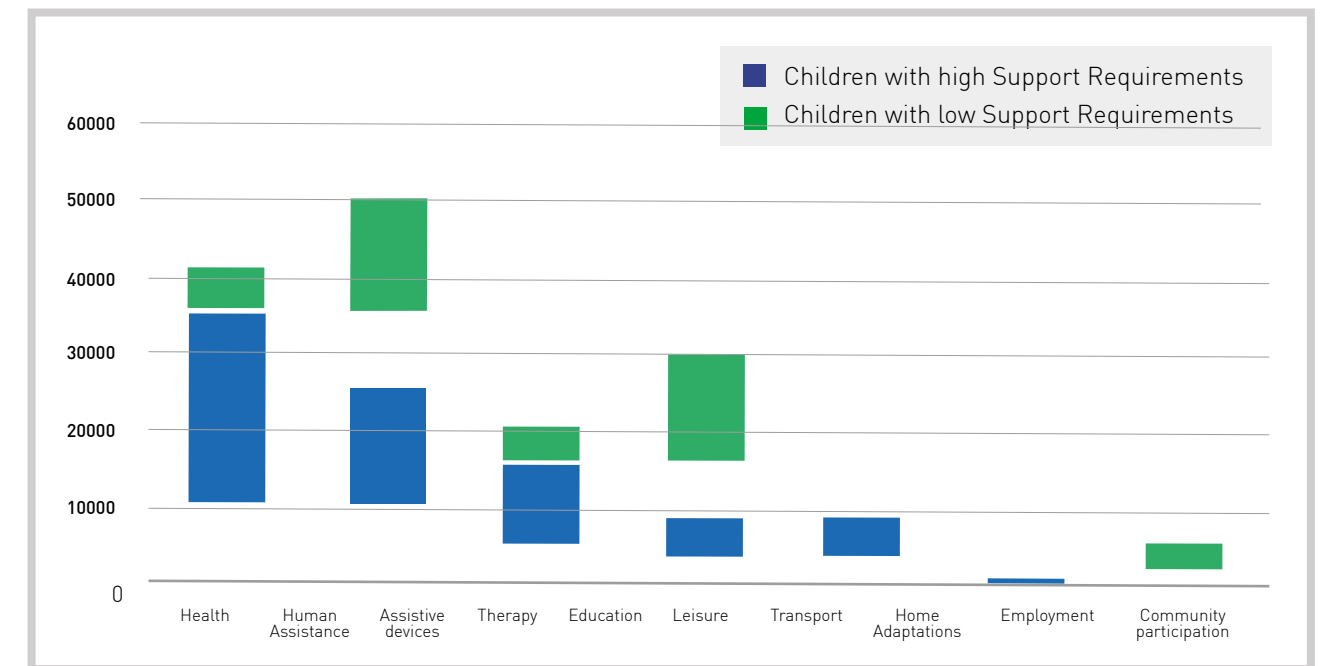
Fig 1.7.1 Range of costs of goods and services required by children with disabilities per month in INR



Unsurprisingly, the cost of services required by children with high support requirements is higher than for children with low support requirements. However, the range of cost of goods is higher for children with low support requirements than for children with high support requirements.

Figure 1.7.2 highlights the range of goods and services required across activities and domains.

Fig 1.7.2 Break up of goods and services required by children with disabilities and their costs per day in INR



Human assistance takes the highest priority, followed by assistive devices and health for children with high support requirements and followed by education costs and among children with low support requirements.

Tables 1.7.1 & 1.7.2 provide the details of categories and sub-categories of goods and services required by deafblind children.

Table 1.7.1: Types and costs of products and services required by deafblind children – low support requirements

Category	Sub-Category	Monthly Costs	Once in 6 months	Once a year	Once in 2 to 3 years	Once in 5 years	Once in a life time
Human Assistance	Caregiver	10000-15000					
Assistive device	Hearing Aid				3000-50000		
	Cochlear implant						

	Voice recorder		3000-5000
	Specs		1000-10000
	Smart phone		10000-20000
Education	Magnifier		3000-50000
	Large Font Books		1000-5000
	Audio Visual Books		3000-5000
	Accessible Lights		100-1000
	Custom Made Furniture		5000-10000
Health	Weight Management	3000-5000	
	Medicines	1000-3000	
	Consultation	500-1000	
	diaper	3000-5000	
Transport		1500-3000	

Table 1.7.2: Types and costs of products and services required by deafblind children - high support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 Years	Once in a life time
Human Assistance	Caregiver	10000-15000					
Assistive device	Hearing Aid				3000-50000		
	Voice recorder			3000-5000			
	Mike and amplifier				5000-15000		
	Head Phone			5000-20000			
	Laptop				50000-75000		

	Smart phone	10000-20000
	Tab	25000-35000
	Sound making spoon	
	Sipper cups	100-500
Home adaptation	CCTV	5000-10000
education	Additional Tutors	5000-10000
	Braille Slate and Stylus	500-1000
	tactile sign interpreter	5000-15000
Health	Pampers	3000-5000
Therapy	OT	3000-5000

Figures 1.7.3 & 1.7.4 highlight the costs of goods and services incurred by the families of deafblind children, and the costs of goods required but not available or affordable for equal participation.

Figure 1.7.3: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - Deafblind children - High Support Requirements

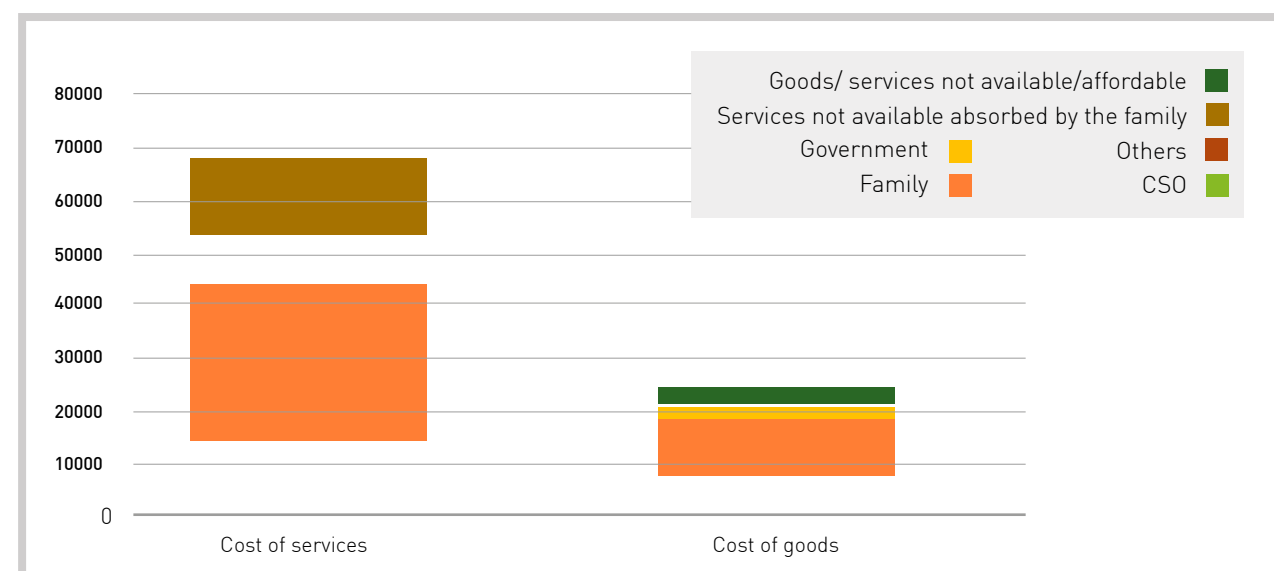
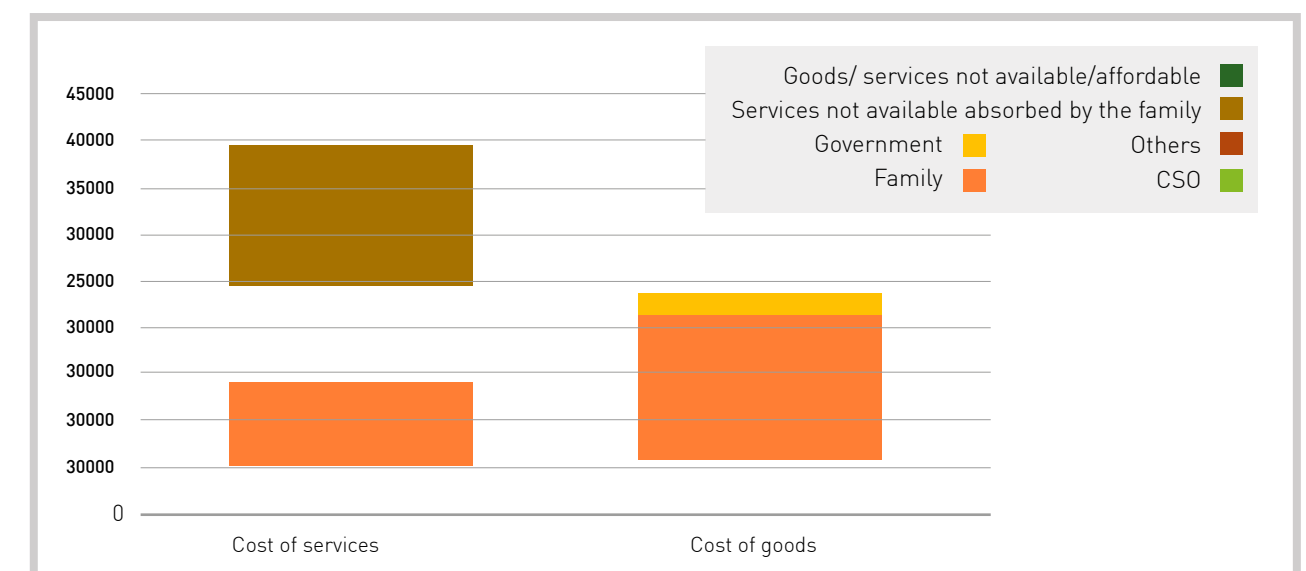


Figure 1.7.4: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - Deafblind children - Low Support Requirements



Deafblind adults

Fig 1.7.5 Cost of goods and services required by adults with disabilities per month in INR



Fig 1.7.6 Break up of goods and services required by adults with disabilities and their costs per month in INR

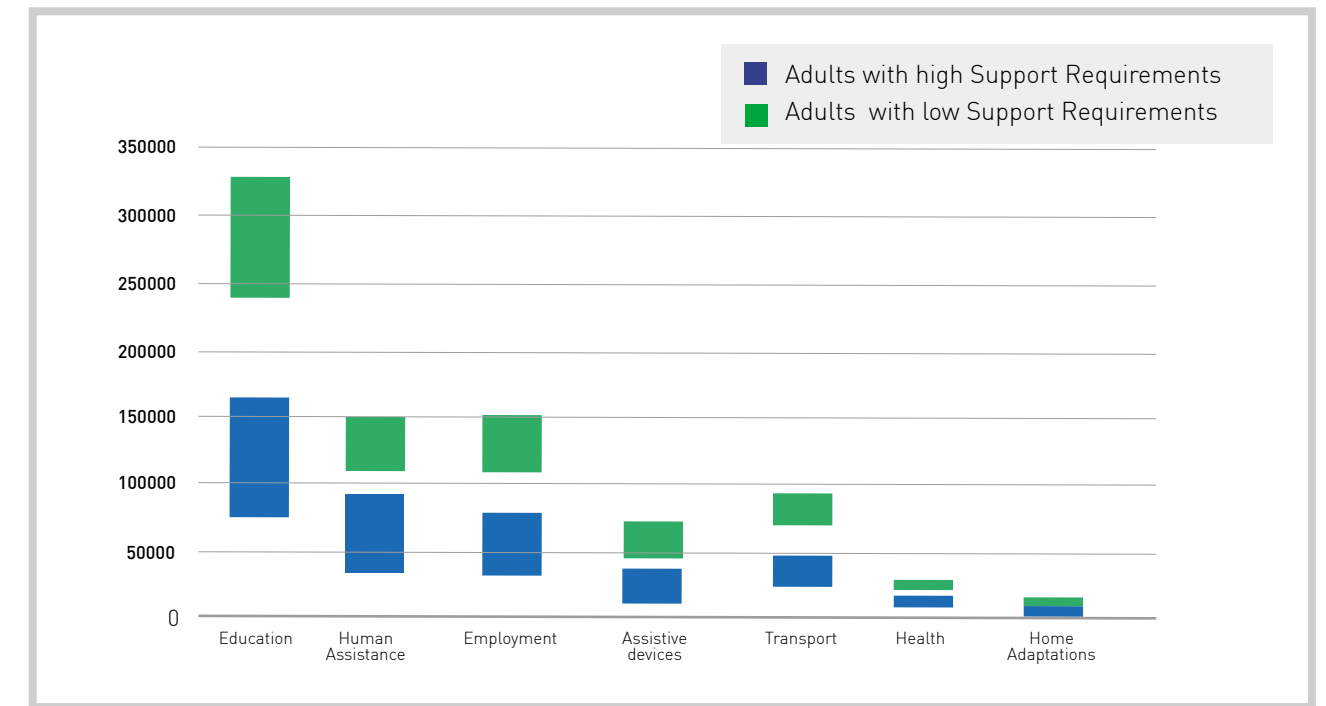


Table 1.7.3: Categories and sub-categories of products and services required by deafblind adults and their costs - high support requirements

Category	Sub-Category	Monthly Costs	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 Years	Once in a life time
Human Assistance	personal assistant for self-care and Leisure	5000-12000					
	Tactile interpreter for education, employment and health	5000-15000					
	Guide Assistance	5000-15000					
	Job Coach	15000-20000					
Assistive devices	Computer				50000-75000		

			20000-50000
	High Speed Internet	1000-1500	
	Colour Coded Cane / smart cane		1000-1500
	low vision keyboard		2000-4000
	refreshable braille display (few and many cells)		45000-200000
	Alexa/ google home		500-1000
	Smart Phone with GPS & large screen		10000-20000
	Torch Light	500-1000	
	magnifier (hand held, illuminated and electronic)		500-50000
	Spectacles (special lenses, filters, field expanders)	1000-10000	
	screen magnifier		6000-20000
	hearing aid		3000-250000
	large display/ braille watch/ clock		1200-6000
Home Modifications	vibrating doorbell		6000-10000
	alerting devices		
	slip free & high contrast mats		200-3000
	adapted cutlery and dish		3000-5000
	braille labeller		6000-10000
	task lighting		2000-8000
	tactile markers	500-5000	

	smart kitchen appliances	2000-40000
	vacuum cleaner (regular or robot)	3000-50000
Education	Braille Books	
	Large Print	50000
	Plain language books	
	Tactile interpretation Training	15000-20000
	low vision device training	15000-20000
	mobility training	5000-10000
	independence training	15000-20000
	technology training	15000-20000
Health	vision care	5000-10000
	review for heart health	5000-10000
	endocrine issues	2000-5000
	digestive and circulatory issues	2000-5000
	seizures	5000-10000
	sleep and nutrition issues	2000-5000
	mental health issues	3000-5000
	dental issues	2000-5000
Transportation	reliable and accessible transport	20000-25000
Employment	Training for computer operating	10000-15000
	training for technology	10000-15000
	training in mobility	10000-15000
	communication cards and strategies for daily life	100-500

Table 1.7.4: Types and costs of products and services required by deafblind adults - low support requirements

Category	Sub-Category	Monthly cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 Years	Once in a life time
Human Assistance	personal assistant for self-care and Leisure	5000-12000					
	Tactile interpreter for education, employment and health	5000-15000					
	Guide Assistance	5000-15000					
Assistive devices	Computer				50000-75000		
	Text to Speech App				20000-50000		
	High Speed Internet	1000-1500					
	Colour Coded Cane / smart cane				1000-1500		
	low vision keyboard				2000-4000		
	refreshable braille display (few and many cells)				45000-200000		
	Alexa/ google home				500-1000		
	Smart Phone with GPS & large screen				10000-20000		
	Torch Light			500-1000			
	magnifier (hand held, illuminated and electronic)					500-50000	
	Spectacles (special lenses, filters, field expanders)			1000-10000			
	screen magnifier					6000-20000	
	hearing aid					3000-250000	
	large display/ braille watch/ clock						1200-6000
Home Modifications	vibrating doorbell						6000-10000

	alerting devices		
	slip free & high contrast mats		200-3000
	adapted cutlery and dish		3000-5000
	braille labeller		6000-10000
	task lighting		2000-8000
	tactile markers	500-5000	
	smart kitchen appliances	2000-40000	
	vacuum cleaner (regular or robot)		3000-50000
Education	Braille Books		
	Large Print		50000
	Plain language books		
	Tactile interpretation Training	15000-20000	
	low vision device training	15000-20000	
	mobility training	5000-10000	
	independence training	15000-20000	
	technology training	15000-20000	
Health	vision care		5000-10000
	review for heart health		5000-10000
	endocrine issues		2000-5000
	digestive and circulatory issues		2000-5000
	seizures		5000-10000
	sleep and nutrition issues		2000-5000
	mental health issues		3000-5000

	dental issues	2000-5000
Transportation	reliable and accessible transport	20000-25000
Employment	Training for computer operating	10000-15000
	training for technology	10000-15000
	training in mobility	10000-15000
	communication cards and strategies for daily life	100-500

In these tables, it could be observed that almost all sub-categories of goods and services required are almost the same irrespective of the level of support.

