

The Amrit Foundation of India is a registered not-for-profit with the mission to build a more inclusive society. Under its Little Peepul Tree flagship programme, it works to improve the lives of persons with challenges posed by Autism, Cerebral Palsy, Down Syndrome and Intellectual Disability.

In 2016, Amrit, in collaboration with Amaltas Consulting Pvt Ltd, undertook a rigorous survey of the barriers faced by children with intellectual and developmental challenges and their caregivers in accessing specialized services in Delhi. The purpose of this Capsule study is to understand the role of Service Providers in managing intellectual and developmental challenges and the attitudes of caregivers from the perspective of service providers.



Capsule Study III

A Service Provider Perspective on Caring for Children with Challenges

Background

To have a disability is to have a complex time dealing with it. Disability sets up a block chain of functional, social and community issues that have far-reaching consequences for the affected individual and family. Particular problems are posed to those with intellectual and developmental conditions, namely Autism, Cerebral Palsy, Down Syndrome and Intellectual Disability.

The Global Disability Summit held in July 2018 in London highlighted the fact that each of us will, at some point of our lives, experience disability. It acknowledged the long-standing neglect of the issue and focused attention on the paucity of useable data for action.¹ The World Disability Report put out by the World Bank and World Health Organisation captures the effects of disability on the human condition, noting the disadvantages that people with disability experience, often worsened by intersectionality with other causes of marginalisation. These include poorer health outcomes; lower educational achievements; less economic participation; higher rates of poverty; and increased dependency and restricted participation.²

Each individual with intellectual and developmental challenges has a unique profile, based on her or his level of language functioning as well as functioning in areas related to mobility, activities of daily living, hearing, cognitive level, abstract thinking and emotional status. Due to the diagnostic heterogeneity, each person diagnosed as having an intellectual and developmental challenge must be considered as an individual case for specialised intervention. Disability itself is not a condition; it simply represents the challenges faced by persons who have levels of functioning at variance from most others in good health. For these reasons, this paper uses the term 'challenges' instead of 'disability' to denote that challenges could, with the right support, be conquered and overcome.

¹ 2018. Global Disability Summit: Official Readout Accessed at https://drive.google.com/file/d/15PZ3CJf841KxpaTLvp3ARE_hilACPro6/view Accessed on 08 December 2018.

² 2011. WHO. Summary The World Disability Report. WHO and The World Bank.

Providers of the specialised services that PwC require, play an important role in naturalising the person within her/his community. They make it possible for to function effectively even within the constraints imposed by a world structured for persons differently abled than themselves.

Sample characteristics

In total, 40 service providers (SPs) were selected to participate in the study. These SPs are engaged in providing services to PwC, ranging from various types of therapies, to offering specialised educational support. The SPs interviewed were as follows: Psychologist (14); Special Educator (7); Occupational Therapist (6); Paediatrician (3); and Speech Therapist (3). Seven were engaged in providing services through multi-purpose facilities. Most SPs (26) had less than 10 years of experience, while only three had between 20-28 years - the highest number of years of experience.

Observations

Observation 1: The service provision landscape is chaotic.

The service provision landscape for persons with challenges is chaotic and unorganised. It involves a wide-ranging range of SPs with a widely divergent experience set. Apart from the formal area of specialisations noted, a number of SPs were providing services not necessarily related to their own area of specialisation. There were also several SPs (11 of 40) without formal educational qualifications.

Recommendation: A better understanding of the landscape of SPs is urgently needed. While the lack of formal training is not necessarily undesirable in of itself, the quality of services provided to PwC must become assured.

Observation 2: SPs feel that most parents are not aware of the symptoms of intellectual and developmental challenges.

Of the SPs interviewed, only a fourth felt that caregivers were aware of the symptoms of intellectual and developmental challenges and able to identify them in their children. An overwhelming majority (31 of 40) SPs interviewed felt that parents/ caregivers were likely to have difficulty in realising that their child needed professional help. Many (15) felt that this was the result of the denial about the conditions, perhaps due to the stigma that is so often associated. Several SPs also felt that many people are not aware of the concept of counselling and hence could not understand this approach to treatment.

Recommendation: Wider awareness of intellectual and developmental challenges is needed amongst the population. Health providers attending to expectant parents should discuss developmental milestones. By raising the awareness about the usual course of development and growth in children and the need to see a qualified practitioner if these falter, the index of suspicion for intellectual and developmental challenges could be very much improved.

