Project CHILD

Children and the International Landscape of Disabilities

Voices from Around the World

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Prepared for

The Doha International Institute for Family Studies and Development (DIIFSD)

Qatar Foundation for Education, Science and Community Development

April 2010

Prepared by

Public Policy Research Institute (PPRI)

Texas A&M University

Doha International Institute for Family Studies and Development (DIIFSD)

Qatar Foundation for Education, Science and Community Development

The Doha International Institute for Family Studies and Development (DIIFSD) is an interdisciplinary global research institute which conducts research and scholarship on the legal, sociological, and scientific basis of the family as the natural and fundamental group unit of society. Through the development of mutually supportive relationships with an international network of family specialists, the DIIFSD promotes family-supportive policy initiatives while reinforcing effective programs that assist the family in successfully fulfilling its numerous roles.

The Doha International Institute for Family Studies and Development was established in 2005 under the patronage of Her Highness Sheikha Mozah Bint Nasser Al Missned and the Qatar Foundation for Education, Science and Community Development. The DIIFSD serves as a global center for providing academic research, interdisciplinary studies, and policy initiatives in support, development, and implementation of family-friendly policies and programs around the world.

Public Policy Research Institute (PPRI)

Texas A&M University

The Public Policy Research Institute (PPRI) at Texas A&M University serves as a key collaborative partner of the Doha International Institute for Family Studies and Development (DIIFSD). The Institute has been recognized as a leading interdisciplinary social policy and family research organization for more than 25 years. During this time, PPRI has successfully completed research projects totaling $110 million in competitive grants, while continuing to provide scientific research and evaluative services to inform more than 90 public and private sponsors engaged in formulating public policy.

The PPRI is a social problem research institute, focusing on critical societal issues such as education, health, and the welfare of families and children. The Public Policy Research Institute possesses the analytical as well as technical capacities to engage in large scale database development and management, family policy examination, and research on the impact of disability on family functioning. The PPRI staff includes experts on women and children with disabilities and their families including United Nations policies and best practices around the world. The PPRI has worked effectively with DIIFSD on several prior projects including development of the world's top online library for family research (Global FAMIS) and Project CHILD, a worldwide study of children with disabilities and their families.

ACKNOWLEDGEMENTS

Project CHILD was made possible with the support of many dedicated people around the world. First and foremost, we would like to thank staff at the Doha International Institute for Family Studies and Development for their commitment to and support of Project CHILD. Additionally, Disabled Persons International, Rehabilitation International and International Disability Alliance all played instrumental roles in connecting us to experts in the field of disability to interview.

This report would not have been possible without support from Sheikha Hissa Khalifa bin Ahmed Al Thani and her continued dedication to children with disabilities around the world. Her work has been a catalyst for increased awareness and understanding of the issues surrounding children with disabilities and her legacy will continue to promote the rights of all persons with disabilities.

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A MESSAGE FROM THE MANAGING DIRECTOR

The Doha International Institute for Family Studies and Development (DIIFSD), Qatar Foundation, is honored to present "Project CHILD: Children and the International Landscape of Disabilities". Project CHILD has three interrelated components: a monograph entitled *United Nations Disability Policy Analysis* (issued separately), the *International Disability Resource Guide* (also issued separately), and this report, *Voices from Around the World*. DIIFSD anticipates that Project CHILD will increase understanding regarding the effects of disability on children and their families; provide helpful information regarding available assistance and resources; encourage increased cooperative action by local, regional and international stakeholders; and spur much-needed action.

The mission of DIIFSD is to develop and support family diplomacy with the assistance of scholars, policy makers, organizations and citizens who are committed to strengthening the family; described by the Universal Declaration of Human Rights as "the natural and fundamental group unit of society" (UDHR, Article 16(3)). Family diplomacy sees the family – not as some incidental or accidental subject of local, regional and international policy – but as the central concern of an integrated and holistic approach to individual and social development.

Nowhere are the links between the family, individuals, and social development more clear than in the case of children with disabilities. Disabilities confront children, their families, and broader societies with unique challenges and opportunities. In large measure, whether families and societies surmount these challenges and build upon the concomitant opportunities determines not only the success of children with disabilities and families, but of their societies as well.

