EXCLUDED FROM LIFE

Report of the first consultation in a series of workshops designed to collect and collate information about obstacles that exclude children with intellectual challenges from accessing services, and construct responses to such barriers.

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BACKGROUND

Individuals with Intellectual challenges are seen by many as fundamentally flawed, having diminished capabilities, and therefore inferior. This places them at the bottom of the social structure. They are thus vulnerable to discrimination which manifests in their marginalization from resources and decision-making.

Due to the lack of a universal definition of disability and its types and categories, there are n22o reliable figures available for the prevalence of disability in India. Nevertheless, it is estimated that about 5.4% of the 18.5 million or so persons said to be 'disabled' in India are persons with intellectual challenges. Available estimates understate the problem, with both the Census (2001) and NSS (2002) leaving out persons with autism and several learning disabilities. The social stigma and discrimination attached to disability is also likely to contribute to under-estimation.

There has been noticeable progress in addressing intellectual challenges in children in India on all fronts. However, there is still a long way to go in recognizing intellectual challenges and overcoming them in a systematic and large enough way. Development of effective, accessible, and affordable interventions would be a start. Barriers to effective services of intellectual challenges in children have to be dealt with a fresh approach. Finally, there is lack of information available on intellectual challenges that could help to demystify the cause of the disabling condition and allow for the questioning of existing stereotypes.

There remains a long way to go in building compassionate systems that can be used by Children in Need (CIN)[1] **and their caregivers.** Systems for the empowerment, care and support of CIN, their families, and their caregivers must be cognizant of and respond to a life cycle approach covering identification, diagnosis, treatment, support, health care, legal and financial concerns, livelihood options and supported living.

Barriers to effective services for CIN need to be looked at with a fresh approach. The formal recognition of discrimination on grounds of disability is a recent phenomenon and laws enacted even twenty years ago generally did not include disability in the list of prohibited discriminations. In particular policy initiatives by Government of India (such as the Right to Education as a fundamental right for all children, includes children with a disability, and the Persons with Disabilities Act (PWDA) of 1995 which advances equal rights and opportunities of all individuals with disabilities) need to be operationalized with greater sensitivity to the needs of those they purport to address.

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[1] We prefer the term Intellectual Challenges to the term Intellectual Disability. This draws attention to the fact that these persons, like others, face certain 'challenges' which can be addressed, rather than having a fixed problem as the term 'disability' implies. Amrit Foundation of India uses the term Children in Need (CIN) to describe those to whom its services are useful.

The **Amrit Foundation of India** proposes to examine the barriers that prevent access to and utilization of basic requirements of CIN and their caregivers. Its vision is the development and well-being of all Indians, irrespective of their religion, race, caste, creed or sex, so that they may individually and collectively reach their full potential. It also seeks to develop and support institutional mechanisms as well as collaborate with other organizations to further its goals of equity and inclusion.

Its flagship program - **The Little Peepul Tree** - is an initiative to provide strategic support to people who deal with intellectual disabilities. It has been set up as an 'information bank' that can meet the informational needs of all stakeholders. Our stakeholders comprise of individuals like parents, family members, school teachers, friends, professionals such as doctors, lawyers, speech therapists, occupational therapists, counselors, researchers, etc., institutions like NGOs, training centers, schools and support groups such as parent support groups, play groups and volunteers. The Little Peepul Tree also functions as a 'clearing house' that will collect, collate and distribute useful knowledge to all those concerned with intellectual challenges. Advocacy with state and non-state entities for supportive policies, laws, actions, and financial assistance to those affected is also included in our domain.

The **Excluded from Life** series of workshops have been designed in collaboration with Amaltas to further understanding of the problems faced by different stakeholders while dealing with CIN and thereby inform a more focused approach in providing support to them. These consultative workshops, it is hoped, would be able to learn from the wisdom of those working with CIN, identify issues affecting them, and help us to scout out suitable solutions. In the first stage of the process, the inquiry aims to question why families are not able to use the services available for CIN. In this context it aims to examine existing stereotypes and decode their roots so that operational responses can be constructed. In the second stage, we will work with experts and practitioners in the field to generate a compendium of solutions. The series will build evidence-based solutions for effective, accessible, and affordable interventions for CIN.

THE CONSULTATION PROCESS

Developed by Harrison Owen in the late 1980s, Open Space Technology (OST) is a methodology based on a simple self-organizing principle to run meetings of groups of any size. An effective tool for generating creative and innovative ideas on complex topics, it stands apart from traditional meeting methodologies by allowing the participants themselves to construct the agenda. This methodology does not rely on presentations, speeches or formal leadership and instead allows the participants manage their own agenda of parallel working sessions around a central theme (which could include sub-themes) of strategic importance.

