

A photograph of several yellow flowers in a clear glass vase. The flowers are in various stages of bloom, with some fully open and others as buds. The background is a blurred outdoor setting with a building and a white object.

halraj foundation of india

EXCLUDED FROM LIFE

Report of the second 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.

New Delhi :: March 2014

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INTRODUCTION

The vision of **Amrit Foundation of India** 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 caregivers like parents, family members, parent support groups, play groups and volunteers; professionals such as doctors, lawyers, special educators, teachers, occupational and speech therapists, counselors, researchers, etc.; and institutions like NGOs active in this area, training centers and schools. 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 build and 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 aimed to question why families are not able to use the services available for CIN by examining existing stereotypes and decoding their roots so that operational responses can be constructed. In this second stage, we worked with experts and practitioners in the field to generate a compendium of solutions.

The **Excluded from Life** series will build evidence-based solutions for effective, accessible, and affordable interventions for CIN.



Capt. Rajbir Singh
delivering a welcome note



Dr. Suneeta Singh delivering
the introductory speech



Ms. Poonam Natrajan
giving the keynote address



Ms. Ruby Singh, Dr. Uma Tuli and Mr. Subash
Vashishth speak to the participants



Mr. Anil Joshi, Ms. Abha Khetarapal & Dr.
Sushma Batra during fish bowl session

Ms. Poonam Natarajan, Chairperson of the National Trust, a Statutory Body under the Ministry of Social Justice and Empowerment for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities since 2006. Ms. Natarajan is actively involved in policymaking at the National level and is a serving member on several committees. Ms. Natarajan is the founder of Vidya Sagar, a Centre for children and adults with developmental disabilities in Chennai in 1985. Ms. Natarajan trained in the field of disability in 1981, from Spastics Society of India, Mumbai (now Adapt), after the birth of her son who had multiple special needs and has been her 'Guru' in her journey with special needs. She has won over 14 Awards for her work in disability. She has also received the UN-ESCAP Asia-Pacific Disability Rights Champions Award on 1st November 2012 in the Republic of Korea.

Ms. Pranavi Sethi, Executive Director of Amrit Foundation of India has completed her B.Sc. degree in Management Science from IILM, Delhi. She has been an avid sports person since her school days. She has several awards relating to all-round development, sports, dance and theatre. For several years she has participated in State and National Games, Special Olympics, winning medals and leading the state contingent. While in college, she enthusiastically took part in college activities, taking leadership positions in activities such as the Corporate Walk. Pranavi is playing an active role in the development and growth of Amrit Foundation as its Executive Director. Her networking skills have placed Amrit on a trajectory of growth.

Ms. Viveka Chattopadhyay, Independent Consultant is working as a consultant for Ashish Foundation for the Differently Abled and Udaan and has been responsible for training teachers, developing assessment curriculum, individual education programmes, and functional assessment tools for children with cerebral palsy and autism. Ms. Chattopadhyay has been an examiner and guest faculty for The Certificate in Professional Practice run by The University of Roehampton at Amar Jyoti. She has developed training modules for teachers on identification of children with disabilities specifically autism, ADHD, and children with learning difficulties, as well as accommodation and modification of classrooms and behaviour management. Ms. Chattopadhyay has worked with Action for Autism for 8 years in New Delhi and at Al Noor School for the Handicapped for 4 years.

Mr. Madhusudan Srinivas, journalist and Founder of Play Time, a Parent Support Group, is the parent of Abhimanyu, a 21 year old autistic person. Abhimanyu was diagnosed with autism in December 1995. Since then, Mr. Madhusudan and his wife Shubhra (also a journalist) have seen themselves as not only as parents of an autistic child but also as advocates for the cause of autism. They have advocated through word of mouth, face to face, through frequent articles in print media, and occasional appearances on television. They have also provided support to the activities of various

NGOs including Action for Autism, and Ashish Foundation. But over the years, their primary satisfaction and joy has come from informally counselling parents of children recently diagnosed with autism.