Voices from Around the World integrates findings from 57 countries. The findings are based upon more than 100 interviews conducted with experts whose collective experience captures the realities confronting 71% of the world's population. In this report, through expert interviewers, the myriad of issues surrounding the care and nurturing of children with disabilities throughout the world is detailed. While there are many difficulties involved in helping these children and their families, there exist several best practices that were shared by experts and policy makers from every corner of the globe. These valuable ideas are placed in their proper perspective and shared in this report—making a solid contribution to all who are concerned with children with disabilities: experts, policy-makers, practitioners and their families.

DIIFSD expresses its sincere thanks to the Public Policy Research Institute (PPRI); Texas A&M University; and particularly PPRI's Director, Dr. Charles D. Johnson, for their exceptional work in conceiving and carrying out Project CHILD. The Institute also expresses its gratitude to Qatar Foundation and its Chairperson, Her Highness Sheikha Mozah Bint Nasser Al-Missned, Consort of His Highness the Emir of Qatar, for their continuing support.

Dr. Richard G. Wilkins
Managing Director
Doha International Institute for Family Studies and Development

FOREWORD

It is my pleasure to introduce this important new report, *Voices from Around the World*. This report derives from a research program entitled Children and the International Landscape of Disabilities (Project CHILD). Project CHILD is of particular interest to me as the rights of persons with disabilities, particularly women and children with disabilities, have been the focus of my work for many years.

In the past decade alone, there has been a shift from viewing disability as a charity issue to realizing that it is a human and civil rights issue. While much has been achieved, there is still much more to do. This report, while documenting positive, transformational change, also reveals that children with disabilities around the world, especially those in developing countries, face significant barriers with respect to social inclusion, education and access to medical care. As a worldwide community concerned with the rights of children with disabilities, we must increase awareness of the barriers to full societal participation that children and their families face.

During my term as United Nations (U.N.) Special Rapporteur on the Standard Rules Equalization of Opportunities for Persons with Disabilities (2003-2009), I had the opportunity to witness many exciting and positive changes for persons with disabilities. Unfortunately, as *Voices from Around the World* documents, there is still substantial room for continued improvement in the policies and practices affecting children with disabilities.

The overall Project CHILD research effort is the result of a partnership between the Doha International Institute for Family Studies and Development and the Public Policy Research Institute. As the title suggests, the current report is indeed a collection of global voices. They are voices for those who are too often denied a voice, children with disabilities. The range of expert respondents and countries included is impressive. Outside reviewers have repeatedly commented on the comprehensive nature of the research, the large number of countries included, and the range of respondents from U.N. policy leaders to direct service providers. Studying this report makes the reader part of a global conversation on the triumphs and challenges of children with disabilities and their families.

Through the experiences, insights and opinions of these experts, we are reminded that children with disabilities and their families face many of the same challenges whether they reside in Russia or the Caribbean. It is my hope that *Voices from Around the World* will be useful to all of us who are concerned with disability rights. For researchers, it places the experiences of 57 countries into perspective; striking similarities can be seen across cultures. For practitioners, the report validates that their work is part of a bigger picture, and they can learn from others' experiences. For families of children with disabilities, it confirms that they are not alone in their struggles. For all people it provides hope for the future. While this report highlights the challenges faced by families of children with disabilities, it also confirms that the work being done in the field of disability rights is having a positive impact. We should continue marching forward to help one another address the relevant problems facing us in a challenging and evolving world of disability.

After carefully documenting eleven important thematic areas, the report concludes with specific recommendations for each of these same areas. These recommendations provide concrete guidance for parents, policymakers and practitioners regarding steps that can – and should – be taken now to (1) improve the lives of children with disabilities, (2) strengthen the families in which they live, and (3) encourage vigorous and sustainable social development. *Voices from Around the World* sounds a clarion call for increased understanding, compassion and – above all – action at the family, community, regional and international levels.

Hissa Al Thani
United Nations Special Rapporteur on Disability (2003-2009)

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INTRODUCTION

The World Health Organization estimates that 10% of the world's population is a person with a disability, with this figure increasing through population growth, medical advances and the natural aging process of large numbers of people. One quarter of people with disabilities are children and 80% live in developing countries. Families of children with disabilities, especially those in developing countries where few supports are available and poverty rates are high, experience significantly greater stress than most other families often leading to abuse, child abandonment and/or the dissolution of the family. Evidence shows that the breakdown of the family often results in negative outcomes for the country including a higher rate of single parenthood, more children being left in government care and the exacerbation of human rights violations. While the past decade has been marked with progress in the form of growing awareness and increasingly positive attitudes toward children with disabilities and their families, more needs to be done to continue this momentum of positive change.

