

Original Article

Title: Meeting the communication support needs of children and young people with intellectual disabilities in the Bolivian Andes

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Abstract

Services available for people with disabilities in Bolivia tend to be fragmented and costly. Children and adults with intellectual disabilities are more likely to have a related communication disability and are thus both literally and metaphorically excluded from having a voice. The following research aimed to explore the experiences of accessing services by people with communication disabilities in Bolivia through semi-structured interviews and one focus group carried out with family members, professionals, service providers, educators and policy makers. It aimed to establish the nature of current services in Bolivia where knowledge, information and resources are scarce. Findings indicated the

need to consider an alternative to a medical model approach through a focus on empowering other stakeholders to participate more fully in meeting communication support needs. Conclusions plot ideas for future service delivery and emphasise the central power of sharing practical and expert

Introduction

Bolivia is a landlocked country in the heart of South America. It is bounded by the high Andes in the western part of the country and by the Amazon jungle to the north and east, covering a land mass of over one million square kilometres and with a population of around 10.7 million (World Bank, 2015). The United Nations ranks Bolivia as 119 on the Human Development Scale out of 188 countries, with a Human Development Index (HDI) of 0.637 (United Nations Development Programme (UNDP) 2015) which is lower than the national average for Latin America. It is classed as a lower middle-income country on World Bank development indicators. However, the levels of inequality are substantial and increasing. The HDI (UNDP 2006) figures show that 20% of the richest people in the country retain 63% of the country's consumer wealth while the poorest 10% have only 0.3% of it. Forty-five percent of the population live below the national poverty line. According to The World Report on Disability (World Health Organization [WHO], 2011), disabled people are estimated to

make up about 20% of the population and are likely to come from the poorest sector. Increased wealth generated within the country from Bolivia's natural resources over the last ten years has helped to move some people out of poverty. However, in a broader discussion of developing countries (of which Bolivia is one), Groce (2013) has argued that despite measureable economic improvements which have generated a positive shift, people with disabilities often continue to be left behind and are not experiencing the same benefits of development experienced by non-disabled people.

Reliable statistics on the numbers of people with intellectual disabilities in Bolivia are unavailable and specific information about people with communication disabilities across the population is non-existent. A positive development was included in the most recent national census in Bolivia (Indice Nacional de Estadística (INE), 2012) in which four questions were asked relating to any perceived 'permanent difficulty' with sight or hearing, communication, mobility, and memory. While the questions loosely covered sensory, physical, and cognitive disabilities, they did not provide specific information regarding intellectual disabilities.

Scior et al. (2016) have estimated that 2% of people with disabilities worldwide have an intellectual disability (around 300 million). More specifically, Hartley and Wirz (2002) estimated from a small scale survey in Africa that 50% of disabled people presented at their health centres had a communication disability. The prevalence of communication disorders amongst people with intellectual disabilities in the developed world has been estimated to be even higher at 75% (Coppens-Hofman et al., 2014; Zimmerman et al., 2007), and 100% in those with more severe and profound cognitive impairments (Belva et al., 2012). The voices of people who have intellectual disabilities and whom also have difficulties communicating are by definition not easily heard. As a result, they are often more rapidly excluded from society and are under-represented by disabled people's organisations (DPOs). The WHO (2011) reports that children with intellectual disabilities are less likely to complete primary education than their physically disabled or non-disabled peers. It is likely that a large proportion of children with intellectual disabilities who also have communication difficulties are further disadvantaged in developing the literacy and numeracy skills which could eventually facilitate them as adults to access work. Improving the lives and agency of people with intellectual disabilities includes maximising their communication potential, thus empowering them through social and political self-advocacy to participate optimally in decision making about their own lives

(Bunning & Horton, 2007). Braithwaite & Mont (2009) in a wide review of studies focused on middle and low income countries and demonstrated how family income generation can be reduced because of responsibilities to family members with disabilities. This in turn can result in lower financial and social capital and a more vulnerable household which further impacts on educational and employment opportunities for family members who have an intellectual disability.