Lack of appropriate early intervention services and lack of trained support services such as tactile interpreter, orientation to various tools and equipments, and interpretation has led to low outcomes in education and employment for deafblind persons.¹⁵ This calls for more and effective investment in training and development of trainers across activities such as education, skill development and work, and employment.

“37.5 per cent of respondents expressing the need for a lot of support and 56 per cent requiring some support. Six per cent of the respondents expressed the need for a lot of support even in familiar places, while 62.5 per cent needed at least little support to travel to and from work and to familiar places. 25 per cent said they could manage independently if the places were familiar to them. When it came to mobility and communication, 87 per cent of the respondents expressed that they have knowledge about the various assistive devices. However, many reported not owning many basic devices. Of the respondents, 12.5 per cent reported to have canes while 50 per cent said they do not have smart canes. 25 per cent reported lack of stylus and slate, 43.75 per cent said they do not have Brailier (Braille typewriter) 37.5 per cent stated that do not have a Braille reader. 78.57 per cent were employed in the informal sector. It also noted that 43.75 per cent of those working reported that they were not paid at par with others; 25 per cent said there is no pay and 50 per cent of the respondents stated that their disability hindered their access to work and employment”¹⁶

¹⁵ “How restricted are Deafblind people in India?” – A fact sheet by SEDB India

¹⁶ “New Report highlights major gaps in access experienced by people with deafblindness, The Indian Express” Posted on August 20, 2020 - <http://www.sedbIndia.org/new-report-highlights-major-gaps-in-access-experienced-by-people-with-deafblindness-the-indian-express/> - accessed on 27.05.2023

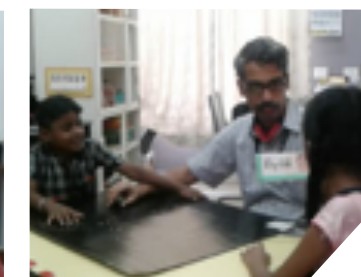
Story of Mahadevan

(deafblind adult)

Mahadevan is a deafblind person with some residual vision. He works as a contractual staff with the National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD). His monthly income is Rs. 16000. At NIEPMD he is teaching children with multiple disabilities, which is one of his passions since he struggled in his childhood to have an appropriate learning environment.

He is married and has a child. His mother lives with him. Goods and services required by Mahadevan include:

- 1. Assistive devices
- 2. Transport
- 3. Personal assistant service
- 4. Health care



Costs for Mahadevan

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Human Assistance	PA for few hours, few days and during Leisure trips	5000				
	Tactile interpreter	5000				
	Mobility Assistant	3000				

Assistive device	Smart phone				25000	
	Tab				30000	
	Magnifier				15000	
	torchlight			500		
	Cane		3000			
	RBD			50000		
	Large print	1000				
	Plain Language	NA				
	Spectacles		10000			
Health care	Blood	5000				
	Medicine	10000				
Transport	Public Transport	1500				

Total Cost / Who Provides / Availability

Category	Sub- Category	Goods monthly	Services monthly	Family /friends	Government	CSO	Cost required	Cost incurred
Human Assistance	PA for few hours, few days and during Leisure trips		5000				5000	Service NA
	Tactile interpreter		5000				5000	Service NA
	Mobility Assistant		3000				3000	Service NA
Transportation			1500		100%		1500	1500

Assistive device	Smart phone	695		100%		695	695
	Tab	833		100%		833	833
	Magnifier	417				417	NA
	Torchlight	21		100%		21	21
	Cane	250		100%		250	250
	RGB	2083			100%	2083	2083
	Spectacles	833		100%		833	833
	Large Print	1000		100%		1000	1000
	Plain Language	NA					NA
Health Care	Blood tests		417	100%		417	417
	Medicine to prevent vision deterioration	1500		100%		1500	1500
Total		7632	14917			22549	9132

Share of Costs

Nature of Expense	Family	Government	CSO	Service Not Available absorbed by the family member	Goods Not affordable & accessible	Total
Goods	5132	2083			417	7632
Service	417	1500		13000		14917
Total	5549	3583		13000	417	22549
Percentage	25%	16%		58 %	2%	100%

“

“We have so many needs. But because we are very small in numbers, we are not considered in the government policies and programs. We need to engage in a massive advocacy.”

”

As shared by Mahadevan during the interview

Annexure 1.8 Autistic People

The RPDA 2016 has clubbed autism spectrum disorder under the category of mental disabilities. Neither Census 2011 nor NSSO 2018 has data on autistic people. According to a report by ETHealth World, there are about 18 million autistic people in India, and 1 to 1.5 % are children.¹⁷

The government of Tamil Nadu has early intervention and rehabilitation programs, including grants in aid programs for autistic children. Autistic people with high support requirements can access the maintenance grant (cash transfer program) of the DWDA.

“Apart from giving essential services there is hardly any awareness on the significance of giving the opportunity for Recreation-Outings to the Individuals with disabilities. Hi tech learning modalities/ gaming experiences and communication services are still at “not reachable” zone for families who are economically weak and also who live in the Rural areas.

Autistic individuals need an affordable and extended infrastructure considering the services for medical, therapeutic, training of personal assistants and employment to independent living at stages across their life cycle.

Early childhood Intervention for autistic individuals come with a comprehensive package of therapeutic services and inclusive education with specific support for a holistic development! The estimate of cost spent during the schooling period would be maximum considering across the life cycle! Urban families spend a minimum of ₹25,000 (as per average) during this period (3-15 years) whereas though the needs and awareness are the same with the Rural based people, they spend lesser because of the restricted available services and spending capacity. There are cases where parents try home based programs and kids devoid of inclusive education owing to financial constraints, both in case of rural and urban based clients!

¹⁷ “18 million Indians have autism: Learn more about 3rd most common developmental disorder: know the basics of parenting children with autism” – et Online Last updated April 02 2023 - <https://economictimes.indiatimes.com/magazines/panache/18-million-indians-have-autism-learn-more-about-3rd-most-common-developmental-disorder-know-the-basics-of-parenting-children-with-asd/articleshow/99182225.cms?from=mdr> – accessed on 30.05.2023

Considering the young adults of 16-25 years, the cost spent is lesser than the phases before. Cost spent is majorly for medical treatment, skill training or higher education with respect to the Individual concerned. Highly individualized and restricted with focus- here as per our focus group discussions/ study/Observations, maximum cost spent ranges from ₹10,000 to 15,000₹ per month.

During adulthood to later adulthood (25+ years) – the major concern is independent living/ living after Parent’s absence! Discussions were about looking out for “care taker support, group homes, hostels and assistive community living as like inclusive”!

Giving a quality life with proper engagement, treatment, support, parents need to look for an ideal place according to their spending capacity. Cost here ranges from ₹15,000 to ₹45,000!

“ This is the most significant phase considering across the life cycle of an Individual.”

Gayathri Sridhar, expert group member, parent of an autistic person ”

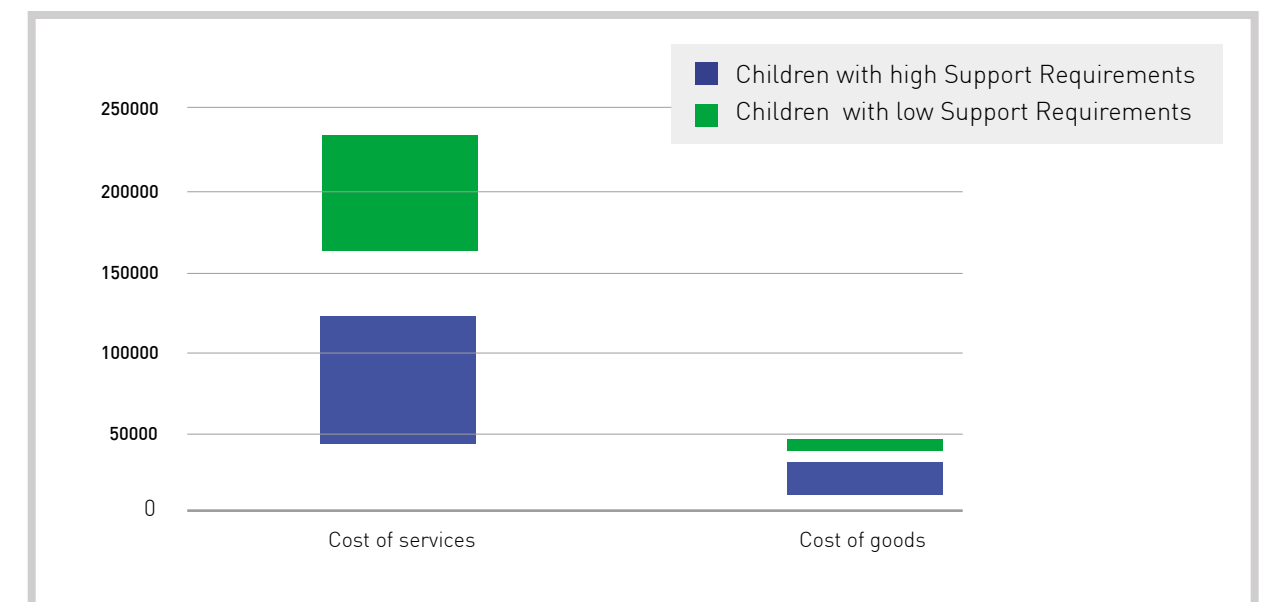
Autistic childrenutism

Figure 1.8.1 highlights the total cost of goods and services required by families with autistic children to ensure full and effective participation.

Irrespective of the level of support, the cost of service required is high compared to the cost of goods required per month.

The total cost of goods and service ranges between Rs. 54758 to Rs. 99917 for children with high support requirements and Rs. 43833 to Rs. 78625 for children with low support requirements.

Fig 1.8.1 Range of cost of goods and services required by children with disabilities per month in INR



The break-up of categories of costs is highlighted in Figure 1.8.2. Human assistance comprises the highest proportion of cost, irrespective of the level of support. This is followed by health care, education and transport for children with high support requirements, and by therapy, education and health care for children with low support requirements.

Fig 1.8.2: Break up of goods and services required by children with disabilities and their costs per month in INR

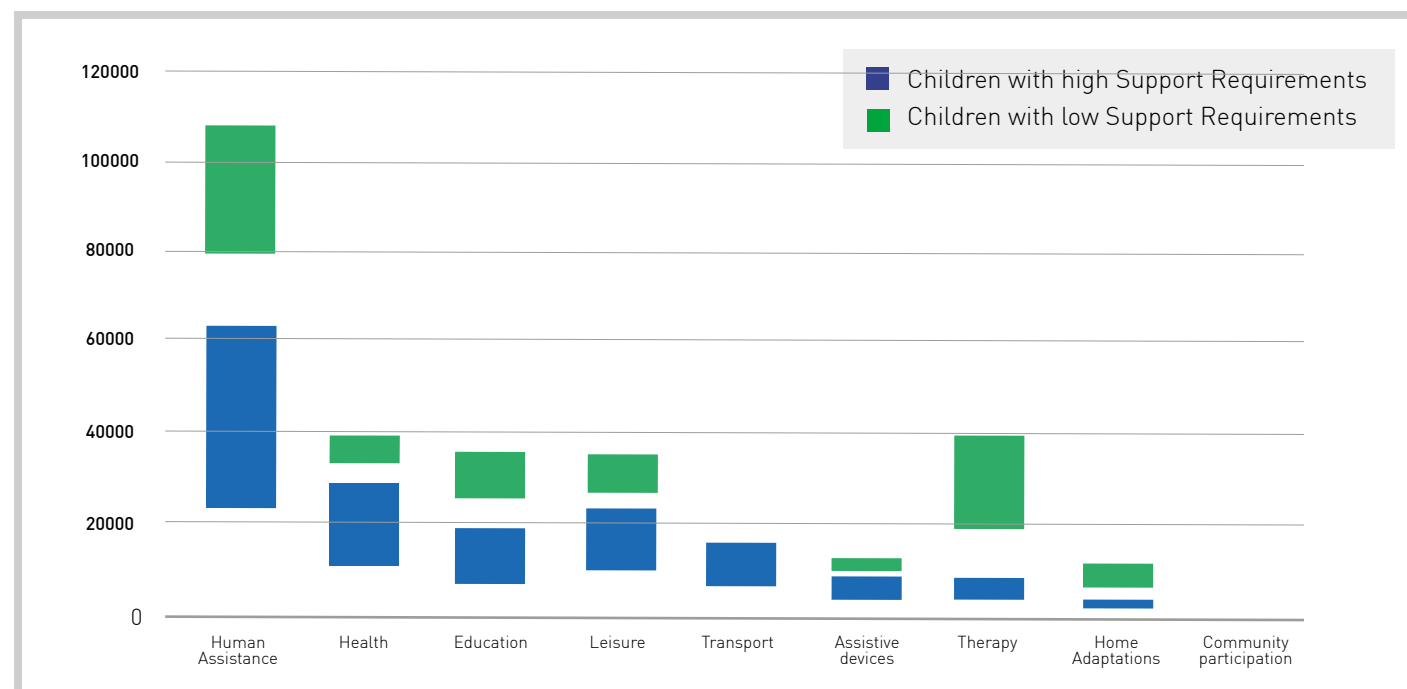


Table 1.8.1: Types and costs of products and services required by autistic children - high support requirements

Category	Sub Category	Monthly	Once in 6 months	Once in a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Care giver	15000-25000					
	Education Support	3000-5000					
Transportation		5000-10000					
Assistive devices	GPS tracker				3000-5000		
	iPad / Tab				25000-40000		
	Smart TV				25000-40000		
	WIFI	1000-3000					
	Bluetooth device				500-1000		
	Sensory toys				5000-10000		
	Activity Table						3000-5000

	Battery Tooth Brush		500-1000
	Absorbent sheets	500-1000	
	Shower Gel/ sanitizers	500-1000	
	Induction Stove		3000-5000
	OTG Oven		10000-15000
	Noice cancelling head phone		1000-3000
home modifications	Shifting houses		15000-25000
	Toilet seat adaptation		1000-3000
	Soft wooden sofa / couch		15000-25000
Education	Para teacher	5000-10000	
	Apps		15000-25000
	individualised Education sessions	1000-3000	
Health	Seizure medication	1000-3000	
	Yoga	1000-3000	
	Dental care		10000-15000
	MRI EEG		5000-10000
	Diapers	3000-5000	
	Nutrition	3000-5000	
Therapy	Speech therapy	3000-5000	
Leisure & sport	Personalised travel		25000-40000
	Music	500-1000	
	Swimming	3000-5000	
	Cinema	3000-5000	

Table 1.8.2: Types and costs of products and services required by autistic children – low support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Care support - self care	15000-25000					
Assistive devices	communication device				15000-25000		
	iPad				25000-40000		
	Internet	1000-3000					
home modifications	Pets	3000-5000					
Education	Additional Coaching	3000-5000					
	Audio Visual aids			3000-5000			
	Subjects of interest	3000-5000					
Health	Dental			10000-15000			
	ENT			1000-3000			
	Nutritious Food	3000-5000					
Therapy	Speech	3000-5000					
	OT	5000-10000					
	Swimming	3000-5000					
Therapy	Sports Training (NA)	1000-3000					
	Video Games/ simulation games etc,	1000-3000					
	Music	1000-3000					

Figures 1.8.3 & 1.8.4 highlight the range of costs of goods and services incurred by the family, and the costs of goods and services required but not available or affordable by families of children with disabilities.