Ms. Abha Khetarpal, President of Cross the Hurdles, Ms. Khetarpal graduated from Delhi University with a Masters' Degree in Economics, English and Psychotherapy. She is a counsellor for students with disabilities at University College of Medical Sciences. Ms. Khetarpal has published numerous papers on disability in the International Journal of User Driven Medicine and Indian Journal of Psychological Medicine. She has presented papers at the Indian Spinal Injuries Centre, JNU, National Symposium on Disability Management in Agriculture and Farming, among others. She has also authored two handbooks, 'Tax Concessions and Exemptions for the People with Disabilities in India' and 'Keeping You Abreast' for women with disabilities for breast cancer self-examination and awareness. Ms. Khetarpal also free-lances as a career counsellor to people with special needs. She has recently launched the first-ever Indian mobile application for people with disabilities called Cross the Hurdles.

Dr. Sushma Batra, Head of Department at Delhi School of Social Work has been teaching research and statistics to M.A. and M.Phil students since 1981. Her interests include working with elders and those with disabilities. She has advised many research scholars on various issues related to social work. Dr. Batra has published four books/monographs in the last five years on the many issues related to their life. In addition, she has also authored articles and publications. She has been involved in research collaborations on Impact Assessment of projects in the field of Information Communication & Technology for empowerment of persons with disabilities by Media Lab Asia. Furthermore, Prof. Batra is presently a member of the Steering Committee on 'Empowerment of Persons with Disabilities and Social Welfare Groups', for the formulation of the Twelfth five-year plan 2012-2017.

Mr. Anil Joshi, Board member of National Trust is an IT professional with over 30 years of experience and has been actively involved in the disability sector for over 20 years. He is one of the founding members of PARIVAAR - The National Confederation of Parents' Organizations; and after serving as its General Secretary (Hons), is now the Technical Advisor (Hons). Mr. Joshi has been a Board Member of the National Trust for over ten years and has been actively involved in disability legislations and related policy issues. He is keenly involved in leveraging Information Communication Technology as a means for inclusion in every sphere of life, so as to improve the quality of life of persons with disabilities. An engineer and management professional, Mr. Joshi is engaged in several multinational corporations for research.

Dr. Uma Tuli, Founder & Managing Secretary of Amarjyoti School She was the first non-bureaucrat appointed by the Government of India as Chief Commissioner for Persons with Disabilities from April 2001 to April 2005. She is the founder of Amar Jyoti Charitable Trust that offers rehabilitative services at Delhi and Gwalior with the holistic approach of providing integrated education, vocational training, medical care and self-employment in one premise. With this pioneering concept of integrated education, the schools run by Amar Jyoti in Delhi and Gwalior have an equal number of children with and without disability studying together. Dr. Tuli desires to accomplish her mission of an India, which places its citizens with disability on the same platform as a non-disabled citizen.

Ms. Arvinder (Ruby) Singh, a parent and activist is a part of the core Administration Team at the World Bank, where she has been working for over two decades. She spearheaded the HIV/AIDS awareness programme among the staff and their families through community outreach programmes and various workshops. With close association and requisite experience, she contributes significantly as our Board Member towards various projects that the Amrit Foundation undertakes.

Mr. Subhash Chandra Vashishth, a Disability Rights Activist is a legal practitioner at the Delhi High Court. His focus is advocacy for human rights and the rights of persons with disabilities. He is also a developmental therapist trained at Action for Ability Development & Inclusion (formerly the Spastics Society of Northern India). His pioneering research work on “Status of Laws protecting the Rights of Persons with Orthopaedic Disabilities in India and Amendments required in various Indian domestic laws to harmonize them with UNCRPD” conducted for national consultations organized by HRLN was highly acclaimed. He consults with Svayam - National Centre for Inclusive Environments. He is a founding member of the Advocacy Committee of All India Confederation of the Blind. He has extensive experience in accessible & inclusive environments, inclusive education and employment, community based rehabilitation, and disability equity & legal rights.