Currently, as defined by Baker et al. (2010), in countries such as the United Kingdom, developing the communication of people with intellectual disabilities is primarily the domain of speech and language therapy services in collaboration with family members, education, health and social care providers. In Bolivia, however, therapeutic services are not routinely available within the public health system. Buell (2009) described a number of large institutions and hospitals, often under the auspices of the Roman Catholic Church that provided limited services such as physiotherapy, occupational therapy, medical treatment and education for children and adults with intellectual disabilities who were resident or who attended school there daily. Per 100,000 population, Bolivia has been estimated to have only 1.06 psychiatrists, 0.34 nurses, 0.46 psychologists, 0.25 social workers and 0.20 occupational therapists (WHO, 2008). The number of

speech and language therapists (SLTs) registered to practice in Bolivia remains unclear. Buell (2013) reported that 63 SLTs were working in Bolivia: 60 in urban areas and 3 part time in the public sector. The boundaries between different professionals were not well-defined and as a result the quality of outcomes of speech and language interventions could not be assured. In a similar setting where SLT intervention was investigated in Kenya (Bunning et al., 2013), different levels of speech and language therapy practices (intuitive /superficial vs. evidence based) demonstrated by professionals had implications for effectiveness and outcome of the treatment.

Existing treatment offered by Bolivian SLTs in private practice was found to be of variable quality and delivered on a consultative basis but it was relatively expensive and beyond the reach for a large sector of the population (Buell 2009). Jaen-Varas et al. (2014) found a similar profile in a review of mental health services in Bolivia. Although a universal health care system has been in place since 2007, 77% of the population has been excluded from access to it due to economic, social, geographical and cultural barriers. The political will to progress services related to rehabilitation is small and the infrastructure does not currently exist to sustain it. This may be a reason why families and caregivers look instead for alternative health care through culturally accepted

traditional healers and community practices based on collective belief systems. In some cases, these may provide support, but for many people with intellectual disabilities, alternative measures are influenced by deeply engrained conceptualisations about intellectual disability and they do not always have a positive impact (Scior et al 2015). There is no comprehensive data to effectively identify and address the gaps in the service delivery systems in Bolivia for people with intellectual disabilities who also have communication difficulties. A pilot initiative was required to gather insights from potential service users and to frame ideas for future effective service delivery models that would be culturally derived and contextually grounded.

Primarily, this study aimed to address the following two research questions: 1). How are the communication support needs of children and adults with intellectual disabilities in Bolivia being met through current networks and services? and 2). What parallels can be drawn from other countries (e.g. the United Kingdom) to identify provision that might effectively meet future needs?

Method

Approach

This study adopted an exploratory, qualitative design. It was underpinned by a transformative paradigm whereby the people within particular circumstances were viewed as best placed to advise about how these could be improved. This respects cultural norms and aims to promote human rights and increase social justice (Mertons, 2012). Semi-structured interviews with 9 - 16 participants was deemed appropriate to enable the study to achieve thematic saturation of 80-90% (Namey et al., 2016). Full ethical approval for this study was gained from the Manchester Metropolitan University Ethics Committee, United Kingdom.

Participants

All participants were identified using purposive opportunity and snowball sampling strategies through contacts known to the work of United Nations International Service (UNAIS), Bolivia. Others were recruited by the researcher through interviewees who identified friends and colleagues as potential participants. These were followed up in person or through phone calls by the lead researcher. This resulted in eleven participants who were willing to be interviewed within the time frame for the study, and three mothers who agreed to take part in a focus group. The focus group was recruited through snowball contacts and developed organically through the express wish of one mother who asked if she could invite 2 other mothers to her interview. The opportunity

to run a small focus group was therefore taken. A 'focused interview' where discussion was mainly directed by participants complemented the information obtained through interviews. It also served as a reliability check for interview data gathered through investigator-directed conversation (Kamberelis & Dimitriadis 2013:7). Together the fourteen participants represented a range of relevant stakeholders (see Table 1) across the large Andean and valley areas of Bolivia.

Insert Table 1 Participants around here

Eleven participants were interviewed individually and three other participants made up the focus group. Two participants were males and the rest were females. Among the participants the majority (n=6) were family members. Three family members were interviewed (one grand-father and two mothers). Each cared for a child or young person under 18 years of age who reportedly had mild-moderate intellectual disability; two had been diagnosed with cerebral palsy and the other with Down's syndrome. Three mothers took part in the focus group. All three of the focus group members cared for a family member reported to have multiple and complex physical and intellectual disabilities. Two of the mothers in the group cared for sons and daughters over 18 years of age and

one cared for a daughter who was under 18. None of the caregivers, who participated in the study, had declared disabilities themselves (see. Table 1).