Irrespective of the level of support needed, the majority of costs are borne by the family. The cost to the family ranges between Rs. 37758 to Rs. 71917 for children with high support requirements and between Rs. 27833 to Rs. 50625 for children with low support requirements.

Figure 1.8.3: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - autistic children - high support requirement

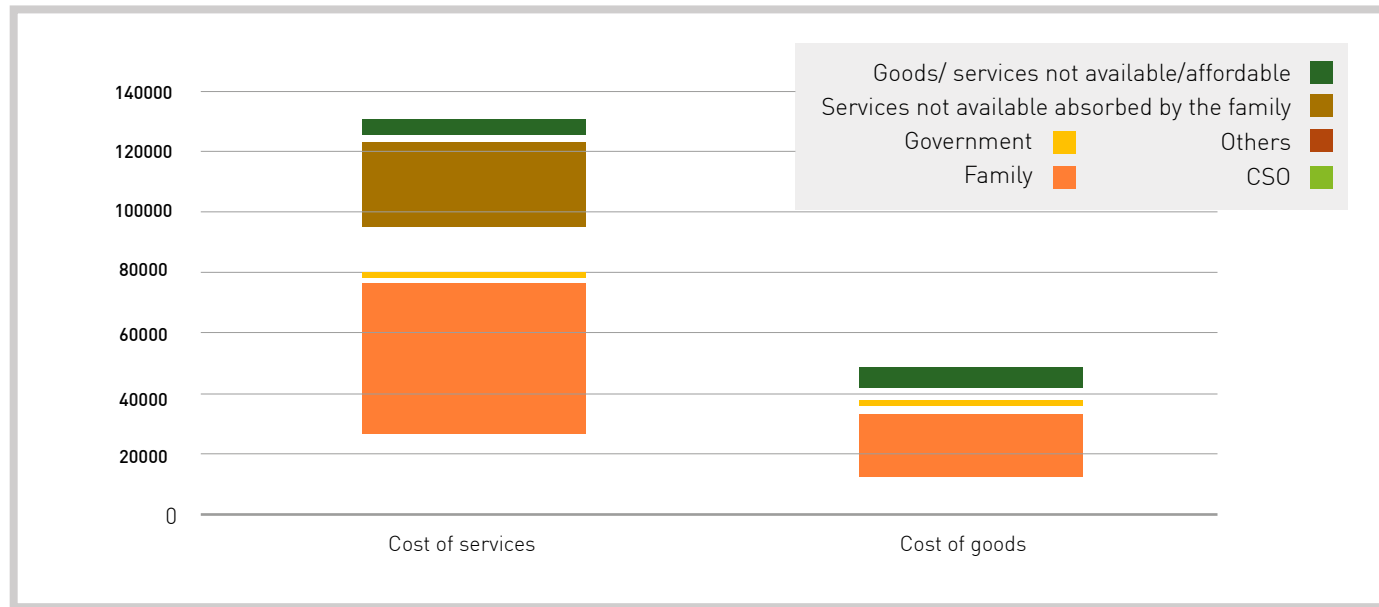
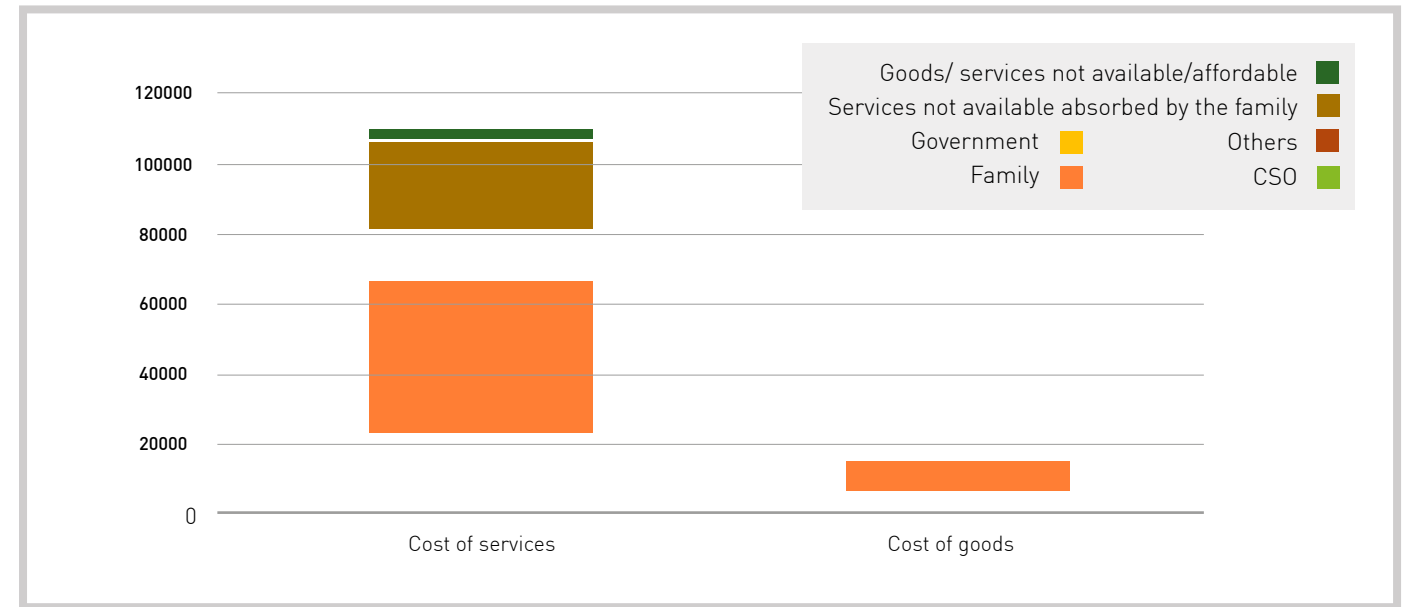


Figure 1.8.4: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - autistic children - low support requirement



Story of Anirudh Hariharan. S

(autistic person)



Anirudh is 15 years old. He was diagnosed for autism spectrum disorder at the age of 2.5 years. He is in the range of moderate-severely autistic, which is marked by disabilities with respect to communication-speech, sensory perception, social adaptability and Intellectual functioning.

Due to his condition, Anirudh requires intense support in all areas of functioning. He requires constant supervision and guidance from parents or care takers, and special and specific services for rehabilitation with concerned professionals on daily/weekly basis with specific assistive aids.

For his schooling and equal participation in everyday activities of social life, he needs appropriate conditions ensured by his parents. They try their best to provide him a life just like other children his age, and also look into how he can spend time productively at his level of participation.

Anirudh's parents are well informed of his needs and means of support services, and about the services available in their neighbourhood and provided by the state/central government. They are connected with service providers in the community. They do avail the monthly maintenance cost given by the government and make use of special reduced costs travel by train when accompanied by one caretaker/parent. However, they incur additional costs to meet Anirudh's needs for health, therapies, school, assistive devices-tech, leisure and personal transport on a day-day basis.

Anirudh's parents are considered to be middle-income, and Anirudh has an elder sibling, for whom they should also spend for education, health, etc. They have to rent a house/shift house accordingly that Anirudh can avail the maximum services needed. Anirudh's mother had to give up her job to be a full-time personal assistant to him.

Costs for Anirudh

Support Category	Subcategory	Month	annual	2years	3years	4years	5years	10yrs	Lifetime
Human assistance	Personal assistant/para	4,166.6	50,000						
	Sum	4,167							

Assistive devices &	Battery brush	58.3	700						
Specific home needs	Hand shower	27.77			1000				
+	Shower gel	80							
Services	Rocker sofa	333.33					20,000		
	Activity table	29.1						3,500	
	OTG oven	100						12,000	
	Sensory toys	166.66	2000						
	Induction stove	20.8						2,500	
	IPad	566.66					34,000		
	Communication cards	31.25				1500			
	GPS tracker	62.5		1500					
	Engraved Pendant	11.6					700		
	Internet	2000							
	Sofa service	58.3	700						
	Ortho shoes	125		3000					
	Avaz app	291.66	3500						
	Clicker app	58.3						7000	
	School materials	416.66	5000						
	Resort membership	2,916							7,00,0000 For 20 yrs
	SUM	7353.8							
Health	Medicines	2000							

	Gfcf diet	3000						
	Dental visit	66.66	800					
	Dental procedure	416.66			20,000			
	Neuro visit	66.66	800					
	MRI	125			6000			
	SUM	5,676						
Transportation	Daily travel	7000						
	Yearly trip	1,666.7	20,000					
	SUM	8,666.7						
Therapies	School fee	7000						
And	OT/Skill	2400						
Education	Speech/communication	2000						
	PT/sports	2500						
	Yoga	2000						
	Music	500						
	Pool fee	416.7	5000					
	Swimming coach	2000						
	SUM	18,817						

Total Cost / Who Provides / Availability

Goods	monthly Cost	Family share	Govt share	Services	monthly cost	Family share	Govt share
Rocker sofa	333.3	333.3		Avaz app	291.66	291.66	
Activity table	29.1	29.1		Sofa service	58.3	58.3	
Battery brush	58.3	58.3		Clicker app	58.3	58.3	
Hand shower	27.8	27.8		Internet	2000	2000	
iPad	566.6	566.6		Education/school	7000	7000	
GPS tracker	62.5	62.5		Personal assistant	4,166.6	4,166.6	
OTG	100	100		Daily travel	7000	7000	
Induction stove	20.8	20.8		Yearly travel	1,666.7	1,666.7	
Engraved pendent	11.6	11.6		Dental checkup	66.66	66.66	
Shower gel	80	80		Neuro check up	66.66	66.66	
Gfcf diet	3000	3000		Dental procedure	416.66		416.66
Medicines	2000		2000	MRI	125	125	
Sensory toys	166.6			OT/Skill	2400		300
Communication cards	31.25	31.25		Speech/communication	2000		300
Ortho shoes	125	125		Yoga	2000	2000	
Study materials	416.6	416.6		PT/sports	2500	2500	
				Music therapy	500	500	
Total	7,029.5	5029.5	2000	Swimming pool fee	416.7	416.7	
				Swim coach	2000	2000	

			Resort membership	2,916	2,916	
			SUM	37,648.4	36,631.8	1016.66
Share of Costs	Goods/month	Services/month	Total/month	Percentage/month		
Family	5029.5	36,631.8	41,661.3	93.2%		
Government	2000	1016.66	3016.66	6.8%		
Total /rounded	7030	37,648.4	44,678	100%		

Autistic adults

As shown in Figure 1.8.5, the total cost of goods and services required for autistic adults ranges between Rs. 64520.5 to 112040.7 per month for persons with high support requirements, and between Rs. 499267 to Rs. 89416 per month for persons with low support requirements.

Fig 1.8.5 : Range of costs of goods and services required by adults with disabilities per month in INR

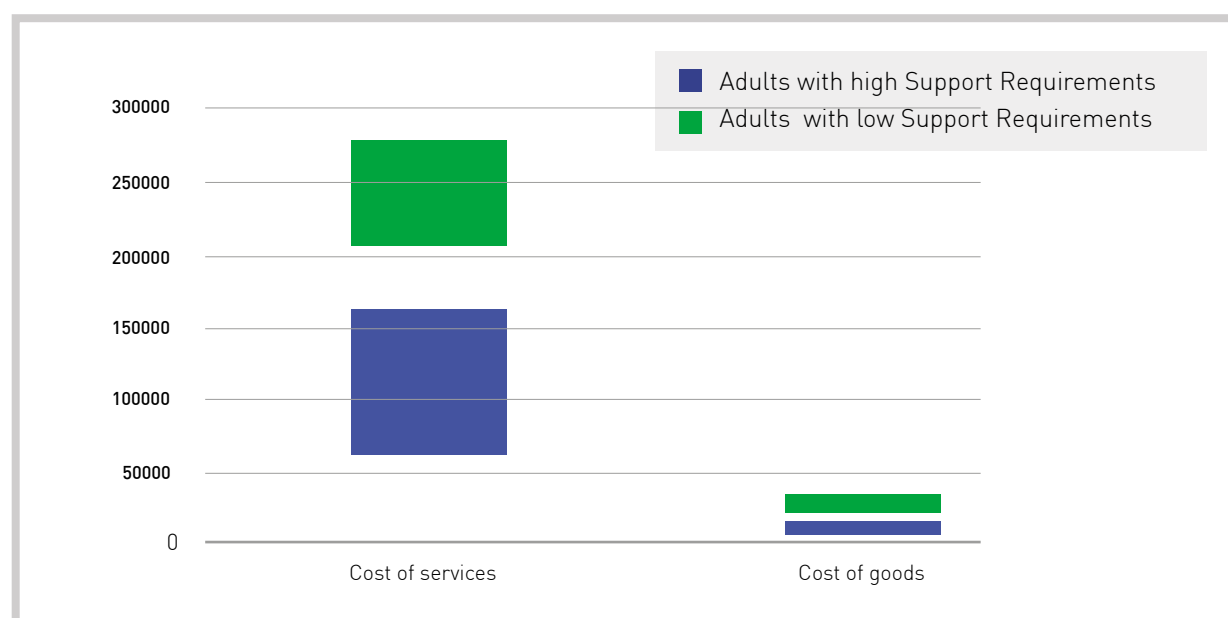


Figure 1.8.6 highlights the break-up of the goods and services required across activities and domains. Human assistance occupies the highest proportion of cost, irrespective of the level of support. This is followed by assistive devices and employment related cost among people with high support requirements, and by therapeutic services and employment related cost among people with low support requirements.