The Approach

There is a minimum set of 'givens', which are the ground rules or non-negotiable for the meeting and the methodology is guided by Four Principles and The One Law. These 'principles' which describe rather than prescribe, were announced during the opening session:

1. Whoever comes is the right people: alerts the participants that attendees of a session class as "right" simply because they care to attend
2. Whatever happens is the only thing that could have: this tells the attendees to pay attention to events of the moment, instead of worrying about what could possibly happen
3. Whenever it starts is the right time: clarifies the lack of any given schedule or structure and emphasizes creativity and innovation
4. When it's over, it's over: encourages the participants not to waste time, but to move on to something else when the fruitful discussion ends

There also exists a law, usually referred to as the 'Law of Two Feet'. This law emphasizes that only people genuinely interested in the topic at hand should attend the discussions. This keeps engagement and participation levels high and also recognizes the value of participants who serve a cross fertilizing role by participating in multiple sessions for a short period.

The Process

OST meetings have a facilitator who initiates and concludes the meeting and explains the general method. The facilitator has no other role in the meeting and does not control the actual gathering in any way. At the beginning of an Open Space the participants sit in an 'Opening Circle'. The facilitator greeted the participants and briefly re-stated the theme of the gathering.

All participants were then asked to identify any issue or opportunity related to the theme. Those willing to raise a topic came to the center of the circle and announced it to the group. The topics are written on sheets of papers which were then organized collectively into 'Agenda Wall'. The person who posts the topic leads the discussion on it. Once all topics have been posted, the time and place for the individual sessions are set and participants sign up for those individual sessions.

After the opening session, the individual groups begin their 'Break Out Sessions'. Individuals are at liberty to decide which session they want to attend, and are allowed to switch to any other session at any time. A participant also has the liberty to be a 'Butterfly', i.e. one who may not want to be in any conversation, preferring instead to sit apart and/or a 'Bumblebee', i.e. one who might move from conversation to conversation cross-pollinating the learning. The person who posted the idea was responsible for starting the session in whatever way s/he chooses and the group self-manages the discussions. The only requirement is that, at the end of the session, the session leader turns in a Report of the discussion with a summary of session ideas and recommendations.

As soon as a report is ready, the facilitator posts it in the 'Gallery' so that all participants of the broader meeting can read about what has happened in each session in the 'Gallery Walk'. It is at this time that participants used sticky dots to prioritize specific recommendations.

At the end of the meeting, there was a 'Closing Circle', in which participants shared their thoughts on the meeting.

The Consultation was conducted to answer the following questions:

- What are the barriers to early identification and diagnosis of intellectual challenges of childhood?
- What prevents families and caregivers from seeking interventions?
- What are the most urgent needs of children with intellectual challenges and why are they not available?
- What services do our children need and what prevents their accessibility?

THE CONSULTATION SCHEDULE

Time	Activity
10:30 am – 10:45 am	Amrit Foundation of India :: Presentation
10:45 am – 11:30 am	Creating the 'Agenda Wall'
11:45 am – 01:15 pm	Discussion :: Break Out sessions
02:00 pm – 03:00 pm	Discussion :: Break Out sessions
03:00 pm – 04:00 pm	Presentation by Groups :: Summarizing discussion
04:15 pm – 04:30 pm	Gallery Walk
04.30 pm – 05:00 pm	Closing Circle
05:00 pm	Vote of Thanks

THE OPENING CIRCLE & AGENDA WALL

The Consultation began with a presentation on Amrit Foundation of India by its founder member Dr. Suneeta Singh. In her role of facilitator of the Consultation, she described the objectives of the workshop and the process and principles of the OST. The participants were asked to identify the themes on which they wanted to discuss around the questions around which the Consultation had been called.

The participants identified several themes and sub-themes, which were collectively clubbed into the following four groups:

- **What are the challenges of inclusion of CIN in terms of awareness, acceptance and sensibility?**
    - Challenges of inclusion in school and in the community.
    - Lack of awareness, sensitivity and acceptance of CIN.
- **What are the barriers to early identification and diagnosis of CIN?**
    - Early identification and early intervention services. Barriers to early identification services and differential diagnosis.
    - The roles and responsibilities of various stakeholders, as ethics seem to be declining and families are confused regarding the needs of the child and what prevents them from seeking services?
    - What prevents families and caregivers from seeking interventions?
- **What are the most urgent needs of CIN and what prevents their accessibility to services?**
    - What are the most urgent needs of children with intellectual challenges and why are they not available?
    - Role of Technology, devices, 2D and 3D tablet and motion sensors to help CIN.
    - Why people do not access services?
- **What about life of CIN after the special school/ centre?**
    - Lack of available options for CIN after special school / center.