Procedure

Prior to interviews taking place, each interviewee was given written and verbal explanations and signed a consent form which included permission for audio recording. Two participants did not give consent for recording and data were gathered in these instances using hand-written notes. Semi-structured interviews (see Figure 1) were carried out in three different cities namely, La Paz, Cochabamba and Sucre. Participants were mainly based in urban areas, but two interviews took place in rural communities. Interviews lasted between 20 minutes and 1 hour. The focus group was carried out in a neutral office space in La Paz where all three mothers could attend easily. In order to provide more structure for this discussion and to allow the group to respond to shared information, three vignettes were prepared and discussed (see Figure 1). This created prompts that were open-ended, and provided a safe space where members of the group could direct the conversation (Kamberelis & Dimitriadis 2013). The focus group lasted for 2 hours. Each participant was allocated a code and their data stored anonymously and securely.

Data analysis

Interviews and focus group discussions were transcribed verbatim in Spanish with all personally identifying information removed. These were reviewed by the researcher in their original language in order to capture the nuances particular to Spanish dialect as used in Bolivia. For one interview, a Quechua-Spanish speaking interpreter was present for translation purposes.

Analysis was carried out based on the process for developing themes as outlined by Attride-Stirling (2001). This involved first an inductive review of the data to gather basic themes. This data was then grouped to identify organising themes and then global themes with close reference to the research questions outlined above. A second revision of the data was then undertaken to code it along the lines of the basic themes that had initially emerged until no further basic themes emerged, indicating a level of saturation had been reached through this level of the analysis. For purposes of coding fidelity and credibility (Guba & Lincoln, 1985), a member of the disability team within the local Bolivian NGO subsequently coded the data, also in Spanish, using the identified basic themes. Comparison of the two raters' basic theme allocations were found to broadly agree and any that were unclear were resolved through discussion. As a further check of credibility and confirmability, peer debriefing was conducted

with the second author, who also checked the quotations once they were translated into English for the purpose of this article, to ensure that they accurately illustrated the associated themes.

Results

Four organising themes including, speech and language therapy services, socio-cultural issues, concerns about the future and grassroots support were developed from a number of basic themes that were initially identified in the data (Figure 2). These were recognised either as barriers to or facilitators of an effective service for people with communication disabilities. Better knowledge and reliable information was ascertained as the global theme, drawing on the detail presented through the four organising themes.

Insert Figure 2 Thematic Networks around here.

The basic themes that comprised each organising theme are illustrated with relevant quotations (translated into English) in Table 2 under headings related to the four organising themes.

Insert Table 2 Interview data around here.

Discussion

A consideration of the four organising themes demonstrated three barriers to the communication support needs of children and adults with intellectual disabilities. They were: current SLT service delivery methods, social and cultural barriers and concerns regarding the future. Grass roots and organisational support was identified as a facilitator.

1) SLT services

The SLT services on offer were viewed as a barrier rather than as a facilitator to improving communication for those who had experienced them. Several basic themes fed into this organising theme, two of which were the lack of transparency and high financial costs.

Poor quality treatment for communication difficulties were being delivered through a one-to-one medical consultation model, often behind closed doors. This was recognised by participants as arising from professionals who worked within an environment without professional standards and with no financial capital to invest in training. Parents described treatment as 'repetitive' and 'expensive' and they did not talk about improvements to their family members'

communication skills or about better techniques disseminated from practitioners to themselves to be used with their family member.

Juxtaposing the findings from the Bolivian data presented here with research findings from developed countries provides a starting point for comparison of service models. Work carried out in Ireland has highlighted that the needs of families are sometimes different from and overlooked by those of professional services and associated professionals (Chadwick et al., 2013; Chadwick et al., 2010). More specifically, from interviews with SLTs and parents in the UK, Marshall et al. (2007) demonstrated that parents saw themselves as the experts and valued different elements within the intervention process compared to the SLTs who worked with them. Similarly, in the data presented in the current study the Bolivian mothers and family members were secure in their place as 'experts' and this did not accord with the direction that the SLTs were taking.

One of the biggest differences between the two settings however, is that the professionals in the UK study (Marshall et al., 2007) were pertaining to an established model of healthcare and therapy which at least claimed to adhere to certain standards of inclusion and transparency. Unlike the families in Bolivia, parents in the UK received a service within national healthcare provision and so

did not pay for it. In the Bolivian setting, the model was very exclusive, there was little transparency and the intervention was expensive. Nevertheless, both families in the UK and in Bolivia wanted the best futures possible for their family members and wished to become more involved in active decision making around their lives.