Observation 3: Parents/ caregivers delay in seeking out treatment for children with intellectual and developmental challenges.

The overwhelming majority SPs felt that parents delay in seeking a diagnosis and treatment for their child with intellectual and developmental challenges. They feel that denial of intellectual and

developmental challenges is universal among parents/ caregivers. Thirty-seven of 40 SPs felt that parents/ caregivers delay the seeking of a diagnosis. Twelve of the 40 SPs said that a delay of 1 - 2 years was common, while the rest felt that the delay was even longer than that.

Adaptive expectation as a reason for prolonged delay in seeking clinical diagnosis is a concern shared by all SPs interviewed. Lack of awareness means that fewer parents are able to correlate developmental delays with intellectual and developmental challenges. Parents of PwC would rather believe that their child is a “late-bloomer” or “will recover naturally from any deviation” than take the child to a paediatrician to seek help. This proves very difficult not only for the SPs, but especially for the children.

“Most of the parents see delayed speech which is one of the first signs of autism, not as a problem rather as a familial pattern of late verbal communication.”

“... the parent of a 3-year-old child consulted me. The father simply left the child at my clinic and walked out. He wasn't interested. It is also a parenting issue.”

Recommendation: Greater awareness of the usual developmental process would help highlight anomalies. A positive societal narrative on intellectual and developmental challenges is necessary so that parents feel comfortable in acknowledging and seeking early intervention for the children with challenges. This has to be built of positive stories about the integration of persons with challenges into wider society.

Observation 4: Parents/ caregivers get information about SPs through several means, including the internet.

Many (17 of 40) SPs feel that parents/ caregivers get information about providers from other providers. But the internet is quickly emerging as an important source of information, with 14 of the 40 SPs using online searches as the primary source of information about SPs. Does the relative anonymity offered by the internet help parents/ caregivers to freely find the services they need for their wards?

Only 11 of the 40 SPs said that parents/ caregivers are the source of information about providers for other parents/ caregivers. This is clearly not enough; there does not appear to be enough being done to create connections between parents, or indeed, to remove the stigma that prevents sharing.

Recommendation: A growing awareness of the possibility of an engaging and productive life is necessary and must become part of the discussion about intellectual and developmental challenges. The emergence of the internet as a source of information is welcome but needs to be expanded through support from government and private sector social responsibility.

Observation 5: Apps such as Practo and the internet are emerging as options of choice to reach SPs; distance is often not a consideration.

Several SPs (13 of 40) are now beginning to use apps such as Practo to become visible to parents/ caregivers. Those that had registered from our sample for the app include doctors, psychologists, special educators and occupational therapists. Just over half (51%) reported that parents/ caregivers use the internet to reach them.

Distance to the SP did not seem to be an issue as reported by 27 of the 40 SPs. However, in the case of speech therapists, most reported that the children with challenges that they provided services to lived close by.

Recommendation: Parents/ caregivers are embracing the opportunities afforded by the internet and phone apps to seek the services they need for their wards. While this may be a feature of modern life in an urban location such as Delhi, it may also portend better days to come for those in India's hinterland, as more liberal attitudes diffuse into them.

Observation 6: SPs adopt a gradual approach to informing parents/ caregivers about the intellectual and developmental challenges that their child faces.

SPs feel that helping parents to come to terms with the diagnosis is only the beginning in a long and difficult journey for both the parents and the SPs. Of the 40 SPs interviewed, 28 take multiple sessions to explain in detail the challenges that the child will face and how parents/ caregivers need to play a pivotal role in navigating those challenges. Part of the reason why SPs take time to help parents absorb the diagnosis, is because parents do not possess the awareness and sensitivity required to immediately deal with the situation.

“Many parents go into shock. They say things like normal people don't do this, he/she should understand.”

One of the SPs observes that, for most intellectual and developmental challenges she shares the results of the diagnosis immediately with the parents; however she chooses to help parents of children diagnosed with autism through multiple sessions. A reason for this is parents find it difficult to come to terms with their child's condition, insisting that the child will eventually respond like so-called 'normal' children. While SPs freely undertake discussion on the diagnosis, all 40 SPs interviewed, reported that they do not have informational material that could help parents understand the situation.

Recommendation: A compassionate and empathetic approach is crucial to help parents/ caregivers accept the diagnosis and ready themselves for the journey ahead. Reader-friendly material that flags important aspects of each intellectual and developmental challenge would help them to do this.