Fig 1.8.6: Break up goods and services required by adults with disabilities and their costs per month in INR

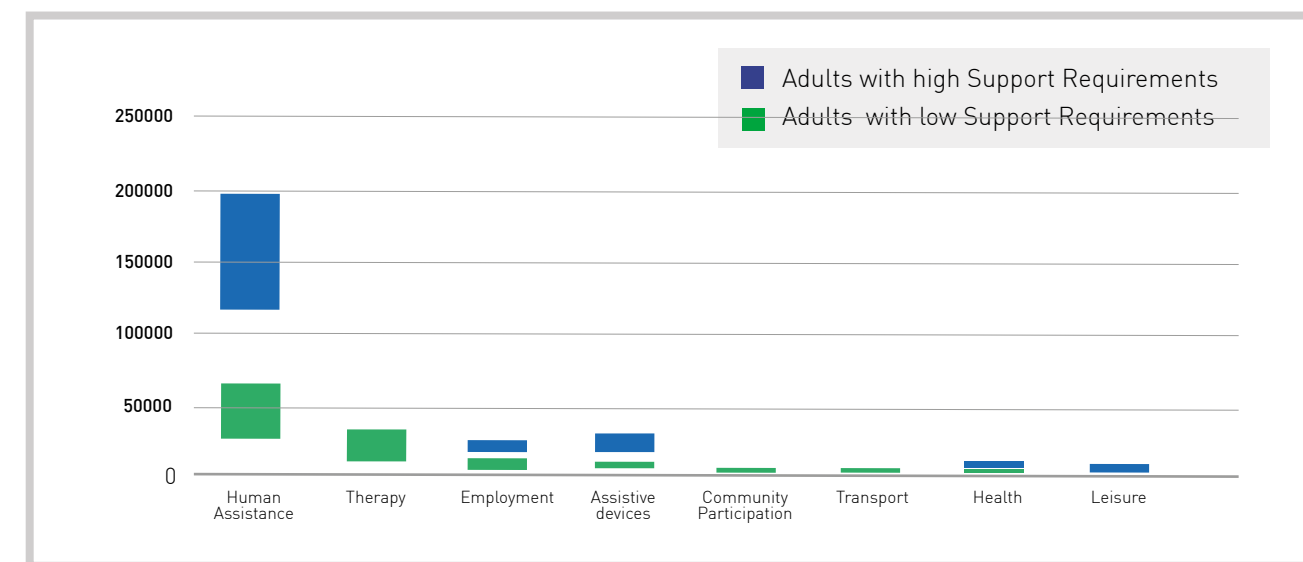


Table 1.8.3: Types and costs of products and services required by autistic adults – low support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once in a year	Once in 2 or 3 years	Once in 5 Years	Once in a life time
Human Assistance	PA	10000-15000					
	Education support	15000-25000					
	Job Counselling				3000-5000		
Transportation		1000-3000					
Community Living		1000-3000					
Assistive devices	Electronic Planner	100-500					
	Smart Phone				15000-25000		
	Sound enhancer				10000-15000		
	GPS tracker				3000-5000		
	Noise Cancelling Headphone				50000-100000		
Health	Counselling	5000-10000					
	Dietician			500-1000			
	Fitness Coach	5000-10000					
	General Anesthesia			15000-25000			
Employment	Marketing consultant			50000-100000			

Table 1.8.4: Types and costs of products and services required by autistic adults – high support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	PA	15000-25000					
	Scribe	10000-15000					

	Job Coach	25000-40000	
	Supported decision making	3000-5000	
Assistive devices	Smart TV		50000-100000
	Tab/ iPad		25000-40000
	Smart Phone		15000-25000
	AAC Device		3000-5000
	Mike / amplifier		1000-3000
	Noise cancelling head phone		15000-25000
	Internet	1000-3000	
	CCTV camera		3000-5000
	Services to products		1000-3000
	Adaptive clothes		5000-10000
	Soft lighting		500-1000
	swing/rocking chair		10000-15000
	Spring Mattress		10000-15000
	Stimming aids	1000-3000	
Health	Seizure medicines	1000-3000	
	Dental Care		5000-10000
	Gynaecology support		1000-3000
Employment	Marketing support		50000-100000
Leisure & sport	Yoga	1000-3000	
	Skating	1000-3000	

Figures 1.8.7 & 1.8.8 shows the extra cost to the family / individual with disability and the cost of goods and services required but not available.

The cost of goods and services incurred by the individual / family is highest among persons with low support requirements. The cost of goods and services required but not available or accessible is observed to be high among persons with high support requirements.

Figure 1.8.7: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - autistic adults - high support requirement

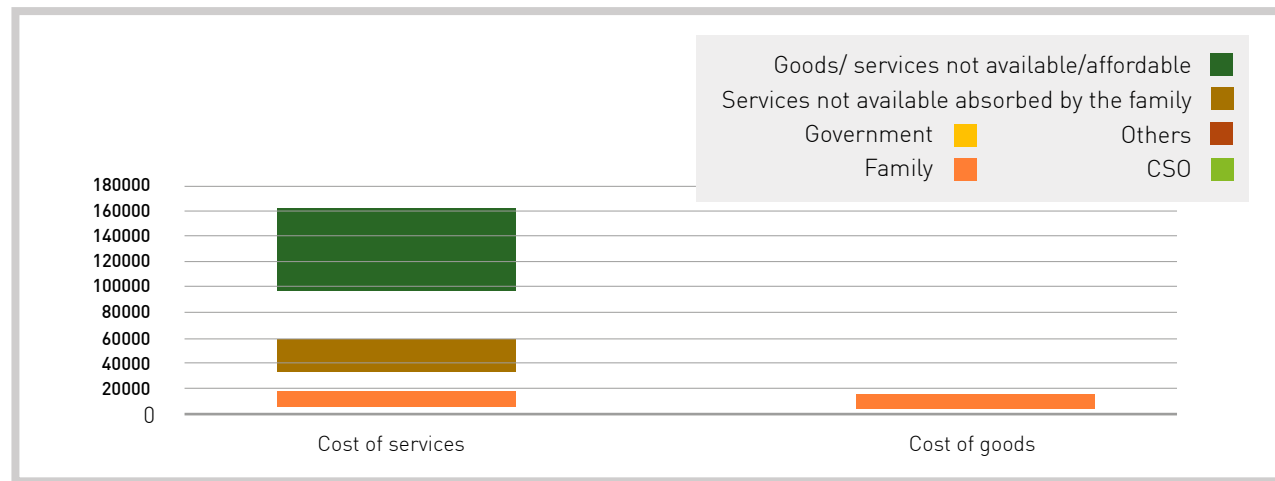
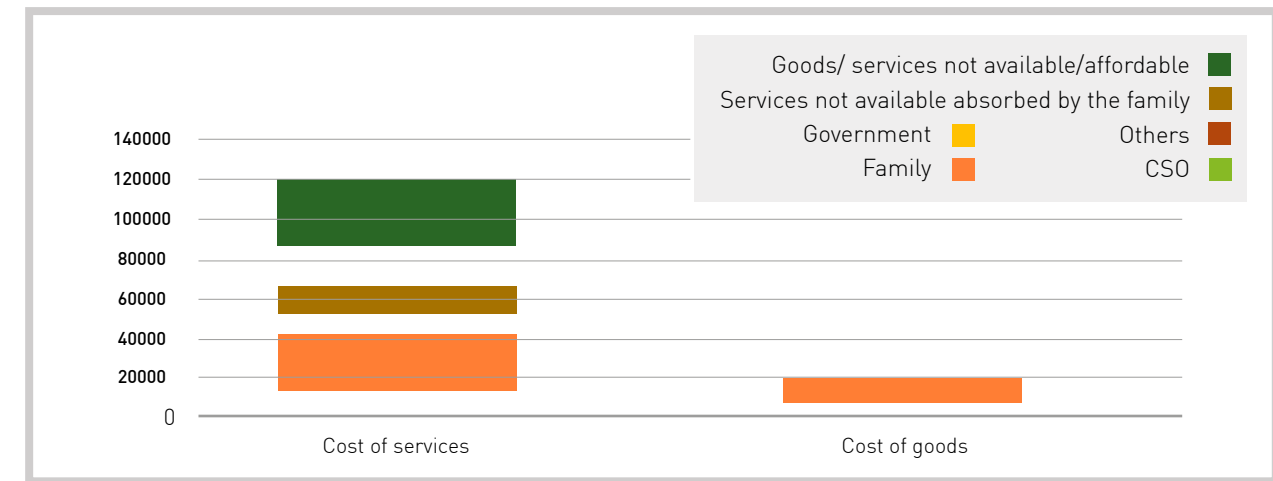


Figure 1.8.8: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - autistic adults - low support requirement





Story of Lavanya

(autistic person, high support requirements)

Lavanya lives with her parents and belongs to a high-income family.

She is not working but engages in activities such as horticulture and arts and crafts. She receives the government maintenance grant of Rs. 2000 per month. Her mother provides all of her basic day-to-day support.

She lives in Chennai and her family is well informed about Lavanya's requirements and the services that are available.

Lavanya's costs include:

- ▲ 1. Human assistance
- ▲ 2. Assistive device
- ▲ 3. Health care
- ▲ 4. Leisure and travel

Costs for Lavanya

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Human Assistance	PA	40000				
	Support for work	20000				
Assistive devices	Computer				50000	
	Mobile phone				8000	

	Smart TV				35000	
	Alexa				5000	
	Adapted Clothes		60000			
	Communication device		7000			
Health Care	Seizure treatment		100000			
Leisure	Restaurant	10000				
Transport		24000				

Total Cost / Who Provides / Availability

Category	Sub- Category	Goods monthly	Services monthly	Family	Government	CSO	Cost required	Cost incurred
Human Assistance	PA		40000	95%	5%		40000	40000
	Support for work		20000	100%			20000	20000
Assistive device	Computer	833		100%			833	833
	Mobile Phone	222		100%			222	222
	Alexa	139		100%			139	139
	Communication Device	583		100%			583	583
	Smart TV	972		100%			972	972
	Adapted clothing	5000		100%			5000	5000
Health Care	Seizure treatment		8333	100%			8333	8333

Leisure	Food		10000	100%			10000	10000
Transport			24000	100%			24000	24000
Toral		7749	102333				110082	110082

Share of Cost

Nature of Expense	Family	Government	CSO	Service Not Available absorbed by the family member	Goods Not affordable & accessible	Total
Goods	7749					7749
Service	100333	2000				102333
Total	108082	2000				110082
Percentage	98	2				100

Annexure 1.9 Persons with Physical Disability

The RPDA 2016 has clubbed many conditions under the category of physical disability. For the purpose of this study, we have included persons with mobility impairments, cerebral palsy, acid attack survivors, people with disability due to spinal cord injuries, and muscular dystrophy.

The government has a wide array of programs, such as provision of wheelchairs, orthoses, prosthetics, crutches, adapted scooters, skill training programs and self-employment subsidies targeting persons with physical impairments. However, not all persons covered under physical disability benefit equally. For example, persons with cerebral palsy cannot access the powered wheelchair program, irrespective of the level of impairment. However, they could access the maintenance grant but cannot access skill training or self-employment subsidies.

Children with physical disability

As shown in Figure 1.9.1, children with high support requirements have a higher cost of services compared to children with low support requirements, whereas the cost of goods seems to be higher among children with low support requirements.

Figure 1.9.2 highlights the range of cost of various goods and services required across activities of life. Human assistance occupies the highest proportion of cost among children with high support requirements, followed by assistive devices, health and therapy-related costs. The cost of assistive devices has the highest proportion of cost among children with low support requirements.

Fig 1.9.1 Range of costs of goods and services required by children with disabilities per month in INR



Chart Title Fig 1.9.2: Break up of goods and services required by children with disabilities and their costs per month in INR

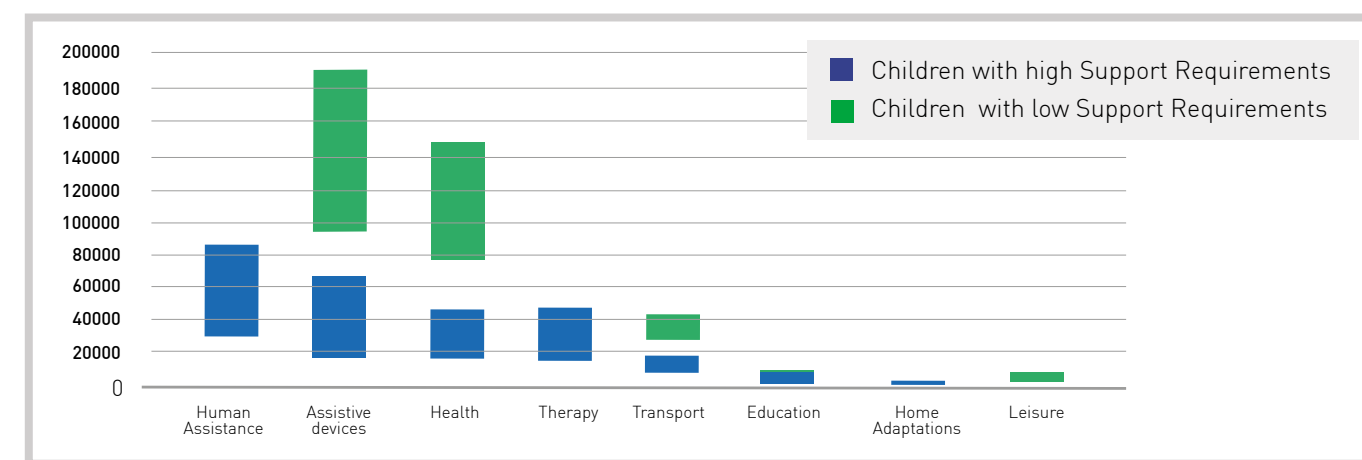


Table 1.9.1: Types and costs of products and services required by children with physical disabilities - high support requirements

Category	Sub Category	Monthly	Once in 6 months	Once in a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Self-care - care giver	15000-30000					
	health care service	500-1000					
	Scribe	1000-3000					
Education	Special Educator	10000-15000					
	Tutor	3000-5000					
Therapy	Physiotherapist	5000-10000					
	Occupational Therapist	5000-10000					
	Pulmonary therapist	3000-5000					
	Speech Therapist	1000-3000					
	Counsellor	1000-3000					
Health Products	Bipap Machine						25000-50000
	Bipap Mask			5000-10000			
	Portable Battery Backup for Bipap				15000-25000		
	UPS					15000-25000	
	UPS service		500-1000				
	Gastrostomy PEG method					50000-100000	
	PEG Button			5000-10000			
	PEG tube			5000-10000			
	Ryles tube	5000-10000					
	Baclofen pump						above 200000

	Implantation of Baclofen Pump		25000-50000
	diapers	3000-5000	
	Surgical Gloves	500-1000	
Assistive devices	customised Wheelchair		50000-700000
	Calliper		15000-30000
	Stair case lift		above 200000
	Body Brace		1000-3000
	AFO		10000-15000
	Collar	100-500	
	Gaiter		1000-3000
	Hip Belt		5000-10000
	Hand Clip		3000-5000
	Transfer Board		5000-10000
	Automated bed to turn and tilt		50000-100000
	Urine Can	100-500	
	Hoist		50000-100000
	Adapted Cushions		5000-10000
	Chest Belt	1000-3000	
	Head Masters collar		15000-25000
	Smart Phone compatible with access switches		15000-25000
	portable Ramp		15000-25000
	xerox notes	1000-3000	

Dictaphone		3000-5000	
Slant Board			500-1000
Audio Visual TLM	1000-3000		
audio text books			3000-5000
Air Bed			1000-3000
Surgical Pad	1000-3000		
Cotton	100-500		
Rubber sheet/under pads	500-1000		
Water bed			1000-3000
Air Pillow			1000-3000
Compression socks	500-1000		
health faucet		100-500	
Adapted Spoon			1000-1500
Adapted Plate			1000-3000
Western Closet			8000-14000
Double handed cups			200-2500
Custom made garment			2500-3000
Bathing chair			1600-9600
Switch			160-800
Custom made furniture			2000-5000
Universal remote for appliance at home			10000-12000

Switch compatible power outlets						5000-7000
Portable Call bell					200-700	
Bean Bag					1500-7000	
Firm Sofa two-seater						8000-34000
Electric Tooth Brush					1500-2000	
Tooth Brush Head	25-50					
lithium rechargeable batteries		500-800				
Transportation		8000-10000				

Table 1.9.2: Types and costs of products and services required by children with physical disabilities - low support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Assistive devices	Customised wheelchair				50000-700000		
	Calliper			9000-30000			
	Crutch			2000-7500			
	Rollator				5000-23000		
	AFO			15000-20000			
	Portable Ramp					20000-75000	
	Propelling Gloves and Gripper			1000-2000			
	Air / Gel Cushion				10000-20000		
	Walker				2000-50000		
	Spirometer			1000-2000			
	Pressure Garments	8000-24000					

	Neck Collar		2000-5000	
	Replacement of Battery, Joy Stick			10000-20000
	Scooter Boards			5000-10000
	Transfer Boards			2000-17000
	Adapted Furniture		2500-5000	
	Computer/Tablet			55000-100000
	AAC charts/Board	200-500		
	Voice Output Communication Device			35000-100000
	Speech Enabled Appliances			20000-200000
	Stool plastic			150-400
	Stepper			1200-5000
	Prosthetic leg		68000-320000	
Self care / home modifications	Hand Shower		500-1000	
	Western Closet			10000-100000
	Health Faucet		1000-3000	
	soaping brush	500-1000		
	Adapted Plate			1000-3000
	Adapted Spoon			1000-3000
	Double Handle cup			1000-3000
	Electric Tooth Brush			1000-3000
	Electric Tooth Briush head	27		

	Adapted Scissors		500-1000
	Adapted Book	1000-3000	
	Pencil grips	100-500	
	School Bags Adapted		100-500
	Adapted Lunchbox		100-500
	C Pen/Portable Scanner		15000-25000
	Slant Board		500-1000
	Speech Recognition Software		
	Text to speech software	1000-3000	
	Voice recorder		5000-10000
	Lesson AAC board	100-500	
Health	Under pads	1000-3000	
	catheter	500-1000	
	Diapers	5000-30000	
	Gels	3000-5000	
	Skin Cream	3000-5000	
	Burn Medication	3000-5000	
	Condom Catheter	10000-15000	
	Bowel Care medicine	3000-5000	
Leisure & sports	Sports Wheel Chair Cushion		10000-40000
	Tyres of wheelchairs		30000-40000
Transportation		10000-15000	

Figures 1.9.3 & 1.9.4 highlight that the majority of the costs of goods and services used by children with physical disability are borne by the family members. Families also absorb the cost of care services, which is unpaid work that adds to the cost to the families indirectly. The cost of goods required but not available is high irrespective of the level of the support.