INTRODUCTION TO
EXCLUDED FROM
LIFE WORKSHOP
SERIES

9:35AM-9:45AM

Welcome Note - Capt. Rajbir Singh, President, Amrit Foundation of India
Introduction - Dr. Suneeta Singh, Board Member, Amrit Foundation of India

Objective: To introduce the speakers to the audience and apprise them of the vision of Amrit Foundation of India

Capt. Rajbir Singh welcomed the participants by acquainting the audience with Amrit Foundation of India and its flagship program – The Little Peepul Tree. The Little Peepul Tree aims to provide strategic support to all those who face and deal with intellectual challenges¹. It is a web based platform that functions both as an information bank as well as a clearing house that collects, collates and distributes useful knowledge on various aspects of intellectual challenges.

Dr. Suneeta Singh Sethi explained that the ‘Excluded from Life’ workshop series strives to understand the compassionate systems for Children In Need (CIN)² and to generate evidence-based solutions for effective, accessible, and affordable interventions. It is a series of consultations with experts and practitioners working in the field of intellectual challenges. Through this medium, Amrit hopes to generate a compendium of solutions for equity in service provision, by defining the paradigm shift needed in the way services and policies are designed for the most vulnerable. The First Consultation was held on 21 November 2013. This Consultation was centred on identifying obstacles faced by CIN and had adopted an *Open Space Technology* approach wherein participants got an opportunity to construct their own agendas.

The discussion was centred on elaborating solutions for issues identified and prioritized during the first Consultation³, such as:

- Late or misdiagnosed intellectual challenges of childhood
- Attitudinal barriers of inclusion of CIN in social processes and institutions
- Increased accessibility of education for CIN through vocational centres, trained professionals and mainstream schools
- Increased accessibility of training for parents of CIN
- Planning for CIN’s future, protection, marriage, employment, legal guardianship
- Possible involvement of the corporate sector to create a disability-friendly workplace.

Key Messages

The ‘Excluded from Life’ series aims to build a common and better understanding on the barriers preventing families from using services for CIN.

The series envisions plans and policies to address the right to a life with dignity of CIN.

The consultations will share experiences, discovery of solutions and coping mechanisms of parents.

Amrit seeks to support and develop institutional mechanisms and collaborate with other organizations.

¹ Amrit Foundation of India emphasised on use of the term ‘Intellectual Challenges’ rather than ‘Intellectual Disability’ based on the premise that ‘disability’ implies something fixed and cannot be overcome, but a ‘challenge’ can be addressed by a strong response and can be overcome.

² ‘Children in Need’ used by Amrit Foundation of India quite often refers to the children who have specific needs and are in need of help, attention, support and love.

³ A detailed report of the first workshop is available on the Amrit Foundation of India website at www.amritfoundationofindia.in

In Consultation II, Amrit hoped to build on learning from the last workshop. In the same series, the Second Consultation was held on 22 March 2014 and was intended to take the discussion forward from identification of barriers to identification of methods of breaking down these barriers as well as tackling hurdles that prevent children from appropriate care and opportunities to develop and grow. The objective of Second Consultation was to chart out a roadmap for a more inclusive society and to mobilize support in order to achieve more equity. The Consultation provided a platform for professionals and experts to share their experiences of tackling exclusion and discrimination faced by CIN, discover solutions and progressive programs for overcoming challenges, and advocate for policy change.

Amrit invited a virtual galaxy of people with immense experience in the field. The workshop consisted of three sessions, as elucidated by Dr. Suneeta Singh:

- Session 1: Parents in Search for Services
- Session 2: State's Responsibility for Children in Need
- Session 3: The Adult Child in Need

It is hoped that this Consultation series will envision plans and policies that will appropriately address the right to a life with dignity, a life that CIN are entitled to, as well as promote inclusivity and cohesively in society.

KEY NOTE ADDRESS

10:05AM–11:05AM

Key Messages

A compendium of solutions is hoped to be arrived at collectively, to suggest various services to help coping by families of CIN.

IQ score computation is highly judgemental. It is unreliable as a tool that describes the capability of a CIN or indeed, or what the child can eventually accomplish as s/he grows into adulthood.

A niche must be created for special children where they are asked to do what they feel like doing, rather than impose the general obvious upon them.