2) *Socio-cultural issues*

The combination of full time caring, prejudice and the lack of support led to reduced social capital for families. These basic themes were represented by participants as barriers to effective services for people with communication difficulties. Families also identified that they were overprotective of their children and this made it more difficult for them to become independent in later life.

Other findings from UK studies (Grant, 2005) included acknowledgement by participants of the presence of negative stereotypes held by professionals about families of people with intellectual disabilities as being overprotective and under-estimating their family member's capabilities, thwarting their independence and rejecting offers of help from services. Although there was mention of overprotection in the Bolivian data by one mother of a child with a disability, she acknowledged it as a cultural issue; one that has been

recognised as integral to the Latin American idea of creating a smooth, pleasant and peaceful environment for bringing up children (Cohen, 2013). It does not therefore carry the same negative stereotype that 'overprotection' might do in a Western culture. Unfortunately, the implication of this familial overprotection is that the self-determination and life opportunities of people with intellectual disabilities which could be developed through improved communication could still suffer.

There was little evidence of participants under-estimating their family member's capabilities in the Bolivian study. Indeed, many mothers seemed to have high expectations of what their children *could* achieve (for example, full independent employment), given the right support and conditions. Indeed, being unable to provide their family members with opportunities for independence was blamed on the inadequacy of supports and services. There was no evidence of negative stereotypes associated with the rejection of services as found in Grant's (2005) UK study.

Nevertheless, despite the high hopes of families, Scior et al. (2016) has warned that in many middle and low-income countries children and adults with intellectual disabilities run a high risk of stigmatisation both from within and

outside families, and this was reflected in excerpts from the data relating to prejudice from other families and from those in the health professions. Prior findings (Chadwick et al., 2013) have demonstrated that the devaluation of people with intellectual disabilities within communities can cause repeated stigma and upset to family carers. Scior, (2011) commented that although attitudes have been shown to differ across cultures, people with intellectual disabilities have continued to be more socially stigmatised than those with physical disabilities. More work is needed to explore the processes and power dynamics within families and between families and professionals in all areas of health in countries such as Bolivia to discover how stigmatisation and negative attitudes are perpetuated through the professional channels that ostensibly facilitate 'rehabilitation' and should exist to improve quality of life.

Families also faced stigma from friends and other family members when trying to secure (often costly) services for the person in their family who had an intellectual disability. Stigma of the type acknowledged by mothers in this data has been documented through studies at a global level (Scior et al., 2015). Although Bolivia was marginally represented in Scior et al.'s (2015) survey, it demonstrated that the overall picture for South America was one where attitudes and beliefs towards people with intellectual disabilities continues to be

negative and detrimental. This contrasted with findings from Western countries where reports have been more positive in terms of change.

Cultural beliefs and views about intellectual disability were woven into the information expressed under these basic themes and this chimes with findings linked to uptake of mental health services in Bolivia by Jean-Varas et al. (2014) who recognised that economic, social, geographic and cultural barriers combined to exclude people from accessing existing services. Inadequate information from medical professionals perpetuated the search for expensive cures by some parents.

3) *Concerns about the future*

Further barriers were identified under the organising theme of 'concerns about the future'. Basic themes were identified relating to being excluded from education, having limited opportunities to participate in education or employment and leaving school with poor language and literacy skills. Negative reactions to young people with communication disabilities were identified as a result of the lack of training in communication and social skills.

Parents and carers of family members with communication disabilities wanted what other parents wanted. Those interviewed wanted their children to be successful, happy, productive and independent. Unfortunately this sometimes meant families having to choose between residential 'special schools' or no schooling at all. Some 'attended' school but left without basic literacy skills despite the having the capacity to learn to read. Parents expressed concern that not being taught to read and write in school had long-term effects for jobs in the future. In terms of employment, people with intellectual disabilities were reported to find it difficult to get the appropriate support and training they needed to create a stable, inclusive workplace that generated a positive attitude towards them amongst other employees.