Figure 1.9.3: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - Children with high support requirement



Figure 1.9.4: Costs of goods and services incurred by the family per month and goods and services required but not available / affordable - Children with low support requirement



Adults with physical impairments

As shown in Figure 1.9.5, the range of the costs of services shares the highest proportion of cost compared to cost of goods required among persons with high support requirements. Among persons with low support requirements, the cost of goods shares the highest proportion of cost.

Fig 1.9.5 Range of costs of goods and services required by adults with disabilities per month in INR

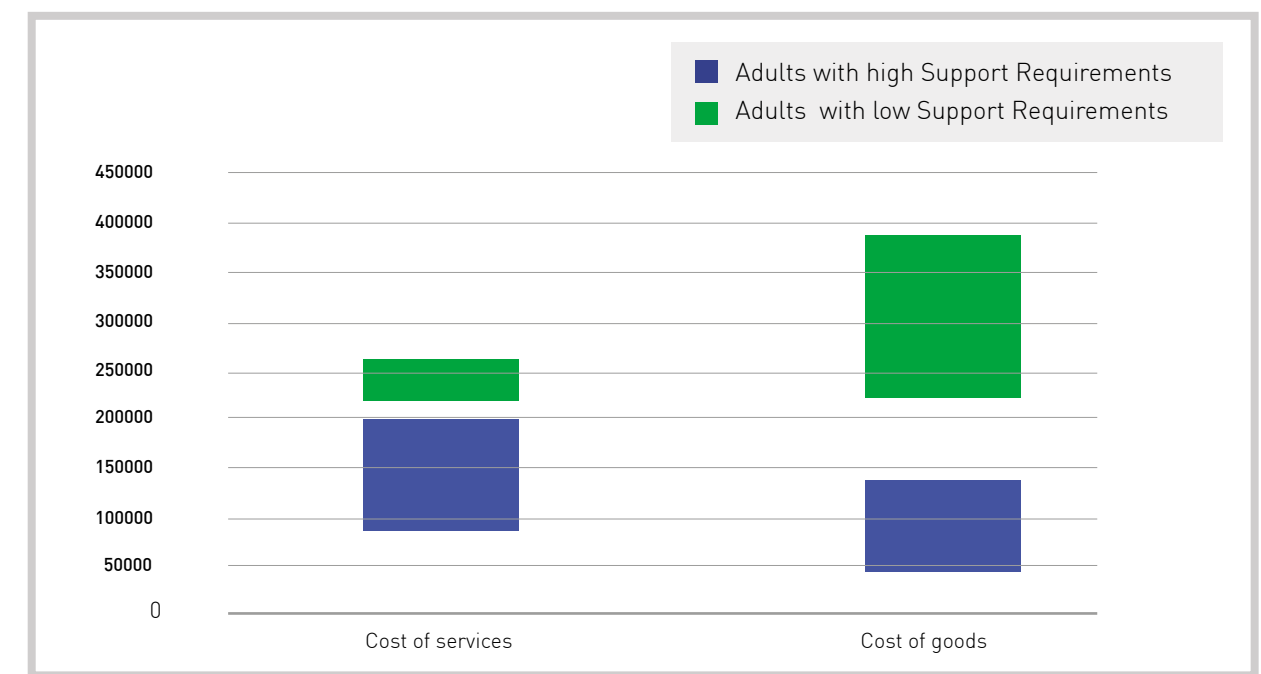


Figure 1.9.6 highlights the break-up of goods and services required by persons with physical disabilities across activities. Similar to children with physical disabilities, the cost of human assistance required shares the highest proportion of cost among adults with high support requirements, whereas cost assistive devices share the highest proportion among adults with low support requirements. However, the cost of assistive devices required is almost the same irrespective of the level of support.

Fig 1.9.6 : Break up of goods and services required by adults with disabilities and their costs per month in INR

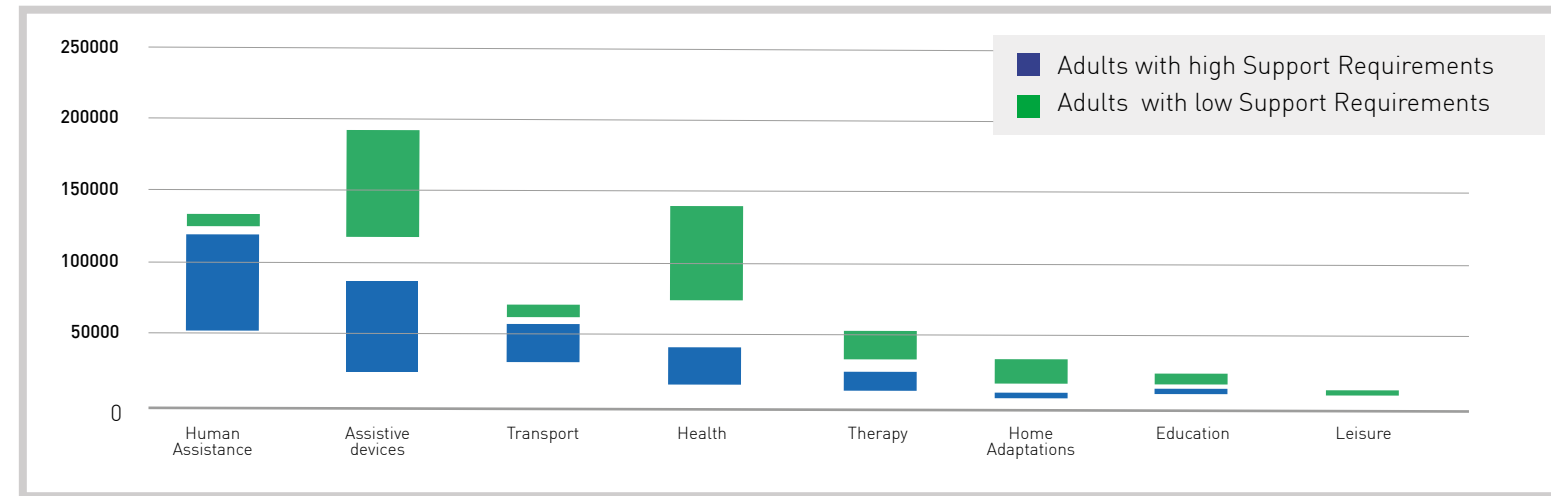


Table 1.9.3: Types and costs of products and services required by adults with physical disabilities - high support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	PA	25000-30000					
	Health care	3000-5000					
	Child Care service	10000-15000					
	Job Coach	10000-15000					
Transportation		25000-30000					
Assistive devices	custom made wheelchair with tilt and recline						50000-700000
	communication aid -laptop					50000-75000	
	adapted switch			2500-100000			
	communication software					10000-15000	
	bathing chair					2500-25000	
	vibratory tooth brush			1500-2000			

	lift				400000
	portable ramp				25000-50000
	Ankle foot orthosis				15000-25000
	adapted cushions			5000-10000	
	collar			2000-24000	
	chest belt			2000-5000	
	adapted vehicle				500000-600000
	Transfer Board			1700-8000	
	Remote operated Hospital bed				64000-80000
	Hoist				45000-100000
	hand grip		4000-5000		
	Smart Phone			15000-25000	
	Staircase Lift				250000-300000
Education	xerox notes	2000-3000			
	Dictaphone		3000-5000		
	scribe-charge	1150-2000			
	Slant Board		500-1000		
Health	diapers	3500-5000			
	Air Bed			2000-3000	
	Surgical Pad	1400-2000			
	Cotton	100-500			
	Rubber sheet/under pads	500-2000			

Water bed		1000-3000
cushion- for wc		1000-3000
Air Pillow		500-2000
Bipap Machine		30000-80000
Bipap Mask		5000-7000
Portable Battery Back up for Bipap		15000-20000
UPS		18000-32000
Gastrostomy PEG method		50000-75000
PEG Button	2000	
PEG tube	900-6500	
Riles tube	350-3150	
Baclofen pump		300000-350000
Implantation of Baclofen Pump		40000-50000
Compression socks	500-2500	
Home needs		
health faucet		500-1000
Adapted Spoon		100-3000
Adapted Plate		1000-3000
Tap with Sensor		5000-14000
Double handed cups		200-2500
Custom made garment		2000-3000
Electric shaver		1500-10000
Bed pan		100-1000

	Custom made furniture		2000-5000
	Universal remote for appliance at home		10000-12000
	Switch adapted remote power outlet control		5000-10000
	Portable Call bell		200-700
	Bean Bag		1500-6000
	Firm Sofa two seater		8000-34000
Therapy	Swimming	1000-3000	
	Physiotherapy	3000-5000	
	Weight management	3000-5000	

Table 1.9.4: Types and costs of products and services required by adults with physical disabilities - low support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	PA	5000-10000					
Transportation		5000-10000					
Assistive devices	Customised wheelchair				50000-700000		
	Calliper			9000-25000			
	Crutch			2000-5000			
	Powered Tricycle				20000-70000		

Portable Ramp		8000-35000
Propelling Gloves and Gripper	1000-3000	
Air / Gel Cushion		10000-20000
Walker		1000-5000
Spirometer	1000-2000	
Pressure Garments		
Arm	1000-3000	
Chin band	500-3000	
women Body suit	3000-7000	
face mask	10000-12000	
Full glove	2000-5000	
Neck Collar	2000-5000	
Replacement of Battery, Joy Stick		10000-25000
Scooter Boards		5000-10000
Transfer Boards		2000-20000
Hand operated Tricycle		
Rollator		2000-23000
Stepper		1000-5000
Stool plastic		100-500
Stool wooden		500-3000
Collar Home made	100-500	

	Headmasters collar		25000-30000	
	Protective footwear	180-1000		
	Prosthetic leg		65000-75000	
	Prosthetic leg			300000-325000 (Upto 7 years)
	Foot Drop Splint		2000-11000	
	Goggles		500-1000	
	wig	5500-20000		
	AFO		200-15000	
Home modifications	Lowering Kitchen Cabinet			300000-350000 (Upto 7 years)
	Widening Doors			
	Lowering electrical points			
	Western Closet			10000-15000
	Electric tooth brush		1000-2000	
	electric tooth rush head	20		
	Soap applicator	200-1000		
	Hand Shower		500-1500	
	Electric Shaver		1500-10000	
	Electric Hair Trimmer		500-2500	
	Induction stove		2500-5000	
	Gloves while cooking	500-1000		
	Pots with long heat proof handles		3000-5000	

Adapted cutting board		1000-7000
Thermal protective Cup Holders		500-1500
Wrist cuff with holders		200-1000
Adapted Scissors		400-1500
Comb with foam padding	40-50	
Double Handle Cups		500-1500
Pull storage shelf		14000-20000
pull down clothes hanger		3000-5000
Custom made garments		2000-3000
Adapted Spoon		1000-1500
Adapted plate		1000-3000
Speech Enabled Home appliances		20000-200000
Education		
AAC, voice out put device or charts		30000-100000
chart	200-500	
Dictaphone		3000-5000
Slant Board		500-1000
Tablets/laptop		35000-100000
Text to speech software		
C pen		15000-20000
smart phone		15000-30000

	pen and pencil grips	80-200	
	Furniture adapted		2000-5000
Health	catheter	500-1000	
	Diapers	5000-10000	
	Gels	3000-6000	
	Skin Cream	3000-6000	
	Burn Medication	3000-6000	
	Condom Catheter	15000-30000	
	Bowel Care medicine	3000-6000	
	Under pad		
Therapy	Physiotherapy	1000-5000	
	Occupational Therapy	3000-5000	
	Weight Management	5000-10000	
Leisure & sports	Sports Cushion		10000-40000
	Tyres of the sports and marathon wheel chairs	30000-40000	
	Planters on raised surface 10 in number		50000-60000
	Adapted Gardening Tools		7000-10000
	Adapted Tailoring Machine		15000-30000



Story of Kamaraj

(adult with physical disabilities, low support requirements)

Kamaraj is 40 years old. He has mobility impairment in one of his legs. He uses a calliper and at times takes the support of human assistance for mobility. He has completed B Ed, MA, MSW and M Phil. He is pursuing a PhD.

He hails from a village in Trichy District of Tamil Nadu. Kamaraj has four sisters, and the eldest has psychosocial disability. The second sister is a single woman with a son. His mother stays with him. His father is not alive.

Despite his qualifications and successes in the eligibility tests conducted by the government for recruitment of teachers, neither the government nor the private school recruited him. Kamaraj has not managed to get a job with regular income despite being a PhD scholar. He used to take tuition before COVID-19. During and after the pandemic, he has not been able to get students for tuition.

Kamaraj receives the government pension of Rs. 1500, which is his primary income.