Ms. Poonam Natarajan, Chairperson, National Trust

Ms. Pranavi Sethi, Executive Director, Amrit Foundation of India

Collaboration with The National Trust has been a critical step in meeting goals and making it possible to step forward on a path of dialogues and discussions through which solutions can be found. The partnership between Amrit Foundation of India and The National Trust lead to a new platform for sharing of experiences such as the journeys of parents in bringing up their children and development of coping strategies that lead to strong impacts on other parents. The compendium can, thus be developed by collating the findings of the consultations and workshops of this series.

The National Trust is a statutory body under the National Trust Act of 1999 and was formed over time through the advocacy of parents of persons with intellectual disabilities. The National Trust creates awareness and safe support systems as well as finds solutions through its various schemes and programmes.

The session laid emphasis on the transition from the early intervention period to successful adulthood. Various life experiences were quoted and shared leading to a catalogue of effective measures. Parents shared their knowledge and life experiences among one another and admitted that solutions have become more accessible as the years have gone by. Many parents were well aware of their child's problems, had accepted them and worked towards their betterment, while there were few parents who did not yet have appropriate information or solutions.

Ms. Natarajan believes that IQ scores are highly unreliable and judgemental as they are tests of ability of a child in language, logical thinking, mathematics, verbal ability, etc. but do not account for the child's ability in kinaesthetic, painting, arts, inter-personal relationships and in a wide range of other kinds of intelligence. It is therefore important to create opportunities and help children so that they are able to carve a niche for themselves. People excel and are happiest when their interests and work overlap. So why do people with disabilities attend special schools that make them work on activities that they have trouble with? It is important to create opportunities that will help all children in developing their potential deeply.

On a personal note, Ms. Natarajan told us that her son taught her how to look at life differently and to not think of being the greatest by running in a competitive world and achieving the biggest things. She has unlearned what she had learnt at school and college and started a life with a very different thought process, in line with her son's ideology.

Key Messages

Living with intellectual challenges is a learning journey through life.

Acceptance of and timely realisation is the first step to overcome problems.

The support of family, friends and the system can help CIN realise their true potential, oftentimes to their own amazement.

Ms. Pranavi Sethi narrated her journey of becoming the Executive Director of Amrit Foundation of India. Her family has been her touchstone - her source of strength. Her mother being her teacher, her father - her supporter, and her brother her connect to the outside world. In a world that is unkind to those who are a little different, her brother was able to help her create a kind of 'normalness'. He helped her develop a circle of friends. Her grandparents, friends and teachers supported her in teaching everything she knows today, to be confident and to believe in whom she wants to be.

Ms. Sethi's education at Vasant Valley School and IILM gave her the confidence to face the world. Journeys through life can be difficult for special children. Some struggle with a stammer, others with deafness, still others with shyness, and some with intellectual disability. Nevertheless, what defines them and what they will achieve is the confidence with which they and their family can step forward to meet the challenge.

Amrit Foundation tries its best to help CIN and their families by pointing them in the direction of attaining services and support that they require. As the Executive Director of Amrit Foundation, it is Ms. Sethi's endeavor to ensure that the voice of all CIN are reflected in the resources that are being put together and that everyone gets the help that they ask for.

SESSION I: PARENTS IN SEARCH OF SERVICES

9:45AM-10:05AM

Mr. Madhusudhan, Play Time, Parent Support Group

Mr. Madhusudhan narrated his experience as a parent of an autistic child and how he never perceived it to be a problem. It is nothing more than being different and coping with differentness. Autistic children have their own characteristics, such as making distracting sounds and loud noises. If society really believes in co-existing with different people then one must be able to cope with the sounds too.

In a traditional society like ours, realising and accepting any kind of problems with one's children takes a long time and possibly longer for men. This delay in coping with the problem leads to delays in further diagnosis. Once the problem is identified, its acceptance is another challenge for parents and this shakes their coping mechanism. He shared how negative thoughts and feelings cross parents' mind and the future appears darker than it is, often leading to depression. There is no magic formula for accepting reality and building understanding. One has to create individual pathways for coping.

Autism is just "Another Worldness" and the tragedy yet the beauty of an autistic child is that they look like any other child. It is through their behaviour that Autism is identified and regarded as a disorder. A lot of patience and hard-work is required to handle the aberrative behaviour of an autistic child but outdoor activities like music classes, long walks or painting should be encouraged. More importantly, ample time should be spent to analyse their behaviour such that an appropriate solution can be developed.

