

A majority within a minority: Services for visually impaired multi disabled children

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How do we deliver effective, high quality services to all visually impaired multi disabled children. Although there are some excellent examples of effective service delivery in India, the issue of delivering services to this complex and heterogeneous disability is one of the biggest challenges to us as we strengthen the disability sector in the region.

This address, I recognise, is based to our situation in India, where we have an estimate of roughly 3000 children who present with the visual impairment and multi disabled condition are currently receiving direct services. This total includes an estimated 600 who we identify as deafblind, are receiving services. There are hundreds of more children who are not receiving services of any kind at present. But for our paper we will focus on the group that are included in some kind of service delivery mechanism. This population is spread over the entire country separated not only by distance but also by many natural geographical, cultural and language barriers. In talking with service providers and users – both deafblind children and their family members in rural and urban India I recognise that in many instances their situations are not dissimilar. In India, there has been a spurt of service delivery models for visually impaired multi disabled children in the last decade. With services being fairly established, most service providers are engaged in reviewing the current service delivery and possible service delivery models are being examined. This session provides an ideal opportunity to examine issues surrounding service delivery mechanisms and discuss possible solutions.

This address is aimed at identifying many of the issues surrounding service delivery to those children, which I hope, will be thought provoking. I am deliberately leaving the question of possible service delivery models to our panel and participants and I hope that the interactive portion at the end of the session will also invoke many other responses and raise other issues.

Who is our target group

Just who are the potential users for a service for visually impaired multi disabled children? There seems to be general agreement that this group of children present with a loss of vision and often accompanied by a variety of conditions including hearing loss, cerebral palsy, mental retardation as well as sometimes autism, learning disability etc. Services for VIMD children have become a melting pot for any child with multiple conditions, more often included by virtue of his diagnosis of more than one condition rather than his abilities and level of independence. Luckily over this period a few heads of non – governmental organisations, enlightened bureaucrats and pro active practitioners have led the way in setting up services for visually impaired multi disabled children. And we are seeing emerging services for VIMD children who are educated in service delivery models where they can access additional support, curriculum takes their individual needs into account and methodology includes an inclusive setting at least within own school

Service Delivery Models

Some of the service delivery models that we commonly see in India are Community Based Rehabilitation (CBR) Home Based Services, Centre based or Special school services, Residential schools, Mainstream schools and Itinerant teacher support and so on. All these service mechanisms are fairly established in the country and as I mentioned before including VIMD children is an extension of earlier services for VI, mental retardation or hearing impaired children. There are several merits of each of these models. The primary one coming to my mind right away - being the capacity of these services to embrace a challenging group of children who are Visually Impaired and multi disabled. And keep the individual child in focus in its attempt to provide education and rehabilitation. However at this stage I am not going to count up the merits and demerits of each model.

What on the other hand I am going to elaborate on is evidence of issues that makes each of these service delivery models successful and wanted. These issues very strongly contrast the so called 'good' programmes from the 'not so good' programmes.

Inclusion

When we talk of evidence of inclusion in a service delivery, it includes not just physical inclusion with mainstream peers for education but also social inclusion, into our every day lives and minds. An example of this is a VIMD child in a special school set up doing his Braille lessons with visually impaired children, even at a time when he had a specialist teacher supporting him on an individual basis. The attempt to do it together with a peer makes that little difference to this particular service or programme. More often we are stumped at thinking creatively for inclusive activities for our children with all their special instructions, sitting, devices and communication modes in mind. And yet you walk into a home setting and find the mother feeding this child along with her

sighted peer, seated next to each other from the same plate. And you think...aah, this is how they will both grow to be equals...respect each other and have high positive regard for each other. Fostering equal opportunities at home goes a step further in ensuring the commitment of the service to extend this within the overall programme.

Inclusion is not an option. It is the way of life. And within this minority population of disabled children, for this vast majority of VIMD children it is their means to access their right to information about the world and its people and actions. It is the medium to educate. A young teenage VIMD boy in a rural village of India helps prepare cattle feed while other family members are away at the fields. This rehabilitation plan worked out for him, because his Community Based Programme reacted positively to the opportunities presented in the young boy's real life settings.

Participation

At the beginning of my presentation, I started off by reiterating how challenging and difficult this target group is. And now I would like to bring in ideas of how children participate in the decision making process. And how it is this element that ensures long term sustainability of a service delivery model. Children participate at all times. During the assessment process, they tell us very clearly what they like and does not like, which strategy worked for them and who they most prefer to work with. A so called 'good' programme encourages children not only to say more about themselves but also underpins its decision about programme planning based on this feedback. Some times these decisions leads to simple changes like increasing the contrast of the material the child uses, changing the distance in which we are signing to the child, to a management level decision of changing the main teacher.

Family members participate too. In programmes in India, and I believe the case would be the same else where in the world, parents are much more participatory and engaging in informal meetings and places rather than a structured 'official' meeting. The replicable value of a particular service delivery model has a direct relation to how much it listens to its primary stakeholders – children and their parents and then how much does it 'change' its thinking and planning based on this feedback. Was a programme able to review and redesign the manner and language in which information about their child's progress was communicated to parents. If the answer is a clear 'yes' it is a resounding confirmation that the service delivery will grow stronger.

Our educators are an interface between actual services and the policies and planning involved in every service delivery mechanism. Yet many a times decisions related to nature of children to be included in the services, area of coverage, allocation of time, money and skills may not be preceded by any dialogue or consultation with the educators. Educators are a major stakeholder of the service delivery mechanism. An educator is the right person to appraise the professional within him /her and determine

what nature of children they are skilled to support in terms of education and rehabilitation.