The importance of the rights of children and adults with disabilities are becoming recognized

For current information on signatories and ratifications of the United Nations Convention on the Rights of Persons with Disabilities visit, *www.un.org/disabilities* by the majority of countries around the world. With nearly 150 signatories to the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD), disability rights are issues upon which nations can agree. Article 7 of the CRPD affirms the right of children with disabilities to the enjoyment of all human rights and fundamental freedoms on an equal basis with other children and recognizes their need for special protection. However, despite the recent attention to their rights, there continues to be a void in internationally available information and research. While more research exists in developed countries, there is a significant shortage of literature providing an international perspective on children with disabilities around the world.

Project CHILD, Children and the International Landscape of Disabilities, embodies a unique and comprehensive world-wide analysis comparing cultural and national responses to children with disabilities including their identification, cause of disability, treatment, education, preparation for adult life, and situational impacts upon their families through the voices of experts on disability around the world. Project CHILD reports on the experiences and information drawn from these experts in an effort to expand on existing international knowledge of children with disabilities and provide recommended actions based upon those shared experiences.

This research initiative represents a cooperative effort between the Doha (Qatar) International Institute for Family Studies and Development (DIIFSD), and the Public Policy Research Institute (PPRI) at Texas A&M University (United States). Providing a global overview, Project CHILD's research strategy includes: (1) reviewing United Nations' actions regarding disability, (2) interviewing experts who work with children with disabilities in numerous countries, (3) confirming interview results through survey methods, (4) identifying Programs of Promise within differing cultural settings, (5) creating a resource guide of childhood disability information, and (6) recommending action steps.

The primary goal of Project CHILD is the improvement of the quality of life for children with disabilities and their families. By drawing on the knowledge of experts and policy-makers around the world, Project CHILD reflects upon how this research will assist scholars, practitioners, parents and children by identifying priorities and best practices in strengthening the families of children with disabilities across cultures and nationalities, while also determining how these practices can best be exchanged globally.

COMPONENTS OF PROJECT CHILD

This special report is one of three products resulting from Project CHILD. Others include the *United Nations Disability Policy Analysis* and the *International Disability Resource Guide*. Project CHILD seeks to facilitate international communication and dialogue about children with disabilities, where personal experience, successful programs, advocacy and information, and documented effective practices can inform future development and implementation of promising programs for children with disabilities everywhere. Much of the information gathered directly involved dedicated people who work with or advocate for children with disabilities and their families.

United Nations Disability Policy Analysis

International research for Project CHILD began with the worldwide focus of the United Nations. The United Nations' leadership in setting an international agenda on disability, served as the backdrop for examining the current status of children with disabilities. A historical review showed that the UN initiated leadership efforts through its documented actions in establishing disability policy. Since its establishment in 1945, declarations, resolutions and conventions by the United Nations promoted policies to improve the status of persons with disabilities. Beginning with the 1948 Universal Declaration of Human Rights that first speaks of the family and its right to protection by society and the state, and continuing through the more recent Convention on the Rights of Persons with Disabilities in 2006, United Nations' policies have been a catalyst for change in many countries.

The same time period of United Nations development, beginning in the 1940's and forward, mirrors the advent of national disability programs and rehabilitation services in many countries, as injured veterans returned home after World War II. This widespread recognition of disability and the effectiveness of rehabilitation services for adults, served as the forerunner of services for children. Results of the UN policy analysis are detailed in a separate report, where its various actions are examined. However, a timeline illustrating significant events, documenting over 60 years of United Nations' disability efforts worldwide, appears in Appendix A.

International Disability Resource Guide

Project CHILD explored the scope of disability throughout the world. First steps included searching for the availability of information, identifying prevalence, and discovering similar studies. A variety of resources were utilized such as the internet, reference libraries, and government and agency reports from various countries. Preliminary searches identified organizations, professional journals, websites, program descriptions, research reports, foundation publications, and conference proceedings, all related to disabilities.

Resources were compiled electronically to gain a better understanding of their breadth and depth. This preliminary resource directory was first organized geographically for ease of use. An array of information and data were required to grasp the international magnitude of childhood disability, to find experts in various countries to interview, to assess common themes and differing cultural responses, and to research program initiatives worthy of sharing. This research would ultimately become the, *International Disability Resource Guide*, which presently contains over 760 entries, including disability organizations, websites, professional journals, information on disability conferences, and Programs of Promise descriptions with contact information from 124 countries.