He incurs the following costs:

- ▲ 1. Transportation
- ▲ 2. Assistive devices
- ▲ 3. Health care
- ▲ 4. Housing due to his accessibility requirements

Costs for Kamaraj

Support Category	Sub- Category	Monthly cost	Annual cost	Once in 2 years	Once in 3 or 5 years	Once in a life time
Housing cost	Due to the required facility like vehicle parking, toilet accommodations	5000				
Transportation	Petrol and maintenance of adapted scooter	2000	3000			
Assistive devices	Calliper			50000		

	Knee braces		4000			
	Shoes		1500			
	Maintenance of calliper		3000			
Health Care	Swimming	1500				
	Counselling	1500				

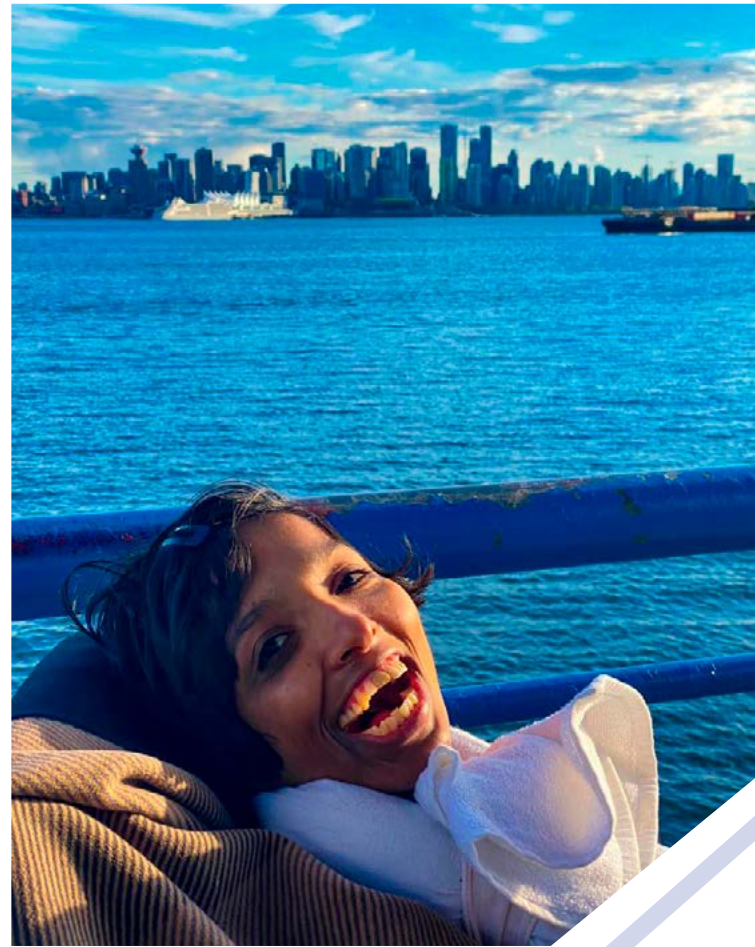
Total Cost / Who Provides / Availability

Category	Sub- Category	Goods monthly	Services monthly	Family	Government	others – friends	Cost required	Cost incurred
Housing cost	Due to the required facility like vehicle parking, toilet accommodations		50000	100%			5000	5000
Transportation	Petrol and maintenance of adapted scooter	2250		100%			2250	2250
Assistive device	Calliper	2083		100%			2083	2083
	Knee brace	333		100%			333	333
	Shoes	125		100%			125	125
	Maintenance of calliper	250		100%			250	250
Health care	Swimming		1500				1500	Cannot afford
	Counselling		1500				1500	Cannot afford
Total		5041	8000				13041	10041

Share of Costs

Nature of Expense	Family	Government	CSO	Service Not Available absorbed by the family member	Goods Not affordable & accessible	Total
Goods	3541	1500				5041
Service	5000				3000	8000
Total	8541	1500			3000	13041
Percentage	65	12			23	100

Kamaraj cites an experience of going for an interview and having to stay in a government office with an inaccessible restroom and related issues. This was a result of him staying in a remote village without an easily accessible transportation facility, and his timing being very early in the morning. He could not afford to hire a room near the interview center.



Story of Bhavna Botta

(person with cerebral palsy, high support requirements)

Bhavna comes from a high-income family. Bhavna runs an online non-profit disability related magazine called Connect Special.

Bhavna comes from a high-income family. Bhavna runs an online non-profit disability related magazine called Connect Special.

Connect Special, launched in April 2016, works towards an inclusive society (Connectspecial.in). The main objective of this digital newsletter is to disseminate information and changing perspectives on equal participation of persons with disabilities in the society.

Connect Special is Bhavna's dream project. She is a staunch believer in inclusion.

Bhavna does not have a sustainable job or employment, though she tried setting up her own business. She had to discontinue it due to lack of availability of accessible space for setting up her cloth store outside her house.

Her costs include:

- ▲ 1. Assistive device
- ▲ 2. Personal assistance for 24 hours
- ▲ 3. Home modifications
- ▲ 4. Health care

Costs for Bhavna

Personal Assistance	Rs. 30,000 per month	Provided by family and hired care care giver for 8 hrs a day
Assistive devices	Rs. 19,308.68 per month	Provided by the family. All her requirements are available
Health care – Therapy	Rs. 23,083.33 per month	Provided by the family
Transportation	Rs. 37,500 per month	Provided by the family
Total cost to Bhavna and her family per month	Rs. 90583.33	No compensation from the government.

Annexure 1.10 Persons with Specific Learning Disabilities

Specific learning disability is recognised as a disabling condition in the RPDA 2016. Programs and policies do not address the specific needs of this constituency of persons with disabilities as of yet. Exemption from language and availing the services of a scribe for writing exams are the few benefits available for persons with specific learning disabilities.

The specific support services and products required for effective participation are not yet recognised by the government. The existing programs, such as smart phones for children in government schools, are not expanded to children with specific learning disabilities.

Children with specific learning disabilities

Figure 1.10.1 highlights the range of costs of goods and services required by children with specific learning disabilities. The cost of services varies between Rs. 13,000 to Rs. 24,000 for both children with high support and low support requirements. The cost of goods varies between Rs. 6776 to Rs. 17675.

Fig 1.10.1 Range of costs of goods and services required by children with disabilities per month in INR

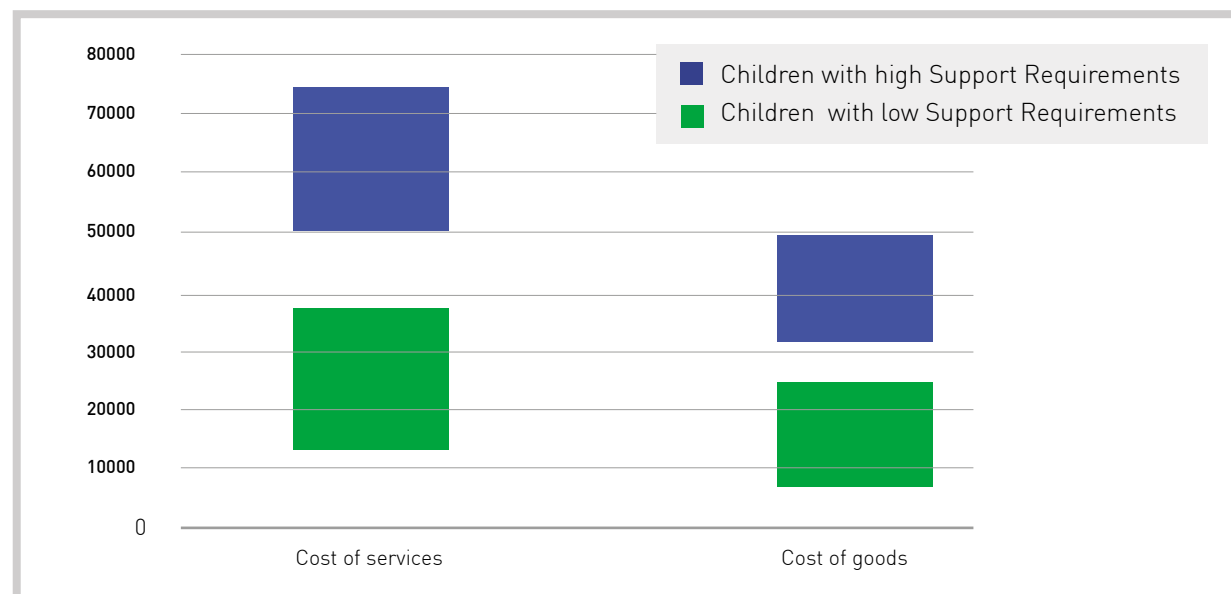


Fig 1.10.2: Break up of goods and services required by children with disabilities and their costs per month in INR

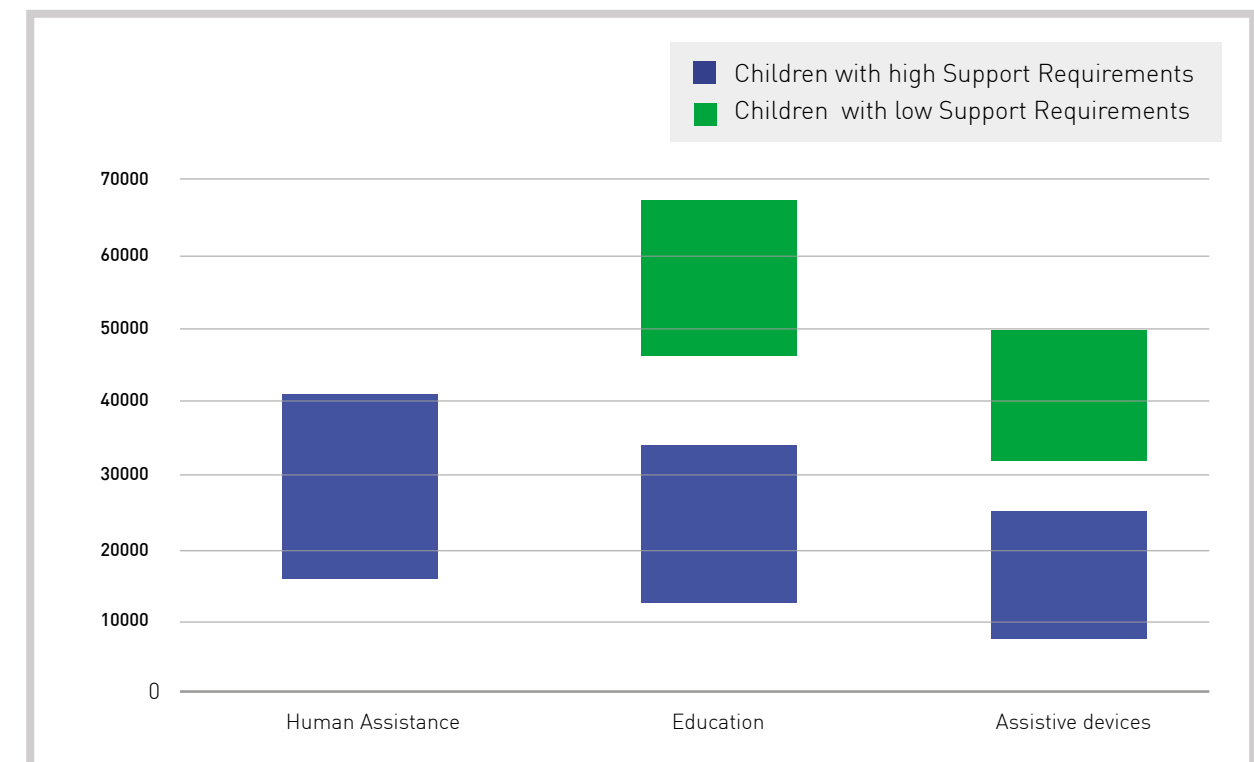


Table 1.10.1: Types and costs of products and services required by children with specific learning disabilities - low support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Scribe	1000-3000					
	Reader	1000-3000					
	Shadow Teacher	10000-15000					
Assistive devices	Smart Phone				15000-30000		
	Speech recognition software						
	Text to speech soft ware			3000-5000			
	Mind Mapping soft ware						
	Scanning Soft ware			500-1000			
	dictation software			1000-3000			
	Spell checkers for dyslexic			5000-10000			
	Word prediction soft ware			100-500			
	grammar checkers						
	Hand reading pen					10000-15000	
	Tab					15000-30000	
	Graphic Organiser			4000-20000			
	Dictionary			500-1000			
	Picture Dictionary with words			500-1000			
	Pencil Grips			100-500			
	Computer with touch screen						60000 - 100000
	Chrome Books with built in AT					15000-30000	
Calculator				500-1000			
Abacus						1000-3000	

Fidgets & Squezy Balls	100-500					
Large font books	100-500					
Adapted pencils	100-500					
Colour Highlighters	100-500					
Window reader / strips	100-500					
Maze			500-1000			
Jig Zaw Blocks			500-1000			
Wi-Fi and internet	1000-3000					
Electrical Tooth Brush			500-1000			
Health Faucet			100-500			
Single Lever Tap			100-500			
Measuring Cups & Glasses			100-500			
Towel Stand						500-1000
Soap Dispenser		100-500				
Tooth Paste Dispenser		100-500				
adapted dress		100-500				
adapted plate			1000-3000			
adapted spoon			1000-3000			
Shoes with Velcro			500-1000			
Loofa with long handle	100-500					
Adapted tooth brush	100-500					
Wooden Scratcher			100-500			
thick double sheets			1000-3000			

Table 1.10.2: Types and costs of products and services required by children with specific learning disabilities - high support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Care support	15000-25000					
	Scribe	1000-3000					
	Reader	1000-3000					
	Shadow Teacher	10000-15000					
Assistive devices	Smart Phone			15000-30000			
	Speech recognition software						
	Text to speech soft ware		3000-5000				
	Mind Mapping soft ware						
	Scanning Soft ware		500-1000				
	dictation software		1000-3000				
	Spell checkers for dyslexic		5000-10000				
	Word prediction soft ware		100-500				
	grammar checkers						
	Hand reading pen			10000-15000			
	Tab			15000-30000			
	Graphic Organiser			4000-20000			
	Dictionary			500-1000			
	Picture Dictionary with words			500-1000			

Pencil Grips			100-500				
Computer with touch screen					60000 - 100000		
Chrome Books with built in AT				15000-30000			
Calculator			500-1000				
Abacus					1000-3000		
Fidgets & Squeezy Balls	100-500						
Large font books	100-500						
Adapted pencils	100-500						
Colour Highlighters	100-500						
Window reader / strips	100-500						
Maze			500-1000				
Jig Zaw Blocks			500-1000				
Wi-Fi and internet	1000-3000						
Electrical Tooth Brush			500-1000				
Health Faucet			100-500				
Single Lever Tap			100-500				
Measuring Cups & Glasses			100-500				
Towel Stand						500-1000	
Soap Dispenser		100-500					

Tooth Paste Dispenser		100-500					
adapted dress		100-500					
adapted plate			1000-3000				
adapted spoon			1000-3000				
Shoes with Velcro			500-1000				
Loofa with long handle	100-500						
Adapted tooth brush	100-500						
Wooden Scratcher			100-500				
thick double sheets			1000-3000				

Figures 1.10.3 & 1.10.4 highlight the cost to the families and the cost of goods and services required but not available/affordable by the families of children with specific learning disabilities.