GROUP WORK

Participants thereafter self-organized into four groups based on their own interests. Some chose to be Bumblebees, none were Butterflies. Group work took place in two sessions. Themes 1 & 2 were discussed in parallel in Session 1 and Themes 3 & 4 were discussed in Session 2 after lunch. Each session lasted for approximately one and a half hour marked by the participants deciding that they had covered everything that they needed to. By the end of each session, each group had identified barriers which they thought had a great bearing on making services inaccessible for our children, thus impacting their overall growth and development.

REPORTS BY THE BREAK OUT GROUPS

Theme 1. What are the challenges of inclusion of CIN in terms of awareness, acceptance and sensibility?

Participants: Adarsh J. Singh, Blessin Varkey, Suneeta Singh, Swati, Viveka Chatopadhyay

Facilitated by: Poonam Bhasin

Issues

- Absence of any modification in classroom despite the Right to Education coming into place and an official policy of inclusive education being adopted.
- Lack of trained teachers, proper screening tools, no flexibility in curriculum affects CIN's inclusion in schools.
- Expensive mainstreamed schools make it difficult for the marginalised to access education.
- Most parents are unaware of the rights of children and hence are in no position to demand it. Need to tackle the environment at various levels on the awareness of rights amongst parents.
- Sustainable CSR is necessary for pay for providing training to parents which otherwise is very expensive and out of reach for most.
- More refined modules for parent's training from National Trust and IGNOU; NIOS should work on bringing about a change in the current module.

Theme 2. What are the barriers to early identification and diagnosis of CIN?

Participants: Indu Chaswal, Krishna Veni, Mansoor Alam, Nirmal Chhabra, Ruby Singh, Sagar Chandola, Smriti Pathak, Viveka Chatopadhyay

Facilitated by: Viveka Chatopadhyay

Issues

- Late or mis-diagnosis and unrealistic prognosis lead to late intervention and hence increased complexities.
- Lack of trained professionals make it difficult to get appropriate care available to most.

- Lack of medical awareness/ training programs for professionals' leads to paucity of trained hands.
- Religious perspectives and social rejection makes it difficult for CIN and their families to openly come out and seek intervention.
- Professional ethics is lacking with many clinics and institutions approaching this as a money making business and exploiting parents.
- Affordability and availability as mentioned above is one of the biggest barrier to seek services.

Suggestions from Break Out Groups 1 & 2

- Need to undertake reliable research so as to facilitate standardized and affordable interventions for our CIN.
- Attach more value to the profession so as to attract good people.
- Need to have early intervention programs for a wider range of disabilities.
- Wider perspective/ mentality to enhance acceptance for our CIN in society.
- Enforcement of laws to endorse ethical standards in practice.
- Spread parent awareness programs
- Widen outreach of NGOs so as to reach out to more and more CIN.
- Bring a positive and constructive impact through schools/ NCC etc.
- Spread awareness through media, documentaries and other communication material.
- Sensitize religious leaders to enhance acceptance of our CIN.

Theme 3. What are the challenges of inclusion of CIN in terms of awareness, acceptance and sensibility?

Participants: Blessin Varkey, Nirmal Chhabra, Poonam Bhasin, Suneeta Singh, Swati, Viveka Chatopadhyay

Facilitated by: Nirmal Chhabra

Issues

- Financial needs are more for families of CIN.
- Educational services on skills of daily living, communication, independent living, social skills, and social acceptance are necessary for the growth and development of our CIN.
- Health/ medical needs for our CIN are more and are specialised.
- Awareness to parents/ doctors is necessary for proper care for our CIN.
- Vocational training is necessary to make our CIN more confident and financially independent.
- CIN need to be loved.
- Lack of knowledge prevents those dealing with intellectual challenges from availing the right services.
- Physical accessibility of services would enhance use of services by our CIN.

- Training to parents and teachers would bring about more coordination in their efforts at school and home
- Attitudinal barriers needs to be overcome to make our society more inclusive.

Theme 4. What about life of CIN after the special school/ centre?