Coping can also come through sharing experiences and the realisation that basic education can be given at home. Family is the fulcrum of what is going on with the child. There is hope that through various kinds of therapies improvement will occur. This, along with new research (Applied Behaviour Analysis) on autism is encouraging. But, first and foremost the child should be given respect without any discrimination.

In fact, it is necessary to demand and to fight for rights and protest. Ultimately it is up to those effected to decide how they choose to cope with their problems. What's interesting is that coping can sometimes have more to do with parents' own perception of differentness rather than their child's.

Ms. Viveka Chattopadhyay, Consultant, Ashish Foundation and Udaan
According to Ms. Viveka Chattopadhyay, childhood and schooling are some of the most instrumental and beautiful phases of one's life. She believes that the "old school of thought" phase is gentler and kinder as compared to the newer thinking of today's age that performs differently. Discrimination can arise due to many of these differences and therefore introducing the concept of inclusion is important. Terms such as 'these children', 'retarded' or 'mentally challenged' are often used in India till date and the practice must stop. These labels are just an additional medium for discrimination.

Key Messages

It is important to adapt and cope with differentness in life.

Traditional societies such as India take a long time to realize and accept problems of special children.

Parents must be willing to work hard, have bottomless patience and remain alert to discover solutions to cope with the problems of special children.

Outdoor exposure and spending ample time with family and friends is helpful to build stronger CIN.

Key Messages

Ironically practicing the concept of inclusion can lead to an obverse discrimination.

Professionals do not always have the answers to problems.

There is a crying need of partnership between parents and professionals.

It is important to involve the fathers of special children to make them understand the depth of the problem so that they can contribute to solving it.

Good quality professionals are the need of the hour.

There is a need of strong partnerships between parents and professionals. Having one common goal instead of two separate ones for home and school is much more conducive to the wellbeing of the child. Parents sometimes feel disheartened when they observe the lack of progress in their children. To combat this, constant emotional support and understanding from professionals is important and encouraging for the parents.

Ms. Chattopadhyay also contributed a very interesting suggestion by voicing that it is important to engage the fathers of children with special needs equally with the mothers. Generally in India, the mothers are counselled as fathers tend to take more time in overcoming the turmoil and emotional imbalance. Fathers must be counselled to cope with the problem as well.

Children do not need pity but a positive mind-set and acceptance by others to arrive at good outcomes. The whole idea about putting stress and pressure on the child is not about the disabled child; rather it is about how parents want to bring up their children. Although parents tend to blame the teachers and the system, they need to be shown direction through proper training programs and involvement.

Verbal, mobile and toilet training are the three most important aspects of eligibility criteria for employment as well as for being in the mainstream school. These are no large feats and together, one must push for mainstreaming of CIN. Hospitality, internships or restaurants are all good places to start.

SESSION II: STATE'S
RESPONSIBILITY OF
CHILDREN IN NEED

11:20AM-12:05PM

Key Messages

The issues pertaining to persons with disabilities are not a state responsibility alone.

The legislations are drafted well but face an unending challenge in terms of implementation making it a poor reality.

Technology is developing and is helpful but has its own consequences.

Academicians and professionals must all come together in support, cooperation and solution finding.

Mr. Anil Joshi, Board Member, National Trust

In his personal view, Mr. Anil Joshi raised a question of how the state is responsible for children in need. He re-iterated that there is a basic crack in the constitutional provisions of things pertaining to the persons with disabilities. Disability is a state subject. But since policies are made by the central government, the task of implementing policies related to disability is difficult.

His experience and observations of legislations in the past 20 years has been positive with respect to provisions. However, the ground reality is starkly different. Discussion of the problems at collective forums does not help solve the lack of provisions of basic services such as education and health for those who are without access to occupational and speech therapies. The overall socio-economic environment is moving towards privatisation at a rapid speed and this results in the government's lack of ability to regulate the situation. ICT professionals are dealing with inclusion on a daily basis. The data that previously took 100 years to generate now only takes an hour. This tremendously adds to development but can have negative consequences. Within this explosion of information comes the issue of inclusion that has a direct impact on the lives of the children. The government needs to re-open this problem and come up with solutions as soon as possible.