Although utilized extensively in Project CHILD, this Resource Guide lays the groundwork for the future development of a comprehensive, up to date, international disability database readily accessed via the internet by individuals with disabilities, their families and service providers worldwide.

Voices from Around the World – Special Report

Interviews with Experts on Childhood Disability

The opportunity to interview experts from around the world afforded a rare experience to gather differing perspectives about childhood disability. The purpose of the interviews was to learn about current needs, issues and services, and to compare similarities and differences across countries and cultural groups. Experts possessed firsthand knowledge of issues faced by children with disabilities and their families in their respective countries. Project CHILD opens an international dialogue whereby experiences and stories shared by experts can inform others, such as policy makers, researchers, service providers, and people with disabilities and their families.

Development of Expert Interview Items

To gain additional insight on capturing relevant information, over 50 people who work in the disability field were contacted. Each person was e-mailed the question, "If you were given an opportunity to talk with experts in childhood disability from various countries and cultures around the world, what information would you want to know"?

Thirty-two people responded in time for their ideas to be considered in the development of interview questions. The final interview instrument, Project CHILD Expert Interview Questions, consisted of 20 open-response items that queried people about a variety of topics (Appendix B). Following pilot testing, the interview questions and consent form (Appendix C) were approved by the Texas A&M University Institutional Review Board (IRB).

Identifying and Contacting Experts

Locating Experts in various countries required a multi-faceted approach. Techniques included internet searches, literature reviews, personal referrals, disability organization websites, and authorship of articles. Some people shared that they were uncomfortable with the term "Expert", but the operational definition of "Expert" for Project CHILD is:

> someone who serves children with disabilities and their families through provision of direct services, program administration or policy creation; knowledgeable about childhood disability issues and services in their country, and interested in participating in the study.

Although not required, most Experts interviewed utilized e-mail, which greatly facilitated communication.

Project CHILD research staff used a standard e-mail letter to invite Experts to participate in an interview. If no response was received, a follow-up e-mail letter was sent approximately one week later. Experts were given the option to participate either by e-mail, Skype or telephone. If the Expert agreed to participate, a day and time were arranged for the interview, unless the Expert wished to participate via e-mail. Internet research methods proved invaluable for on-going communication with Experts worldwide. Copies of the invitation letters and a list of the Experts interviewed by country of residence appear in Appendices D, E, and F respectively.

All participants were e-mailed the Project CHILD Expert Interview Questions and a Consent Form prior to their interview. This offered the opportunity to become familiar with the questions and provided time for forethought before the interview. Forethought was particularly important since most interviews were conducted in English, and English was not the first language of many Experts. At the beginning and end of each interview, participants were asked if they wanted their responses to be confidential or to waive confidentiality. Their answers regarding confidentiality were audio recorded and noted on the Consent Form. At the close of the interview, Experts were asked to recommend others in the field of childhood disability who might offer additional perspective. This "snowball" method aided in the identification of several more Experts.

This interview process resulted in 99 separate interviews, with 102 Experts participating. Two Research Associates conducted 93% of the interviews; with one facilitating the interview, while the other monitored the audio recording equipment and documented key statements. For the remainder (7%), only one researcher was present. With permission from the Experts, each interview was recorded using Audacity software.

Details about the interviews are bullet listed below.

- 281 people were contacted by e-mail and invited to participate.
- 102 people completed interviews, 36% of those originally contacted.
- 70% were completed by telephone, 21% by e-mail, 7% through Skype and 1% in-person.
- 69% of Experts waived confidentiality so that they could be quoted with their name included in the results, while 31% preferred confidentiality.
- 97 interviews were with one Expert, one interview included two Experts, and one interview was conducted with three Experts in one location.
- 45 minutes was the average length of interviews, with the shortest being 21 minutes, and the longest 2 hours and 13 minutes.
- 22 of the interviews were conducted outside the normal work day for the Research Associates, most of these between midnight and 5:00 am (GMT-6), to accommodate the various time zones of the Experts.
- Of the 102 interviews, 98% were conducted in English, with English likely being a second language for many. One was done by telephone with a French translator, two were e-mailed in Chinese and then translated, one was e-mailed in Spanish and translated and one was conducted via a sign language interpreter using Skype.
- Two- thirds of those interviewed were female (67 Experts) and one-third were male (35 Experts).
- Although the question was not specifically asked, 11 Experts voluntarily indicated that they were a person with a disability and five said they were a parent of a child with a disability.
- Experts worked for a variety of organizations, including 55% in non-governmental organizations (NGOs), 21% for government agencies, 5% for United Nations entities, 6% for faith-based organizations, 6% for universities, 3% for private organizations, 3% were affiliated with multiple organizations, and 1% were no longer affiliated with any organization.
- Experts held a variety of positions within their organizations with the majority being directors, service providers and educators.

