



**Challenges faced by
children with mobility
impairment**

**Lack of devices and adaptations
for activities of daily living
for children with a severe disability**



Challenges faced by children
with physical disabilities



Availability and accessibility of adaptations and devices for children with limited upper trunk control at the local market is a big challenge.



Challenges faced by children
with physical disabilities



Parents often end up having to design a product by themselves or customize ready-made products to suit the needs of their child.

Parents have to do a lot of ‘out of the box thinking’ .

Since local carpenters are not aware of the intricacies of the adaptation required, very often parents end up with a product that is not up to their expectation.

Then they have to make do with whatever is available because of the effort taken and the cost involved.





Whatever good products are available in the market are not listed in a single portal.

Not all the parents have the resources, time, or the capacity to mine the internet.

Local medical/surgical shops too do not have many products for children nor do they offer services for adaptations.

Impact

Due to lack of affordable and readily available devices :

- 1. Children become heavily dependent on parents** for their daily activities. This undermines the child's independence and subsequently their self esteem
- 2. Physical strain on the parents and caretaker increases** manifold especially as the child grows and becomes taller and bulkier and simultaneously parents / caregivers become old and frail. .



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This is Tejas...

Tejas is a 13 year old boy with severe cerebral palsy, coupled with scoliosis and vision impairment. He has no upper trunk control and requires assistive devices that would take care of this condition.

Tejas goes to Vidya Sagar, which is a special school in Chennai. He has an elder brother and a family that is very supportive. He loves car rides and his mother has designed a car seat for him so that they can take him out on a long drive.



Tejas's mother wanted to give him as much of a regular life as possible.

However, her journey in making that happen has proven to be extremely arduous.

There was no one-stop shop (online or offline) detailing products available that could help Tejas perform his daily tasks. . It was a struggle to find devices for simple activities such as as bathing, eating, etc. So his mother had to painstakingly customised devices for him by researching on the net. Some examples of custom-made devices are :





Modified Wheelchair

“Getting a paediatric wheelchair with strap and harness for him was not easy. The available wheelchair for CP person in the market was too wide. Since he has no control over his body he was falling on one side. The product had to be tweaked. The company refused any type of customization”

Wheelchair modified to include chest support, butterfly strap, protective covering that provides support to the leg and prevents his leg from getting stuck under the footplate



Commode + Bathing chair

“We use a plastic chair and tie him up with a cloth
This is not ideal as he often cannot sit by himself and his hips tend to slide. Water and soap makes it even more slippery. There are mobile commodes which could be possibly used but these are for adults and not for children. Additionally, these do not have straps hence requires customization”.

Cloth is used to hold their trunk of the child to prevent them from falling.
Front bar is for added protection



Modified Car seat

“Regular car seats would not work for children with low upper trunk control. There are car seats for babies but nothing for children of Tejas age. I had to make a few different versions before I finally got the one that is currently being used now”.

Tailor made car seat for Tejas.
Normal car seat are available only
for babies in smaller sizes.

“ While I can afford the best of devices for my child , it is frustrating to see them easily available abroad and no mention of the same here. I research a lot for devices that can be used for Tejas...I take a picture and show it to the vendor or carpenter and get these adjustments done. Since these people don't work on it, they don't understand the intricacies. So many times I had to dispose off what was made and start afresh. It is frustrating, time consuming and expensive”

Pramila, Tejas's mother



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“The cost of disability is high here and **there is no state ownership to ease the burden on parents**. In the US every child is provided with a home chair, wheelchair. State sends a physiotherapist and a designer home who studies the contour of the child and the wheelchair would be done as per the child’s need. They provide upgradable wheelchair which can be used for 7-8 years by a child vis-a-vi in India where you need to buy a wheelchair every 2-3 years as the frame is permanent.”

Mother of CP Child

There is a lack of information on assistive devices / adaptation required for day to day activities. Parents do not know what to purchase and where to get it from. Though few organizations in the sector do take the effort to put this information together, clearly a lot more needs to be done”

Smitha Sadasivan, Disability Rights Alliance India



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“My son is a confident, motivated person. Having the right devices or adaptations will help him become more self reliant, independent and lead a life of dignity”

Mother of child with Cerebral Palsy

Some possible solution ideas:

1. **Videos showing ideas for accessible household areas** such as living rooms, bathroom and persons doing day to day activity with various assistive device, adaptation, etc.
2. **Online platform for parents to share their custom-made designs** with other parents so they don't have to constantly re-learn the same things.
3. **An online database of the products available** along with details of persons who can help customize the product .
4. Some of the **bigger brands like Fischer Price can be sensitized** to make commonly required products such as bathing chair, car seat, etc. for children with special needs