He also applauded the fact that mobile phone technology has shown us the light of way and that this power can reside in the hands of everyone in order to communicate indirectly.

Dr. Sushma Batra, Head, Department of Social Work, University of Delhi

Learning from her professional journey, Dr. Batra explained how the medical model has transitioned into a social model over time. This demands change in the environment which itself requires our spaces to be equipped.

After representing the University of Delhi for over 20 years, she criticised and shared that the university is yet to achieve appropriate standards for providing services to the people with disabilities. This includes the introduction of a barrier free environment. There are many government schemes already in existence but they are not implemented to their full potential. Majority of the student body as well as the faculty are not even aware about such schemes thus increasing the need to create more and more information so that a demand for change is created.

Inclusion means participation and leads to the removal of structural barriers as well as modification in behaviours and attitudes both of parents and professionals in the field. It is important for us to come together with the support of academicians and fight for the wellbeing of children with disabilities, children with special needs or children with needs.

Dr. Uma Tuli, Founder & Managing Secretary, Amarjyoti School

Key Messages

The state authorities are not always cooperative and personnel often shirk their responsibilities.

When demand is strongly put, mechanisms do mobilize but need serious and dedicated follow up.

The concept of assigning a legal guardian to adults with special needs is an important one and should be undertaken not only for the well-to-do, but for all sections of society.

There is a lack of cooperation on the part of the state authorities. They tend to resist work out of paucity of time and shirk responsibilities causing a negative impact on the future implementation of policies. One of the biggest obstacles is to collate separate state commissioner teams for LLCs and for PWDs.

When efforts are made to get across a point that is duly supported by a highlighted need, mechanisms do mobilize. However this an ambitious motive for all 700+ number of districts. A common approach is by studying statistics; for one person with intellectual disabilities at least 10 people are directly or indirectly involved. If a point is brought across to the authorities with a focussed question and diligent pursuance, it is considered. We just have to be provide the catalyst for getting them into action.

If members of the NGO of the LLC actually do most of their homework (home-visit, undertake needs assessments) and assess the need of legal guardians, then they would be doing some serious work towards breaking structural barriers. Once this work is achieved then the state level representatives can be queued to intervene. In Delhi, some NGOs have already broken this barrier.

There is yet a need to develop a collective social concern in the IAS personnel for which education is key. Sensitization is most crucial to work with people with disability and to address their needs.

SESSION III: THE ADULT CHILD IN NEED

12:05PM-01:05PM

Key Messages

A huge stigma is attached to people with intellectual challenges.

Vocational training courses and communications must be linked with self-care and lead to independent living.

Most legal cases are related to employment issues pertaining to providing adequate facilities at workplace.

Many parents with children with borderline issues push them into marriage to acquire benefits.

Marriage is voidable on the basis of unsoundness of mind and this term has not been clearly defined in the law.

There are no mainstream schemes in implementation other than the Nirmaya Scheme.

Ms. Ruby Singh, Parent and Activist

Ms. Ruby Singh facilitated a small movie screening about a special school in Secunderabad which works on the aspects of vocational training and communication skills. In this school the children are taught to look after themselves, their house, and have an independent lifestyle. At the same time there are provisions of care takers in order to provide assistance and to avoid trouble. The children are also rewarded for high productivity in work that they undertake with ample concentration. The movie was motivational and made everyone realise that all children with special needs have potential that just requires a little attention in order to fully develop. The parents of the children must also have will in place and must guard their children with immense strength. At the same time, parents must assure the comfort and safety of their children.

Mr. Subhash Chandra Vashishth, Disability Rights Activist

It is very rare for lawyers to get cases about or from people with intellectual challenges. In fact, 90% of the cases are mostly related to employment, education and lack of access to services. Parents don't often take up the role of petitioners by visit lawyers or courts but instead prefer visiting counseling centres.