Figure 1 illustrates countries contacted by Project CHILD for participation. Countries highlighted include those where people did not respond to e-mail attempts and those where interviews occurred. Experts were selected based on their professional experience with childhood disabilities and their willingness to participate. The opinions they expressed are their personal perspectives and not necessarily those of the organization where they work or the country where they live. The diversity of these Expert Interviews offered wide ranging perspectives regarding children with disabilities and their families around the world.

Identification of Programs of Promise

Analyzing the vast amount of information in the *International Disability Resource Guide* led to experts in the field and to programs that offered promise in addressing disability issues cross-nationally. Identifying prevalence, needs, cultural views and service responses offered intriguing research through which Programs of Promise were ultimately identified. Project CHILD defined Programs of Promise as:

> successful models for delivering services or advocating for children with disabilities and/or their families that could be replicated in whole or in part in another area of the world, with similar expectations of success.

Programs of Promise were also identified through the Expert Interviews. In many cases, Experts spoke about their respective programs as well as those of colleagues. To elicit even more recommendations, a follow-up inquiry by e-mail asked Experts to suggest specific programs in their countries that were of merit. Their endorsements resulted in approximately 15 additional Programs of Promise. While *Voices from Around the World* incorporates relevant Programs of Promise to address key issues and themes discussed by the Experts, there are many more in the *International Disability Resource Guide* and countless Programs of Promise worldwide yet to be discovered.

Countries Represented in Project CHILD

In 2009, a variety of sources documented the existence of 229 countries worldwide, although there were some discrepancies. Once identified, these countries were viewed through a variety of lenses including geographic dispersion, ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), UNICEF Multiple Index Cluster Survey (MICS) data on childhood disability (available for 39 countries), geographic features, population size, dominant religions, economic development status, political stability and warfare (UNICEF, 2007). Countries that have signed or ratified the CRPD and its Optional Protocol are identified in Figure 2.

Project CHILD staff examined diverse countries that were representative of the world's population and developed a priority list of countries to include in the study. Additionally, countries in which Project CHILD Experts worked also provided a representative sample of the four levels of the United Nations Human Development Index (HDI) (2007).

The HDI combines three measures: health, knowledge, and standard of living. Health is measured by estimates of life expectancy at birth; knowledge is measured by a combination of adult literacy rate and the combined primary, secondary, and tertiary school gross enrollment ratio; and the standard of living by Gross Domestic Product (GDP) per capita (UNDP, 2009). Countries that have a high HDI usually have longer life expectancy, higher adult literacy rates and a higher gross domestic product per capita than those lower on the HDI scale.

Applying the HDI to the 57 countries represented in the Expert Interviews indicated that 32% of the countries had a very high HDI, 31% of countries a high HDI, 35% of countries a medium HDI, 17% of countries a low HDI, all displayed in Figure 3. One country included in Project CHILD, Iraq, is currently unranked by the HDI. Figure 3 illustrates by geographic distribution the Human Development Index rankings of countries who participated in Project CHILD.