I must say, encouraging and affecting participation has less to do with the structure of a service delivery mechanism and more with the underlying principle it is grounded on. That of respecting the views of other people in your team and taking them on board.

Empowerment

Without exception all service delivery models believe in helping individual children reach independence. And this journey towards independence is empowering. How does a particular service delivery model ensure empowerment for all its stake holders. Let me elucidate this with a particular example from a Home Based Service in the state of Bihar. Bihar is located in Eastern belt of India and is counted as one of the poorest state in terms of economics, infrastructure and development. A few parents of multi disabled children travelled out of a couple of villages in Bihar to attend a larger family network meeting in another part of the country. Their interactions in this large meeting was characterised by a lot of huddling together, always on the fringes of a group discussions and certainly no brave hands going up to volunteer for a task. By the second day however during meal times and evenings, we could see them engaged in hesitant conversations with other members who for this discussion here call them 'regulars' in network meetings. A few months after the meeting there was a clear shift in the number of days in a week the educator visited the child at home and the hours the educator gave to the child in each visit. A little probing indicated that in the family members' discussion with other network members they realised that their children were getting much less service then what was rightfully theirs. And therefore the pressure to change all of that!!

A CBR worker in a programme for multi disabled children in Trichy a small town in Southern India, has made mud corner chairs, one in Orissa has stitched together a sensory mat from coconut fibre, palm leaves and fish net among other things. A third educator from Basti, a small town in the state of Uttar Pradesh has translated the first functional hearing assessment tool (a western one) she could come across, in a regional language, in the absence of any other available tool to help her start recording how her children can hear. Clear indications of educators empowered to take decisions that they are sure will work out best for the child they are working with!!

How does a certain structure of a service delivery model influence the way the major stake holders think and act upon?? None I would say, if we have that experience of walking through the journey towards independence and learning from our experiences in the process. This then resulting in effective decision making leading to good leadership of the programme.

Quality

It is not enough to have a service delivery mechanism. It is imperative to have the best one. Common sense says long term sustainability of a programme is directly proportionate to the quality of services it provides and maintains over time.

The multi disabled group is by no means homogenous, with many of the needs of the children being quite different from one another. Most of our services for VIMD are an extension of existing service delivery mechanism for either blind, deaf, mentally retarded, cerebral palsy and so on. This is quite an advantage as our children then draw from the already established resources and expertise. With demands on programmes increasing with greater identification, there tends to be pressure for taking in more and varied nature of children. Although services in India are not yet clearly taking a stand on the heterogeneity of the group that they can include under VIMD multi disabled services, they have started to share concerns about this issue. A common chain of thought that is emerging points towards taking in children for whom their trained human resource would be able to support.

The philosophy of education for multi disabled children especially ones with one or the other sensory loss is based on enhancing communication. A communication rich environment is seen in much specialised school set ups as much as it is seen in CBR programmes, home based programmes and mainstream schools. A child in an urban slum programme in Delhi pushes himself on his back to move towards the sun streaming down at the door – away from the cold and airless hut. The grandmother picks him up and takes him to the cot out in the sun, where she was shelling peanuts. The child said 'I want to go out to the sun' and more importantly the carer 'listened'! Evidences of a service that is embedded in communication.

A programme in Gujarat, running CBR services for VIMD children invest heavily on staff development. They employ a variety of informal and formal methods ranging from peer tutoring within the team, weekly staff meetings, periodical 'big plan' meetings in which teams working with similar children but in different areas join together, to more formal mechanisms like direct supervision, certified training course, in-service workshops and so on. A direct output of this investment is seen in latest trends and research findings in the area of multiple disabilities being translated into tangible practices in villages across Gujarat, be it personal passports, calendar systems or documented assessment profiles.

Sustainability

While I have talked about the presence of all the above issues leading towards sustainable services for VIMD and Multi disabled children, let me just focus on a few specifics in this section. All said and done in India as always in the region, you will comment – but where do we find the money to continue what we have started. I am not a finance person. Therefore I am tempted to suggest to keeping doing our work.

Somehow the money will find us. However, I appreciate that this is one of our foremost concern when we talk about sustaining services. I shall therefore give evidences again of what is working currently and it might be worthwhile to replicate these practices. Active participation by family members, staff team gives a greater ownership to the programme. Inversely this results in a collective responsibility to conscious look for local opportunities to raise money. A family member uses contacts to support an excursion for all children; an educator impresses on village seniors to lend a room for weekly therapy sessions. Realistic planning and allocation of resources leads to its maximisation. A family's home doubles up as a pre school for all children, including VIMD children. Keeping the long term objectives in mind it might be worth investing in Fund Raising for the service. A skilled person appointed with the specific task of raising resources for establishing a vocational training centre has paid off.

Clear and well established management information systems within a service delivery model supports in long term running of the service rather than being based on a few motivated personnel.

It pays not only to deliver good quality services but also to document and talk about our growth and achievements, risks and problems faced, lessons learnt and dreams for the future.

Conclusions

I would like to end here. So in retrospect what picture have I created so far about VIMD services. A significant group of children and their families who are instrumental in a steady increase of services in India; a wide range of service delivery models; covering parts of rural and urban India; a heterogeneous group of children; issues that significantly impact the long terms sustainability of services. I am aware that I have not shown empirical evidences of sustainable services nor have I suggested my individual preferences. It is apparent that the designing of service delivery models, to cater for the needs of this group of children will, provide challenges even in those situations where circumstances appear to be reasonably favourable.

I have raised a number of issues concerning the underlying foundations of service delivery mechanisms. I am sure that our panellists and all of you will have interesting comment on these issues.

I thank you for your attention.