There is no justification of the expulsion of disabled people because there is no difference between the rights of people with disabilities versus people without disabilities. The Amrit workshop very aptly specifies this subject. The Persons with Disabilities (PWD) Act, 1995 covers all disabilities from perspectives of giving rights and facilities. The act specifies only 3% reservations in employment areas whereas all other benefits are equally applicable to people with intellectual and developmental disabilities. In the PWD Act, 1995, despite most provisions being applicable, people do not approach the lawyers for avilment. The parents are often burdened and engulfed with care and worries about the future of their children. There is a huge scope for advocacy which still needs to be explored and it is very unfortunate that till date the options of state interventions have not been undertaken.

In fact there is discrimination within disabilities. In most physical disabilities, if one is suffering with $\leq 40\%$ disability, they become entitled to certain benefits/reservations, but in case of intellectual challenges and/or developmental disabilities, a huge tag of incapacity is attached. It is difficult to enter a contract based on the 'disability of mind'. There are problems within the legislations which have not been addressed despite of the fact that the UN Convention was signed in 2006 but India has so far not made much progress. The advocacy must be from the perspective of the uniqueness of

needs. The parent groups should be the primary force in advocacy as in a lot of cases, the children cannot advocate for themselves.

Despite all the challenges to overcome, a lot of parents push children with borderline cases into marriages just to acquire benefits. Sustaining a marriage is a challenge and there are times when a marriage only sustains on continuous supply of money from the girl's father. Furthermore, marriage is voidable on the basis of unsoundness of mind and this term has not been clearly defined in the law. Often parents undergo marriage counselling instead of legal advice, mostly in cases of property rights. Most of the people who visit for legal assistance are not the stakeholders themselves but the people who are going to take advantage of the disabled which cause dilemmas about justice for lawyers. Insurance of persons with disabilities is a completely silent matter and needs to be addressed with a strategy in mind for the future. The Niramaya scheme under The National Trust is the only insurance scheme which is currently in implementation.

During a physical health examination of a child, the moment it is declared that the child has intellectual disabilities, a big question arises. The law, governing actuaries and the policies disallows the family to claim insurance on the basis of disability. The moment the word "neurological" is uttered, the case is no longer considered. Even today the laws which govern the employees with disabilities in government cause them suffrage.

One possible solutions to some of these problems is the introduction of smart cards that enable all children with special needs to store and easily access information when needed for appropriate assistance and diagnosis. These smart cards could be for social security, financial assistance bodies and specifying information on old age homes. However, this does not belittle the urgency of having a legal guardian for children in need.

LIST OF THE
CONSULTATION
PARTICIPANTS

Name	Organisation
Mr. A Guha	Action for Autism
Ms. Vaidehi Subramaniam	Akshay Pratishthan
Mr. J S Kang	Amaltas
Ms. Priyanka Dubey	Amaltas
Mr. Ankan Chatterjee	Amaltas
Dr. Uma Tuli	Amarjyoti
Capt. Rajbir Singh	Amrit Foundation of India (C&C Constructions Ltd.)
Mr. Gobind Singh Sethi	Amrit Foundation of India
Ms. Kriti Singh	Amrit Foundation of India
Ms. Upasana Changkakoti	Amrit Foundation of India
Ms. Nidhi Vatsa	Amrit Foundation of India
Ms. Apurva Rastogi	Amrit Foundation of India
Ms. Pranavi Sethi	Amrit Foundation of India
Dr. Suneeta Singh	Amrit Foundation of India
Ms. Rashi Bijlani	Asha Hai and Centre for Dance Movement Psychotherapy
Ms. Ema Jamal	Asha Hai and Centre for Dance Movement Psychotherapy
Mr. Augustus Lightwriter	Augustus Photography
Mr. J.L. Sippy	Awaaz Special School
Mr. C.S. Sethi	C&C Constructions Ltd.
Mr. A R Goyal	Consultant
Ms. Chitra	Consultant
Ms. Viveka Chattopadhyay	Consultant, ACPCP
Ms. Abha Khetarpal	Cross the Hurdle
Ms. Sapna Zarwal	D Potential Kidz
Ms. Rajni	D Potential Kidz
Dr. Sushma Batra	Department of Social Work, University of Delhi
Mr. Subhash C Vashisth	Disability Rights Activist
Dr. R K Hora	Ex-Director VIMHANS
Mr. Anil Joshi	National Trust (IBM)
Dr. Masoor Alam	ICD, Delhi
Dr. Vijay Kansal	Kalyan Medicare
Mr. Vijay Pal	Khushboo Welfare Society, Gurgaon
Mr. Vikas Kumar Jain	Ministry of Railways
Mr. Somesh Purey	Music Therapy Trust
Ms. Poonam Nataraj	National Trust
Ms. Shweta Bhatt	Navjyoti Institute
Ms. Neda Samer	Navjyoti Institute
Major Gen. Jagdish Singh	Parent
Mrs. A J Singh	Parent