In summary, the communication support needs of the families represented were being met by professional services only superficially, with very little gain in terms of quality of life or in the development of literacy and language skills for life and future employment. Superficial levels of service to support language and communication for children with intellectual disabilities were similarly identified by Bunning et al. (2013) in Kenya. Language and communication provide the foundations for literacy and social integration, and Groce & Bakhshi. (2011) has clearly outlined the far-reaching financial and social implications of

limiting literacy education for adults with disabilities who live in developing countries.

4). Grassroots and organisational support

In contrast to the less positive outcomes revealed through the previous three themes, grassroots support and organisations represented the beginnings of supportive networks of knowledge and skills that Bolivian parents were building for themselves, incorporating functional methods learned from each other. Their will to develop strong knowledgeable groups for parents run by parents points to a form of provision that might be polarised from the professional avenue of service but promised cheaper, more effective, inclusive and visionary support. Basic themes of support within close family groups and between family networks were recognised. Individuals within families were often named by participants as being particularly supportive, for example, a sister, an aunt or a grandparent. The strongest positive elements amongst family members who had children with communication difficulties and intellectual disabilities were the support groups and parent networks that they formed themselves. These groups were strongly represented amongst interviewees. They often provided the social and financial help and specialist training from outside Bolivia that offered them the opportunity to develop knowledge and skills. These were

understood as facilitating factors and provided the kind of support that families wanted. Findings from this Bolivian study showed that parents of children with intellectual disabilities were one of the main driving forces in the struggle against stigma and prejudice. This was corroborated by Scior et al. (2015:101) who found parents and non-governmental organisations to be instrumental in combating stigma in developing countries.

As described earlier, the global theme of having better knowledge and information showed two faces: the thirst for reliable information from parents and families on one side, and on the other side, the continued search for knowledge by professionals to provide a service whilst also making a living. Whether bridges can be built between families and professionals depends on whether both groups can work together to address the barriers that have been created. Within the prevalent neo-liberal model in South America where professionals are inclined to protect knowledge as an expensively-won tool, knowledge sharing within a patient – professional relationship did not appear to take place effectively. However, knowledge sharing between parents was revealed to have a positive influence in empowering them to take the lead on improving the lives of their family members. .

Some of the struggles families faced in trying to gain services for their family members do appear to parallel those found in previous literature (Chadwick et al., 2013; Power, 2009). For example wanting further information and training was a keen concern of family carers in Irish settings. The nature of these challenges may differ in subtle ways and result in different courses of action. For Bolivian parents, it led them to share information and knowledge with each other. The power differences that underpinned relationships between families and services are thrown into sharp relief in this research study. Mothers expressed a strong lack of agency when talking about professionals and this was reversed when they spoke about each other and about each other's children.

A number of writers have expressed the need for families and services to work in a collaborative partnership towards the benefit of the family (Summers et al., 2007). Others have advocated power and funding redistribution to families and people with intellectual disabilities away from services (Williams et al., 2003). In essence, the goal of funding redistribution was shared by the mothers interviewed in the Bolivian study, although they talked of generating their own funding to create their own centre. They also expressed an interest in

collaboration with professionals but the power differential was great and in many ways insurmountable from their position as 'patients'.

Limitations & Strengths

This qualitative study synthesises the views of a number of key stakeholders providing a breadth of perspectives grounded in the context of an understudied service setting in Bolivia. Little research exists that examines the dynamics between families and services as they bid to achieve good communication support for their family members with intellectual disabilities in Latin America. Nevertheless, further research is indicated to explore the relationships of power between those that provide services and those that are searching for them if only to avoid a repetition of the same power dynamics being set up within an informal structure. Including people with communication disabilities themselves as participants could provide further insight into services and this has been identified as an area for further investigation. Member checking of the findings with all stakeholder groups would have helped to enhance the trustworthiness of this research, although viable trustworthiness checks were conducted where possible within the pragmatic constraints of the study. The translation of the data from Spanish to English and the use of a translator during one of the

interviews may have affected the fidelity of the data presented although checks were made to try to alleviate these potential issues. Ideally we would have liked up to 16 semi-structured interviews to enable more certainty regarding achievement of saturation of themes (Namey et al., 2016). In this investigation we had eleven interviews with an additional three participants taking part in focus groups which although close to achieving this goal means the study may not have achieved saturation. Finally, this study is also limited in generalizability by its small sample size. Larger scale studies based in Bolivia and other global south countries are required to further illuminate and contextualise current services with a view to improving access to better quality support.