Observation 7: Doctor shopping is commonplace; and all parents/ caregivers will seek services from at least 2 SPs before settling down.

SPs report that parents/ caregivers spend at least 1 - 2 years to accept the diagnosis of their child. Most often (28 of 40) it takes even longer for them to achieve acceptance and find the SP they need. In a fourth of cases, it was due to dissatisfaction with the services and in search of quicker results. Nineteen of the 40 SPs shared that most parents make it a point to seek diagnosis from at least 2 to 5 SPs.

Of the 40 SPs interviewed, 27 SPs find that parents often drop out of treatment and discontinue specialized services for the child with challenges. Only a fourth of SPs thought that parents/ caregivers understood the problem that their child had and fewer than those believed that parents/ caregivers were ready to address the issues as they appear. Thirty one SPs felt that parents/ caregivers have a mixed response to the professional advice tendered by them. This further hampers the proposed intervention for the child.

“We are not giving a medicine which is for a short time but focusing on therapy that seeks to bring about behavioural modification which takes time, consistency and homework. It requires skilful, knowledgeable, consistent and whole behaviour modification approach. We are not changing the child, we are trying to modify the environment around the child in accordance with the needs of the child, so that the child can learn faster.”

As one SP noted, feedback from other caregivers often plays a critical role in determining the dropout rate. A negative feedback ripples a reaction chain causing other caregivers to drop out of treatment in search of other SPs for better and quicker results. SPs also claimed that the caregivers often return to them after months, and in some cases, years.

“I explain to them that they come to me not for improvement but to protect from deterioration.”

The SPs feel that the return to specialized services is a consequence of the realization by parents, that without regular therapy the behaviour of their child often deteriorates.

Recommendation: Without awareness of the condition and standard practices in place, doctor shopping is likely to continue to be a feature of the patient pathway. Education of the parents/ caregivers will have to form an important part of the SPs armament of interventions, as it is well recognised that environmental circumstances have a lot to do with the well being and achievements of the child.

Observation 8: Complementary services are an important feature of treatment, but one that parents/ caregivers seldom take.

Complementary services are those that complement the principal therapy. Of the 40 SPs interviewed, 27 SPs recommended multiple complementary services for children with challenges in the last one month. In an overwhelming number of cases (90%), SPs indicate only the kind of services that would benefit the child but provide little guidance as to where to get it. It is left to the parents/ caregiver to locate a suitable SP. Mention was also made of the little research that was available on the utility of these services on the child’s progress. While international research supports the use of complementary services, much more research is required in the Indian context.

It is small wonder that the use of additional services recommended by the principal SP is poor. Only 16 SPs claimed that caregivers were receptive to the idea of complementary services while 22 SPs felt that most parents had mixed - negative view of these services. The reason for this is that they saw these as hobby classes and felt further burdened by it. At least 6 SPs alluded to the extra financial burden that these placed upon the parents.

“Last week a family visited me whose child has a challenge.....The mother is worried about having to give up her job and the income that comes with it.”

Recommendation: The primary SP values additional services and correctly views the needs of the child with challenges to be multi-faceted. Uptake among parents/ caregivers could be enhanced if financial support were available or free-to-use services could be provided to their child. Doing so could have significant benefits, accelerating progress and resulting in much better outcomes for the child.

Study Details

This study builds upon the findings of the Patang Project, which had found that the 4 index challenges pose a significant social and financial burden on the families of children with challenges. A capsule study was undertaken between 1 June – 6 July 2018.

The qualitative study was conducted through telephonic interviews with SPs of PwC practicing in Delhi. Only SPs who self-identified as working with PwC were included. SPs were identified from databases with Amrit, Practo and JustDial. Informed consent was obtained from all participants at the start of the telephonic interviews. Participants volunteered their time and were not compensated.

All interviews were conducted in English using a closed-ended questionnaire. The interview guide was designed to capture the service providers' perspective in caring for PwC.

Data was transferred to Microsoft Excel (*ver* 2007) for cleaning and analysis. Respondent names were replaced with index numbers to ensure confidentiality of the responses collected.

Since the issues probed were sensitive, the study faced the following limitations:

- Hesitation in SPs to share information on how they perceive the attitudes of the caregivers.
- Some SPs were reluctant to discuss their own limitations in adequately convincing the parents of PwC.