Ms. Rashmi Joshi	Parent
Ms. Neeru Sachdeva	Parent
Ms. Madhumita Puri	Parent
Ms. Alka Nath	Parent
Mr. Abhishek Singh	Parent
Mr. Tejender Sukheja	Parent
Ms. Anuradha Sukheja	Parent
Ms. Ruby Singh	Parent & Acitivist
Ms. Sweta	SASR, Faridabad
Ms Kausar Ara	SASR, Faridabad
Ms. Rama Tandon	Vasant Valley School
Mr. Kapil Kumar Aggarwal	Viklang Sahara Samiti
Mr. Satish Kapoor	Brotherhood
Mr. Madhusudan Srinivas	Parent
Yeann	Consultant

Fishbowl Discussion

The Fishbowl is useful tool for data collection, interpretation/generating conclusions and recommendations, communicating/reporting and teaching/learning evaluation. Its primary advantage is to reduce the divide between the expert and the audience. In the Fishbowl approach, one group interacts while the larger group watches, such as fish in a bowl. Four or six inner-circle chairs are occupied by the experts, the animator, and two or three participants. The animator kicks off the discussion, which begins with a short introduction to the topic discussed by the experts. Then a program partner can choose to occupy the 'participant chairs' and have a discussion with the experts. When the discussion has run its course, a fresh pair of participants will occupy the participant chairs. The audience can choose to join the discussion - when this happens, an existing member of the Fishbowl must voluntarily leave and free a chair. When time runs out, the Fishbowl is closed and the facilitator summarizes the discussion. The experts and the animator are referred as the fish in the bowl. The audience members moving back-and-forth are scuba divers. And the remaining participants are spectators.

CONSULTATION
AGENDA

EXCLUDED FROM LIFE: A Consultation on the Intellectual Challenges of Childhood

SEMINAR HALL NO. 1, INDIA INTERNATIONAL CENTRE, NEW DELHI – 110003

22 MARCH 2014, TIME: 9:00 AM-1:00 PM

Time	Session
9:00-9:30	REGISTRATION
9:30-9:35	Welcome Address Capt. Rajbir Singh , President, Amrit Foundation of India
9:35-9:45	Presentation on 'Excluded From Life' Dr. Suneeta Singh , Board Member, Amrit Foundation of India
9:45-10:05	Keynote Address Speakers: Poonam Natarajan , Chairperson, National Trust, (Act of 1999), Min of Social Justice & Empowerment, Gol Pranavi Sethi , Executive Director, Amrit Foundation of India
10:05-11:05	Session I :: Parents in Search of Services Speakers: Madhusudhan , Play Time, Parent Support Group Viveka Chattopadhyay , Consultant <i>Chaired by Dr. Suneeta Singh</i> , Board Member, Amrit Foundation of India
11:05-11:20	COFFEE & TEA BREAK
11:20-12:05	Session II :: State Responsibility to Children In Need Speakers: Anil Joshi , Board Member, National Trust, (Act of 1999), Min of Social Justice & Empowerment, Gol Sushma Batra , Head of Department, Delhi School of Social Work <i>Facilitated by Abha Khetarpal</i> , Founder, Cross the Hurdle
12:05-1:05	Session III :: The Adult Children In Need Speakers: Ruby Singh , Parent & Activist Subhash Chandra Vashishth , Disability Rights Activist <i>Chaired by Padma Shri Dr. Uma Tuli</i> , Founder & Managing Secretary, Amarjyoti School
1:05-1:15	Vote of Thanks Jagmohan Singh Kang , Board Member, Amrit Foundation of India
1:15 onwards	LUNCH