Conclusion

The findings of this study have suggested that family carers in Bolivia, similar to many family carers of people with intellectual disabilities in contexts in the UK and Ireland face parallel but more extensive challenges in attempting to access communication services and support. Financial and power imbalances, societal and professional attitudes and the lack of sustainable training appear fundamental to preventing access to good quality communication advice and intervention. For Bolivian families, the current medical model service provision for children and adults with intellectual disabilities is falling short of expectations

held by parents. A more powerful alternative model based on shared practical and expert knowledge amongst families is suggested. Acknowledging the expertise of these family carers and imbuing within them the capacity, knowledge and information to deliver communication support would appear to be a contextually grounded positive direction on which to build a future service to address speech, language and communication disabilities. Viewed through the lens of a developing country context, the concept of a service model as understood in a UK context requires deconstruction. Reconstruction based on input from local experts by experience, in this case parents and other stakeholders, can then begin.

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Table 1. Details of participant groups interviewed

Participant	Participants initially interviewed n	Participants in focus group n	Total
Parents /Family members	3	3	6
Local NGO co-operative manager	1		1
Special Education Policy Maker	1		1
University Lecturer	1		1
Government / Policy making	1		1
Health Professionals (SLTs)	2		2
NGOs with international links: disability project workers	2		2
TOTAL	11	3	14

Table 2: Summarising the thematic analysis from the qualitative data gathered around communication services and supports for people with intellectual disabilities with illustrative quotations

Organizing Themes	Basic Themes	Illustrative Quotations
1. SLT Services not meeting need (Barrier)	Lack of Transparency	“Also...they don’t even let us, the mothers, into the SLT session. We don’t know what’s going on inside. You suppose they’ve been working, but we don’t know what they’re doing do we? Because for us, the fundamental thing is to work a bit with the father, the mother, with the person that’s with the child.” (Mother of a young child with cerebral palsy and intellectual disabilities)
	Medical Model Approach	“I think this is one of the big mistakes in the running of SLT [services] in our country. It has a very strong medical focus and they just work on weak oro-facial muscles; you can’t solve the child’s problem just with that.” (Mother of a daughter with Down’s syndrome)
	Very expensive	“without knowing what it was [what my daughter had]...no one told me what it was...I sold my flat to pay all the debts that we had accumulated.” (Mother of adult daughter with multiple and complex intellectual disabilities) “Yes, it took me 5 years to get her to talk. I’ve spent a fortune on the SLT and her assistant. Like my friend says, the SLT took her for 30 minutes, charged a huge amount, three times a week. She went in with her workbook, she wrote in it what we had to do at home, 5 or 10 minutes she said of this work.” (Mother of a daughter with Down’s syndrome)
	Poor quality & Doesn’t ‘work’	“This girl for example, it seemed to us that she could understand us. Or at least that she could recognise lots of things, but she can’t talk. When she came to the centre they gave her these cards. They didn’t explain what she had to do with them, and they were expensive. Faces, and underneath they said ‘no, yes, happy’ and I don’t know what else. Her mum thought that she was supposed to learn how to copy the faces...they hadn’t explained it to her and that’s what she thought. So you can imagine the disorientation...so ok, yes, but have more SLTs? ...what we need are people who are better trained in these areas – in alternative communication.” (NGO/Co-operative worker)
	Lack of standards/ courses	“...because what we are doing is looking at the quality of the course, and I think one of the fundamental criteria would be the practical training because we can’t have a repetition of the same mistake. Instead of having lecturers, we have good people that want to run a course, but who don’t have any idea how do it.” (University Lecturer; Special Education)
	No financial capital	“Part of the university [problem] was that they didn’t have the capital to draw professionals so that those professionals could then provide a service to the people that use [public] institutions.” (Special Needs Policy Maker)
	2 Socio-cultural issues (Barrier)	Overprotection of children and adults
Less social capital		“The mother has to dedicate so much time to the child with disability; more even than to her other children. We know mothers who make a living washing clothes all day. They just don’t have any time to get involved [in other community activities].” (Mother of child with Down’s syndrome)
Prejudice from other families		“And someone said – why are you worrying about this child, he won’t give you anything tomorrow. You should worry about the healthy ones because in the future they’re going to be looking after this sick one. That’s what the doctors say – it’s better to look after the others than after him.” (Mother of child with Down’s syndrome)
Prejudiced medical opinion		“[The doctor] said...your baby will die...you should concentrate on your healthy children” (Mother of a child with multiple and complex disabilities)
Lack of support		“It’s the scarcity of valid information...[we want something that’s...] valid for real life, not from compassion, not from pity. We don’t want them to hide [information]...or disorientate [us]...” (Mother of adult with multiple and complex disabilities)
Cultural views about disability		“...because she fell and hit her head and that was where the problem began, there was something dormant, let’s say, there inside. But she fell and the syndrome came out. She had it, it was always there, but hidden. There was no shock, no nothing, but it was there, hidden.” (Mother of child with multiple and complex disabilities) “Why did they tell me he’s ‘wrong in the head’ when he understands everything? Why do they say he is ‘wrong in the head’? I don’t think he’s ‘wrong in the head’.” (Grandfather of child with cerebral palsy)