Participants: Adarsh J. Singh, Blessin Varkey, Indu Chaswal, Mansoor Alam, Sagar Chandola, Smriti Pathak

Facilitated by: Sagar Chandola

Issues

- Dearth of vocational centers which impart training to our CIN. Limited training in occupational/ skills of independent living do not leverage the capabilities of our CIN.
- Lack of services available at the college level makes it difficult for our CIN to go for higher studies.
- Social isolation of families and lack of respite care services.
- Medical problems with our CIN need to be taken care of by experts in a more sensitive manner.
- Change in family dynamics has an impact on the emotional and psychological needs of the children and their families and needs to be handled by counselors.
- Protection and employment issues, legal issues are important and need special attention.
- Concerns of parents regarding the future of CIN of how they would sustain after them.

Suggestions from Break Out Groups 3 & 4

- Identification of individual skills at an early age to prepare for vocational training.
- A variety of models – sheltered workshops concentrating on special needs, inclusive set ups, small scale business set ups, open employment should be explored to identify those best suited to their needs.
- Involve our CIN in community activities is necessary to inculcate a sense of self-worth.
- Independent or supported decision making skill is necessary to build their self-esteem.
- Concept of 'privacy' needs to be instilled.
- Behavioral counseling wherever possible should be provided.
- Sensitize corporates to offer flexibility in employment, pattern of work, timing so as to make employment more inclusive.

The discussions in the Break Out Groups were followed by presentation by each group leader on main points of discussion within the groups.

GALLERY WALK

During the Gallery Walk, participants had a chance to once again review all the points raised by the Consultation. They prioritised the following as being the most important:

- Concerns of parents regarding the future of CIN of how they would sustain after them.
- Lack of medical awareness/ training programs for professionals leads to paucity of trained hands.
- Dearth of vocational centers which impart training to our CIN. Limited training in occupational/ skills of independent living do not leverage the capabilities of our CIN.
- Late or mis-diagnosis and unrealistic prognosis lead to late intervention and hence increased complexities.
- Expensive mainstreamed schools make it difficult for the marginalised to access education.
- Lack of trained professionals make it difficult to get appropriate care available to most.
- Need to have early intervention programs for a wider range of disabilities.
- Spread parent awareness programs
- Sustainable CSR is necessary for pay for providing training to parents which otherwise is very expensive and out of reach for most.
- Training to parents and teachers would bring about more coordination in their efforts at school and home
- Attitudinal barriers needs to be overcome to make our society more inclusive.
- Lack of services available at the college level makes it difficult for our CIN to go for higher studies.
- Change in family dynamics has an impact on the emotional and psychological needs of the children and their families and needs to be handled by counselors.
- Protection and employment issues, legal issues are important and need special attention.
- Concept of 'privacy' needs to be instilled.
- Sensitize corporates to offer flexibility in employment, pattern of work, timing so as to make employment more inclusive.

THE CLOSING CIRCLE

In general the group felt that the consultation provided a unique opportunity to build a common understanding of the day to day challenges faced by parents, professional and institutions while dealing with our CIN by bringing up their concerns. They were particularly pleased with the OST methodology – they felt it is very effective and allowed equal participation from all participants.

Some of the issues that came up during the Closing Circle:

For the first time people had an exposure to an OST consultation.

"It was a wonderful experience. As a professional as well as a parent, I found it enriching. The open space technique, bumble bee and butterfly technique were all new and great".

They also expressed the need for enhanced services for our CIN, not only in the urban but also in rural areas and slums.

"Hearing the view points from different people was a knowledgeable experience and hope that in the future we will come up with solutions not only for the tier I cities but also for small cities."

Another participant stated that:

"This was a discussion on the issues and barriers which the CIN face, the consequent consultation should be on solving these problems and acting on it."

The Participants strongly felt that the documentation of the consultation was absolutely necessary and should be shared with all. Otherwise the wealth of information generated in the process will be lost.

LIST OF PARTICIPANTS

S.No.	Participants	Organization
1.	Adarsh J. Singh	Parent
2.	Anjali Krishan	Amaltas
3.	Apurva Rastogi	Amrit Foundation of India
4.	Blessin Varkey	Tamana
5.	Dr. Krishna Veni	Tamana
6.	Dr. Suneeta Singh	Amaltas
7.	Indu Chaswal	Independent Consultant
8.	Kriti Singh	Amrit Foundation of India
9.	Mahima Sapru	Amrit Foundation of India
10.	Mansoor Alam	Institute for Child Development
11.	Nirmal Chhabra	Delhi Society for the Welfare of Special Children
12.	Poonam Bhasin	Parent
13.	Pranavi Sethi	Amrit Foundation of India
14.	Ruby Singh	World Bank/Parent
15.	Sagar Chandola	Tamana
16.	Smriti Pathak	Delhi Council for Child Welfare
17.	Swati	Dew Drops Learning Solution
18.	Viveka Chatopadhyay	Independent Consultant