Figure 1.10.3 Cost to families and goods and services required but not available / affordable - Children with low support requirements



Figure 1.10.4 Cost to families and goods and services required but not available/ accessible - Children with high support requirements



Adults with specific learning disabilities

Fig 1.10.5: Range of cost of goods and services required by adults with disabilities per month in INR

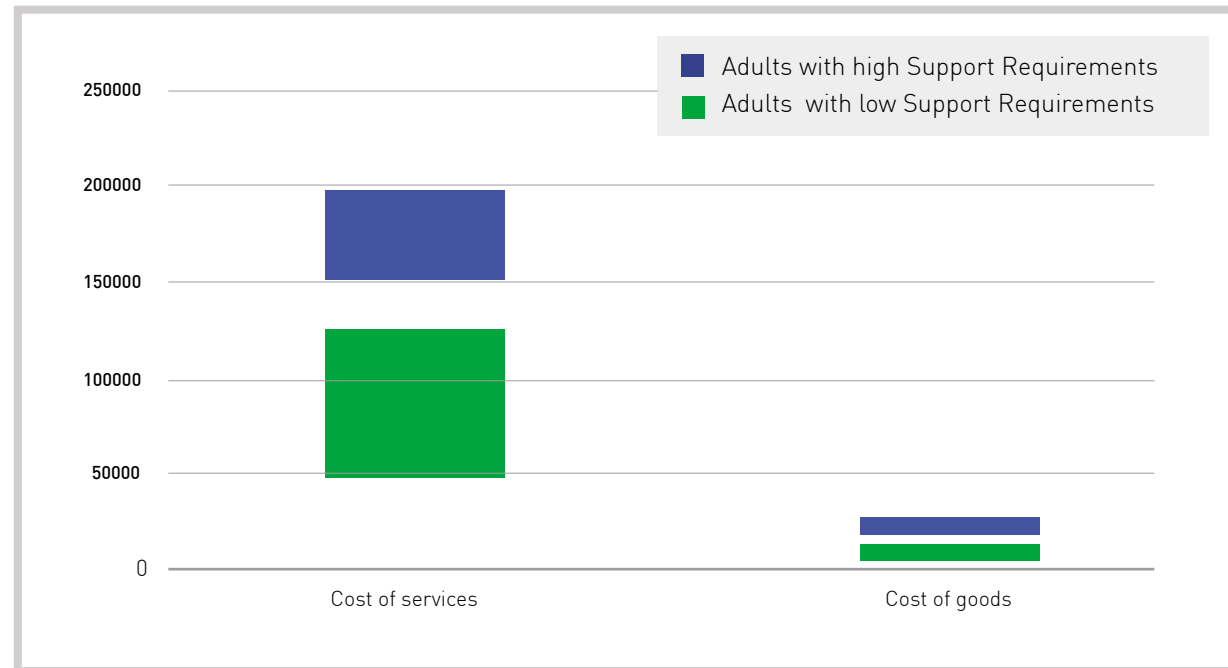


Fig 1.10.6 Break up of goods and services required by adults with disabilities and their costs per month in INR

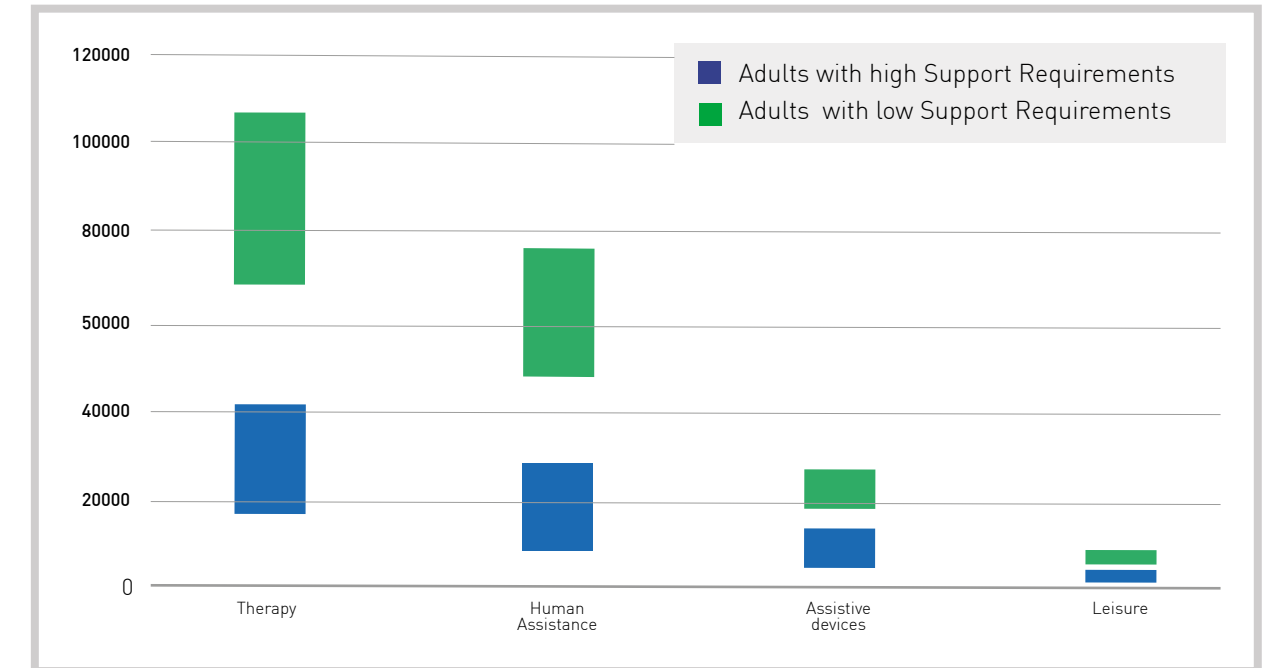


Table 1.10.3: Types and costs of products and services required by adults with specific learning disabilities - low support requirements

Categories	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3 years	Once in 5 years	Once in a life time
Human Assistance	Child care service	10000-15000					
	Domestic help for cooking, organising	3000-5000					
	PA for organising and planning	3000-5000					
	Financial management support	3000-5000					
Human Assistance	Printer				3000-5000		
	I phone				25000-50000		
	Kindle soft ware				5000-10000		

	Audio books	1000-3000					
	MAC					60000 - 100000	
	Office APP soft ware			10000-15000			
	Wi-Fi and internet	1000-3000					
Health	Occupational Therapy	3000-5000					
	Counselling	3000-5000					
	Alternative Therapy	10000-15000					
	Gym	10000-15000					

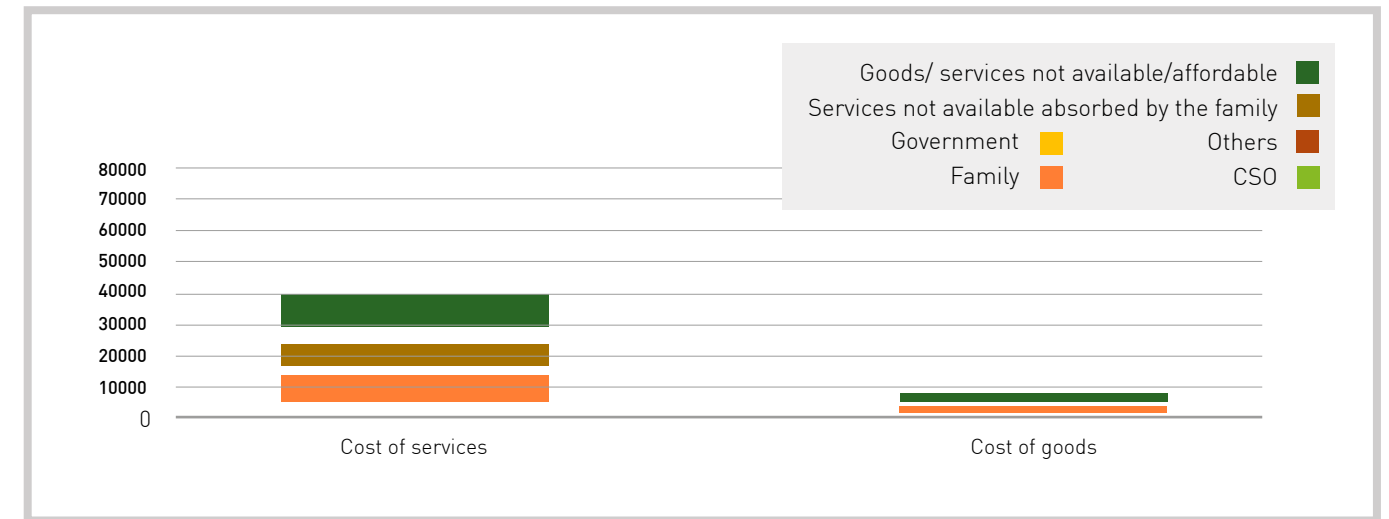
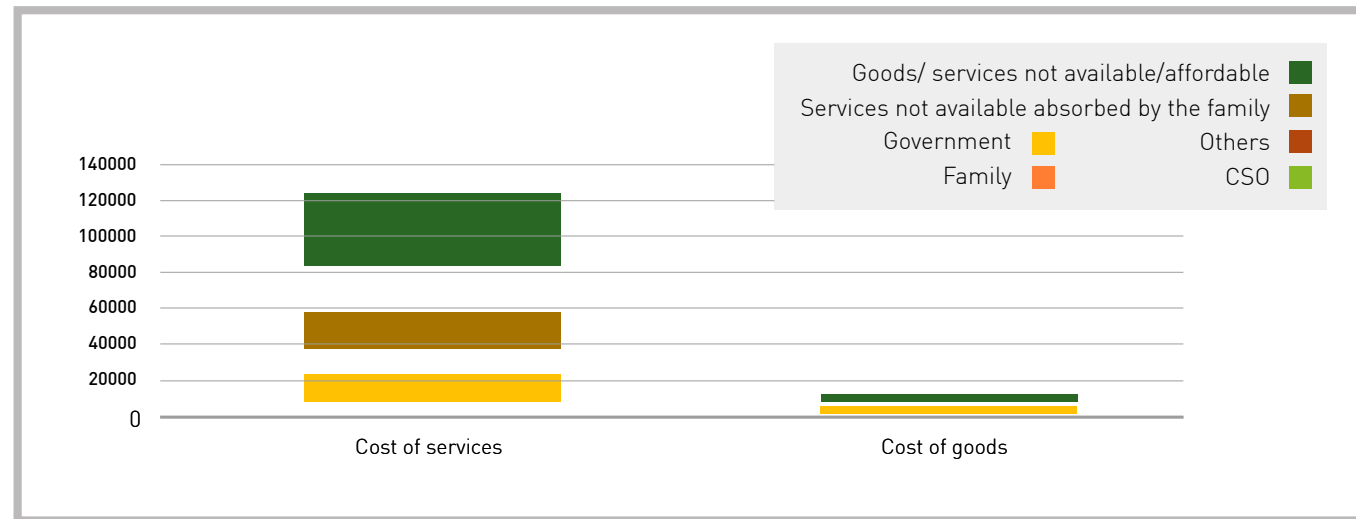
Table 1.10.4: Types and costs of products and services required by adults with specific learning disabilities - high support requirements

Category	Sub-Category	Monthly Cost	Once in 6 months	Once a year	Once in 2 or 3years	Once in 5 years	Once in alife time
Human Assistance	Household support	5000-10000					
	PA for travel, leisure'	1000-3000					
	Job Coach	1000-3000					
	Supported decision making for money transactions	1000-3000					
Assistive devices	Printer				3000-5000		
	I phone				25000-50000		
	Kindle soft ware				5000-10000		
	Audio books	1000-3000					
	MAC					60000 - 100000	

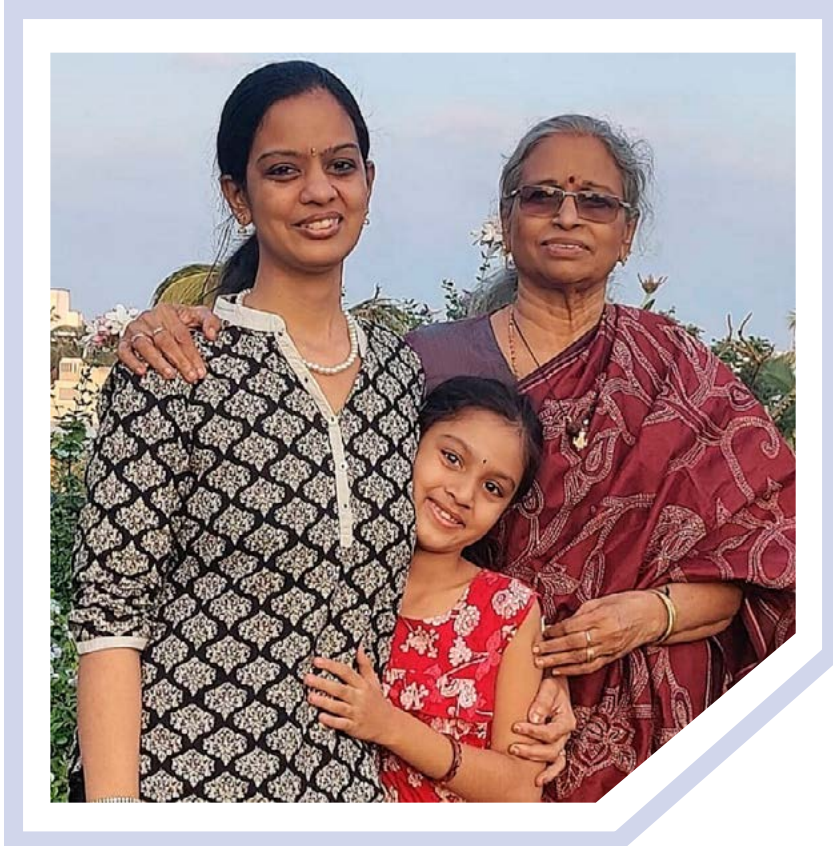
	Office APP soft ware			10000-15000			
	Wi-Fi and internet	1000-3000					
Health	Occupational Therapy	3000-5000					
	Counselling	3000-5000					
	Alternative Therapy	10000-15000					

Figure 1.10.7 Cost to families and goods and services required but not available/ affordable - Adults with low support requirements

Figure 1.10.8 Cost to families and goods and services required but not available/ affordable - Adults with high support requirements



The cost of goods and services not available is highest among persons with specific learning disabilities.



Story of Divya

(person with specific learning disabilities, high support requirements)

Divya is 38 years old and is a single mother living with her mother, who is 60 years old. Divya does not have a regular income. She and her daughter are dependent on her mother's deposits to their family income for day-to-day living. They live in a rented house in Chennai.

Divya's mother is her primary support person and Divya needs support in organising and planning day-to-day activities and managing finances. Her mother supports her in child care as well.

Their family income is Rs. 30,000. Divya does not receive any support from the government. She lost her temporary job as a library assistant due to COVID-19.

Divya's costs include:

- 1. Human assistance
- 2. Child care
- 3. Assistive devices
- 4. Temporary support for job
- 5. Transportation cost

Total Cost to the Family

Category	Sub-Category	Monthly Cost	Availability	Who provides
Human Assistance	Personal Assistance	15,000	Not Available	Mother
	Child care	15,000	Not Available	Mother
	Financial management	5,000	Not Available	Mother
	Job support	5,000	Not Available	Mother
Assistive device	Smart phone	375	Available	Family
	Lap top	667	Available	Family
	Smart Tv	833	Available	Family
	Maintenance cost	583	Available	Family
Total Monthly Cost		42,458		

Annexure 2

Measures taken by the government in the provision of goods and services for persons with disabilities

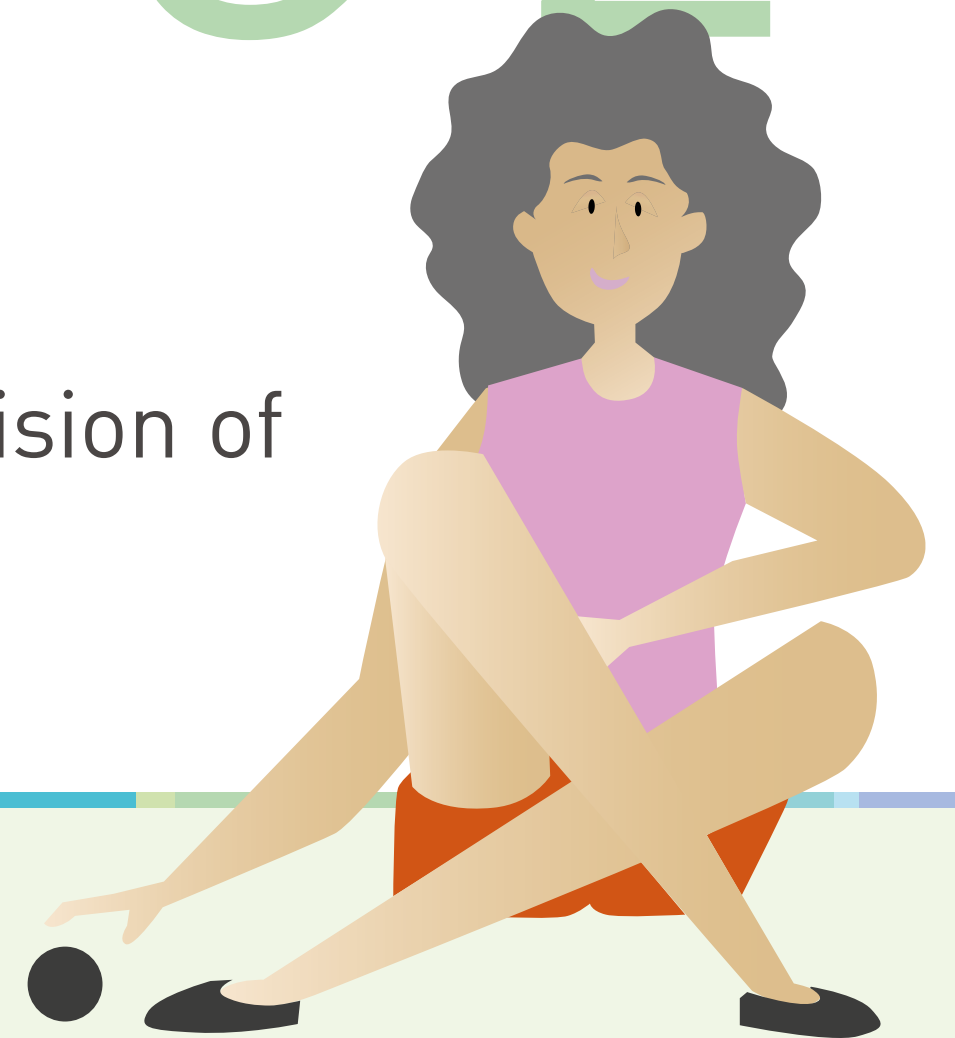


Table 2.1: Goods and services provided by Government of Tamil Nadu and Union Government for children with disabilities