3. Concerns about the future (Barrier)	Excluded from education	<i>"He's a child with special needs', I told [the teacher]. 'I won't be able to', he said, 'I don't have much room or time to teach him'...and that's why I didn't put him there either." (Mother of boy with cerebral palsy)</i>
	Limited opportunities in education	<i>"...when he went [to the residential centre], he got very depressed; when I found him it was sad, he was crying a lot and so I suffered too and that's why I brought him back here. Now he doesn't go to school at all." (Grandfather of child with cerebral palsy)</i>
	No literacy and language skills	<i>"Most young people and adults [with intellectual disabilities] have gone through the process of school, but without any accompanying education. They've gone to occupy a seat, but they haven't learnt anything, let alone how to communicate better." (Mother of boy with cerebral palsy)</i>
	No opportunities for employment	<i>"Sadly, the companies are one step behind in accepting a young person with intellectual disabilities. It's very complicated because they don't believe in inclusion and if there are any difficulties....I don't think that they're prepared to address them." (NGO, Disability worker)</i>
4. Grass-roots support and organisations (Facilitator)	Within-family support	<i>"Who is really the best person for the job? We are the experts on our own children". (Mother of child with Down's syndrome) "I mean, with the little one is saying a few words now. But it's not a result of speech and language therapy, it's the result of the workshops that he went to, where he learnt, and in his work with him and his mother. That was the result, but not from a professional." (Mother of a child with cerebral palsy)</i>
	Family associations	<i>"[we need more knowledge...] so that they don't consider us parents as ignorant, that we can't learn and we can't know things. Instead, we need to break this barrier of the specialist and the parent, so that we can work at home with our children". (Mother of child with multiple and complex needs)</i>
	Training by 'specialists' from developed countries	<i>"I was able to be with one SLT who was a language therapist. She had studied in the United States, which is very different to the repetitive speech therapy and I was with her for a while, but it was really expensive and I couldn't continue...." (Mother of daughter with multiple and complex disabilities)</i>
	Local parent fundraising	<i>"So that's why... we have proposed the idea of creating a centre for parents, specifically designed for parents, administrated by parents". (Mother of child with multiple and complex disabilities)</i>

Figure 1. Interview questions and example of focus group material

Interview questions and associated probes:

- What does 'communication disability' mean to you?
- Do you know someone with a communication disability?
 - How do you communicate with that person?
 - What do you think would be useful for them/you in overcoming those difficulties? Can you describe the difficulties they/you have in communicating?
- Do they/you work? Where? (or why not?)
- Have they/you ever had specific support with their communication?
 - Where?/ How much?/ At what cost?/Do you (they) still go?/ Who with?/ What did they do?/ Did it help?/ Would more help?
- What do you understand by 'speech and language therapy'?
- What kind of other support is available to you/them for communication?
- Who do you think could help you to improve language and communication with [name]?

Example of focus group pre-prepared scenario to facilitate discussion:

Maria has two children and lives on the money she makes from a kiosk selling sweets and also sewing dance costumes for carnival. They live in [a suburb of the capital city] in a one room house that her brother rents to her. Her older child, Nayra is 10 has cerebral palsy. She cannot walk alone and although Maria always knows what she wants, she does not communicate with other children or go to school yet. Maria's younger child Paolo, is 7. After school he sits with Nayra and they sell sweets from the kiosk while his mother sews. Sometimes Maria can hear them laughing together. She knows that Nayra makes sure Paolo gets the change right and thinks that maybe one day her daughter will grow up and be able to take over her mother's work in the kiosk.

Figure 2. Thematic networks extracted from the data on barriers to and facilitators of services