Nature of Impairment	Goods Required	Goods provided by the Government	WHO List	Services Required	Compensated by the Government
Deafblind children	Hearing Aid - Braille Slate - Magnifier Braille Books - Large Print - Lap top Smart Phone	Hearing Aid	Deafblind communicators Braille note takers - Braille Magnifiers - Magnifiers digital Hearing aid, Hearing aid batteries	Tactile interpretation Care giver - Vision Care Early Intervention -Transport	Transport- Concessional bus travel
Children with complex medical conditions	Bathroom adaptations - Soft walls Wheelchair - Suction pump for excretion Adapted writing instruments - Diapers Medicines - IV Syringes - Catheter	Medicines	Fall detectors Incontinence product absorbent Hand rails, grab bars Personal emergency alarm system	Care giver - Extra coaching Blood transfusion - Blood tests Inhibitor Therapy - Physiotherapy Counselling - Transportation	Blood Transfusion
Autistic children	AAC device - Lap top - Computer Noise cancellation head phones Medicines for seizure	Nothing	Key board and mouse Personal digital assistant	Care giver - Sports training - Internet Extra coaching - Transportation Occupational therapy	Nothing
Children with intellectual impairment	Computer Laptop TV	Nothing	Simplified mobile phones Recorders Time management product	Care giver - Sports training Occupational Therapy - Physio therapy Speech Therapy - Transportation	Bus concession
Children with specific learning disabilities	Laptop / computer - Organiser Battery operated tooth brush Adapted Cutlery, plates and bowls Teaching learning material Spelling and grammar checker Word prediction software	Nothing	Travel aids Time management products Recorders Personal Digital assistance	Reader Scribe Specific training Care giver	Nothing

Children with physical disabilities	Wide doors - Adapted toilets Handrails - AAC devices Walking Aid - Adapted utensils Wheelchair - Crutches - Orthoses Rollators - Standing frames Lap top - Medicines for seizure Catheter - Urine Bag - Diaper Burn Medication	Wheel chair Crutches Orthoses Urine Bag Catheter	Canes/ stick - Crutches, axillary / elbow Chairs for shower/bath/toilet Incontinence product, absorbent Hand rails/ grab bars Orthoses, lower limb - Orthoses, Spinal Orthoses, upper limb Prostheses, lower limb Ramps Portable - Rollators Pressure relief cushions Pressure relief mattress Walking frame - Standing frame Wheelchairs, manual and active Wheelchairs, manual assistant controlled Wheelchairs – manual with Postural support Wheelchairs electrically powered	Care giver Internet Physiotherapy Occupational therapy Speech & Language therapy Counselling Transportation	Nothing
Children with visual impairment	Cane - Magnifier Recorder - Braille Stylus Braille Slate - Spectacles Braille Books - Lap top	Cane Magnifier Filter glasses	White canes Spectacles, low vision short distance, long distance, filters and protection Screen readers - Recorders - Magnifiers Magnifiers, digital - Braille Display Braille writing equipment Audio players with DAISY capability Watches – tactile, talking	Care giver Transportation	Transportation for the child
Children with speech & hearing impairment	Hearing Aid - Cochlear implant Smart phone - Laptop Sign language video lessons Teaching learning material	Hearing aid Cochlear implant	Alarm signallers with/ light/ sound/ vibration Closed captioning Hearing aids (digital) and batteries Hearing loops/ FM systems Travel aids - Video communication	Sign language training and interpreter Internet\ Ear Check up Speech therapy Transportation	Transportation for the child

Children with multiple disabilities	Adapted toilet - AAC devices Wheel chair - Orthoses Adapted glass - Vibrating tooth brush Medication for seizure - Diapers	Orthoses Medicines for seizure	Canes/ stick - Crutches, axillary / elbow Chairs for shower/bath/toilet Incontinence product, absorbent Hand rails/ grab bars - Orthoses, lower limb Orthoses, Spinal - Orthoses, upper limb Prostheses, lower limb - Ramps Portable Rollators - Pressure relief cushions Pressure relief mattress - Walking frame Standing frame Wheelchairs, manual and active Wheelchairs, manual assistant controlled Wheelchairs – manual with Postural support Wheelchairs electrically powered	Care giver Leisure support Communication support Dental care Physiotherapy Occupational Therapy Speech therapy Transportation	Therapy
Children with Psychosocial disability	Medicines	Nothing	Personal digital assistance Personal emergency alarm Time management products	Care giver Counselling	Nothing

Table 2.2: Goods and services provided by Government of Tamil Nadu and Union Government for adults with disabilities

Nature of Impairment	Goods Required	Goods provided by the Government	WHO List	Services Required	Compensated by the Government
Deafblind people	Spectacle - Colour coded cane Magnifier - Braille IKS 46 Smart Phone - Refreshable Braille Display Internet connection - Doorbells with light Braille Books - Plain language Large print	Colour coded cane – Union Government RBD base model	Deafblind communicators Braille note- takers Braillers Magnifiers Magnifiers digital Hearing aid, Hearing aid batteries	Tactile sign interpreter Guide interpreter Personal Assistant Financial transaction assistant Transportation cost Vision Care - Counselling Job Coach/ Orientation trainer	Transport- Concessional bus travel

Persons with complex medical conditions	Bathroom adaptations - Soft walls Wheelchair - Mobility Aids Thermal protective holders Laptop - Smart phone - Internet Air conditioner - Suction pump for excretion Adapted writing instruments Medicines - IV Syringes - Diapers Catheter - Customised furniture at workplace	Medicines	Fall detectors Incontinence product absorbent Hand rails, grab bars Personal emergency alarm system Wheelchairs	PA - Home nursing support Domestic help - Job coach Blood transfusion - Blood tests Inhibitor Therapy - Physiotherapy Counselling - Transportation Medical emergency Profalactic treatment - Nutrition	Blood Transfusion
Autistic people	AAC device - Lap top - Computer Noice cancellation head phones Devices that would be required for sensory readiness Medicines for seizure	Nothing	Key board and mouse Personal digital assistant	PA - Fitness coach - Job coach Transportation - Internet Dental care with GA Work place counselling	Nothing
Persons with intellectual impairment	Spectacles Seizure medication	Nothing	Simplified mobile phones Recorders Time management product	PA for travel, self care, financial transaction Education facilitator - Job coach Counselling - Transportation	Bus concession
Persons with specific learning disabilities	Laptop / computer - Smart phone text to speech software - task organiser audio books - internet - spell checker grammar checker Speech recognition software Medication	Nothing	Travel aids Time management products Recorders Personal Digital assistance	PA for financial transactions Day to day planning and organising Child care Supported decision making Counselling - Occupational therapy	Nothing

<p>Persons with physical disabilities</p>	<p>Wide doors - Adapted toilets -Handrails AAC devices - Walking Aid Adapted utensils - Wheelchair Crutches - Orthoses - Lap top Medicines for seizure - Catheter Urine Bag - Diaper - Burn Medication Portable ramp - Bowel care medication Compression socks -Pressure garments</p>	<p>Wheel chair Crutches Orthosis Urine Bag Catheter Adapted sewing machine Tricycles Adapted scooters</p>	<p>Canes/ stick - Crutches, axillary / elbow Chairs for shower/bath/toilet Incontinence product, absorbent Hand rails/ grab bars Orthoses, lower limb Orthoses, Spinal - Orthoses, upper limb Prostheses, lower limb Ramps Portable - Rollators Pressure relief cushions Pressure relief mattress Walking frame - Standing frame Wheelchairs, manual and active Wheelchairs, manual assistant controlled Wheelchairs – manual with Postural support Wheelchairs electrically powered</p>	<p>PA Transportation</p>	<p>Nothing</p>
<p>Persons with visual impairment</p>	<p>Spectacles - Cane - Magnifier Recorder Braille Stylus Braille Slate Spectacles Braille Books - Lap top Text to speech software Science and math education software</p>	<p>Cane Magnifier Filter glasses</p>	<p>White canes Spectacles, low vision short distance, long distance, filters and protection Screen readers - Recorders Magnifiers - Magnifiers, digital Braille Display Braille writing equipment Audio players with DAISY capability Watches – tactile, talking</p>	<p>PA Mobility support Child care services transportation</p>	<p>Transportation for the child</p>

Persons with speech & hearing impairment	Flashlight calling belle CCTV - Hearing aid - Smart phone Laptop - Internet Sign language video lessons Sign language dictionary Work place dictionary	Hearing aid Cochlear implant	Alarm signallers with/ light/ sound/ vibration Closed captioning Hearing aids (digital) and batteries Hearing loops/ FM systems Travel aids - Video communication	Sign language interpreter Transportation	Transportation – free bus travel
Persons with multiple disabilities	Adapted toilet - Wider doors Kitchen adaptations Adapted Cutlery and utensils Computer / laptop - Smart phone AAC devices - Wheel chair Orthoses - Adapted glass Books with enlarged font adapted books Vibrating tooth brush Medication for seizure Diapers - Catheter Work place modifications	Orthoses Medicines for seizure	Canes/ stick Crutches, axillary / elbow Chairs for shower/bath/toilet Incontinence product, absorbent Hand rails/ grab bars Orthoses, lower limb - Orthoses, Spinal Orthoses, upper limb Prostheses, lower limb Ramps Portable - Rollators Pressure relief cushions Pressure relief mattress Walking frame - Standing frame Wheelchairs, manual and active Wheelchairs, manual assistant controlled Wheelchairs – manual with Postural support Wheelchairs electrically powered	PA Scribe Job Coach Hospitalisation Physiotherapy Occupational Therapy Counselling Accessible transportation	Therapy
Persons with Psychosocial disability	Medicines Reproductive health care	Nothing	Personal digital assistance Personal emergency alarm Time management products	PA - Guide teacher - Job coach Domestic help Support for decision making Counselling - Alternative therapy	Nothing

Annexure 3

Detailed Methodology



Methodology

Central to this study has been the involvement of persons with disabilities and their representative organisations, not only for their critical insight into the costs faced by people with disabilities, but to generate understanding and support for what the project is hoping to achieve.

- ▲ **1. Recruitment and training of experts** – The expert group included experiential experts representing the diversity of persons with disabilities, parents of children with disabilities, and rehabilitation professionals. The experts underwent a two-day training program on the scope, purpose and methodology of the study.
- ▲ **2. Formulation of advisory committee** – Includes representation from OPDs representing the diversity of persons with disabilities, rehabilitation experts, and members representing UNICEF.
- ▲ **3. Development of focus group guide (per disability group)** – The researcher, in close consultation with the expert group members, developed a field guide that could elicit information on goods and services used, the extra time spent by family members and others providing support, unmet needs, barriers faced and the goods and services they need. Guides were developed for both children and adults with disabilities. The guides were based on the guide used by a UNICEF study in Georgia on the extra costs of disability in children.
- ▲ **4. Focus group discussions (FGDs)** – Twenty-one focus group discussions were conducted among parents of children with disabilities and adults with disabilities. The FGDs had two parallel sessions for collecting information about the goods and services required by people with disabilities, one for those requiring high support and one for those requiring low support. The FGD participants include representatives from both rural and urban areas. In total, 208 people were consulted. We followed a survey methodology to collect information from deafblind adults based on the recommendation from the expert group.

Using the field guides, information was then gathered from each group of FGD participants on what goods and services they use or would need for both basic and full participation, how much they spend on them, whether they are available, who spends, and how often. The information collected through the FGDs became the primary data for further costing and data inputs by the expert group members.
- ▲ **5. Expert group guide** – The expert group members worked on an expert group guide with the inputs from the FGDs. This guide laid out definitions and categories of spending and the approach to assessing what goods and services were required by people with various disabilities and levels of support needed. The expert group members did extensive research on the costs of the various goods and services required by the diversity of persons with disabilities.
- ▲ **6. Data processing** – The data collected from the expert and focus groups were organised by the type of expenditures required (i.e., human assistance, assistive devices, home adaptations, etc.) for participation in education, employment, transportation, leisure and community living, and participation in decision making processes. The information was further processed to understand the costs of goods and services incurred by the individual / family, the cost of goods and services not available but absorbed by the family, the costs of goods and services required but not available / affordable, and compensation from government programs.

- ⁱ General Statutory Rules, Notifications, Orders, Regulations, etc., issued by Secretariat Departments, framing of rules the Tamil Nadu rights of persons with Disabilities rules, 2018. [G.O. Ms. No. 28, Welfare of Differently Abled Persons (DAP 3.1), 27th July 2018, https://cms.tn.gov.in/sites/default/files/rules/TN_Rights_Persons_Disabilities_Rules_2018_0.pdf - accessed on 29.04.2023
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- ⁱⁱⁱ Ipek, E. (2019). The costs of disability in Turkey. Journal of Family and Economic Issues, 1- 9.
- ^{iv} NSS Report No.583, Persons with Disabilities July – December 2018
- ^v Census 2011
- ^{vi} Mitra, S and Yap, J., (2021) The Disability Data Report 2021, Disability Data Initiative, Fordham Research Consortium on Disability, <https://disabilitydata.ace.fordham.edu/wp-content/uploads/2021/05/The-Disability-Data-Report-2021.pdf>
- ^{vii} Performance Budget 2022, Government of Tamil Nadu - https://cms.tn.gov.in/sites/default/files/documents/wda_e_pb_2022_23.pdf - accessed on 29.04.2023
- ^{viii} Guidelines for the purpose of assessing the extent of specified disability in a person included under the Rights of Persons with Disabilities Act, 2016 [49 of 2016] - https://upload.indiacode.nic.in/showfile?actid=AC_CEN_25_54_00002_201649_1517807328299&type=notification&filename=Guidelines%20notification_04.01.2018.pdf - accessed on 30.04.2023
- ^{ix} Policy 2023-24, Government of Tamil Nadu - https://cms.tn.gov.in/sites/default/files/documents/wda_e_pn_2023_24_0.pdf - accessed on 29.04.2023
- ^x About Tamil Nadu - https://en.wikipedia.org/wiki/Tamil_Nadu - accessed on 30.04.2023
- ^{xi} Rights of Persons with Disabilities Act 2016 - <https://disabilityaffairs.gov.in/content/page/acts.php> - accessed on 30.04.2023
- ^{xii} The NSDP per capita income for Tamil Nadu stands at 275,582.63 INR for 2023. <https://www.ceicdata.com/en/india/memo-items-state-economy-net-state-domestic-product-per-capita/nsdp-per-capita-tamil-nadu#:~:text=NSDP%20Per%20Capita%3A%20Tamil%20Nadu%20data%20was%20reported%20at%20275%2C582.631,to%202023%2C%20with%2012%20observations>. Accessed on 16.10.2023
- ^{xiii} Policy Note 2023-24 Government of Tamil Nadu - https://cms.tn.gov.in/sites/default/files/documents/wda_e_pn_2023_24_0.pdf