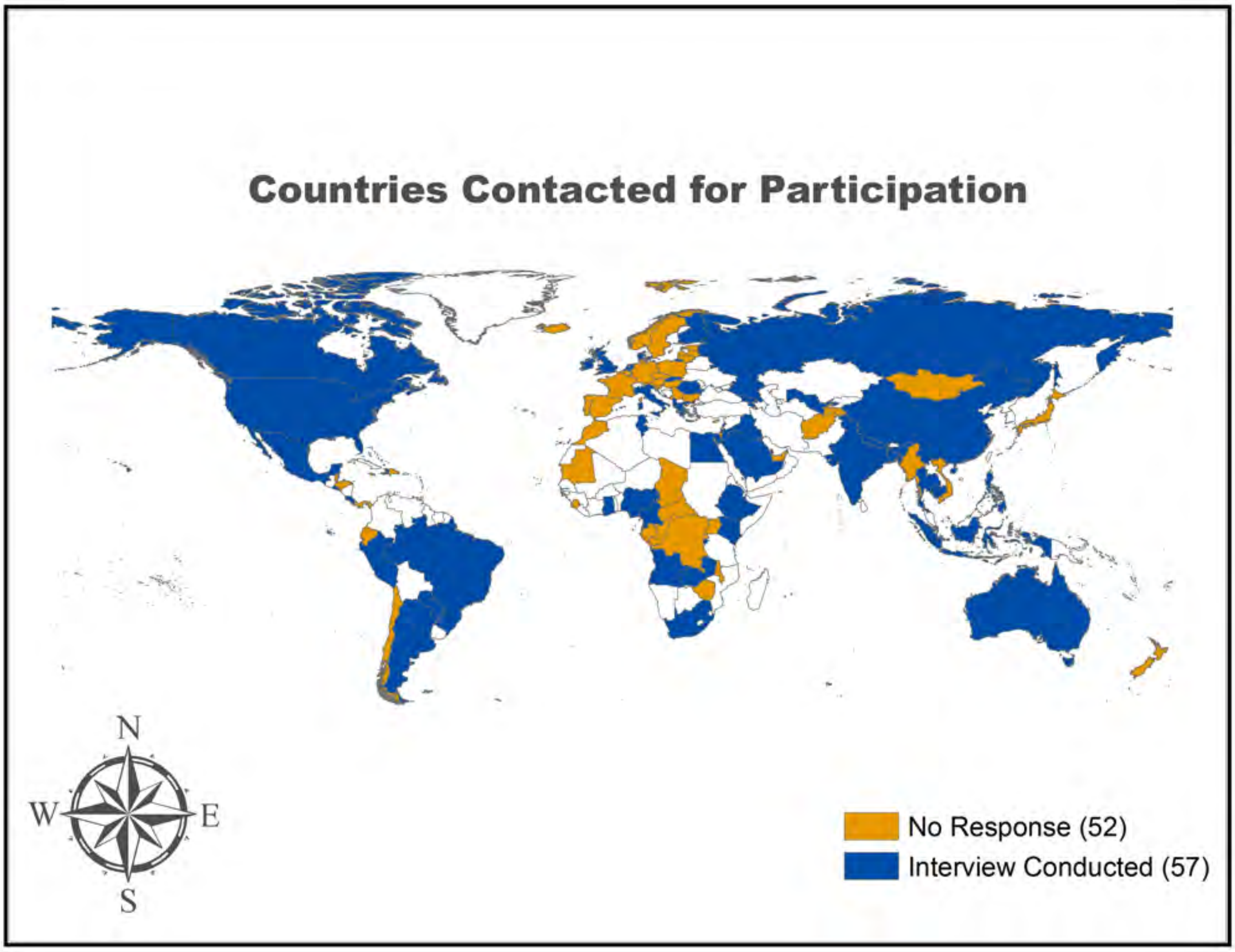

Figure 1: Experts contacted/participated in Project CHILD

Information about countries represented in the Interviews reveals the following:

- Experts were identified from 109 of 229 countries;
- The 102 Experts who were actually interviewed represented 57 countries, 25% of the 229 countries;
- These 57 countries are home to over 4.8 billion people, or 71% of the world's population;
- Based on these population figures and estimates of childhood disability prevalence, as many as 120 million children with disabilities may live in these 57 countries;
- Eleven of the 57 countries have UNICEF MICS data on childhood disability; and
- Fifty of the 57 countries signed the CRPD (88%) and 24 (42%) have also ratified it.

Confirmation Survey

A qualitative analysis of the dialogue from the 102 Expert Interviews identified common themes regarding children with disabilities that were prevalent across the various countries. The analysis further showed that these themes were surprisingly similar, even among disparate countries. Examples include need for educational options, physical accessibility to the environment, resources providing family support, and quality health care. To verify if these themes were indeed prevailing in their country, a follow-up electronic survey measured how strongly each Expert agreed or disagreed with issues included under each theme area. By using a Likert-type rating scale, survey results added quantitative confirmation to the rich qualitative interview narratives.

The Research Analysis Interview Theme - Confirmation Survey (RAIT) consisted of 53 items organized by emergent theme areas, plus one multiple choice and one open-response item. An electronic format provided for the RAIT to be e-mailed to each Expert inviting them to take the

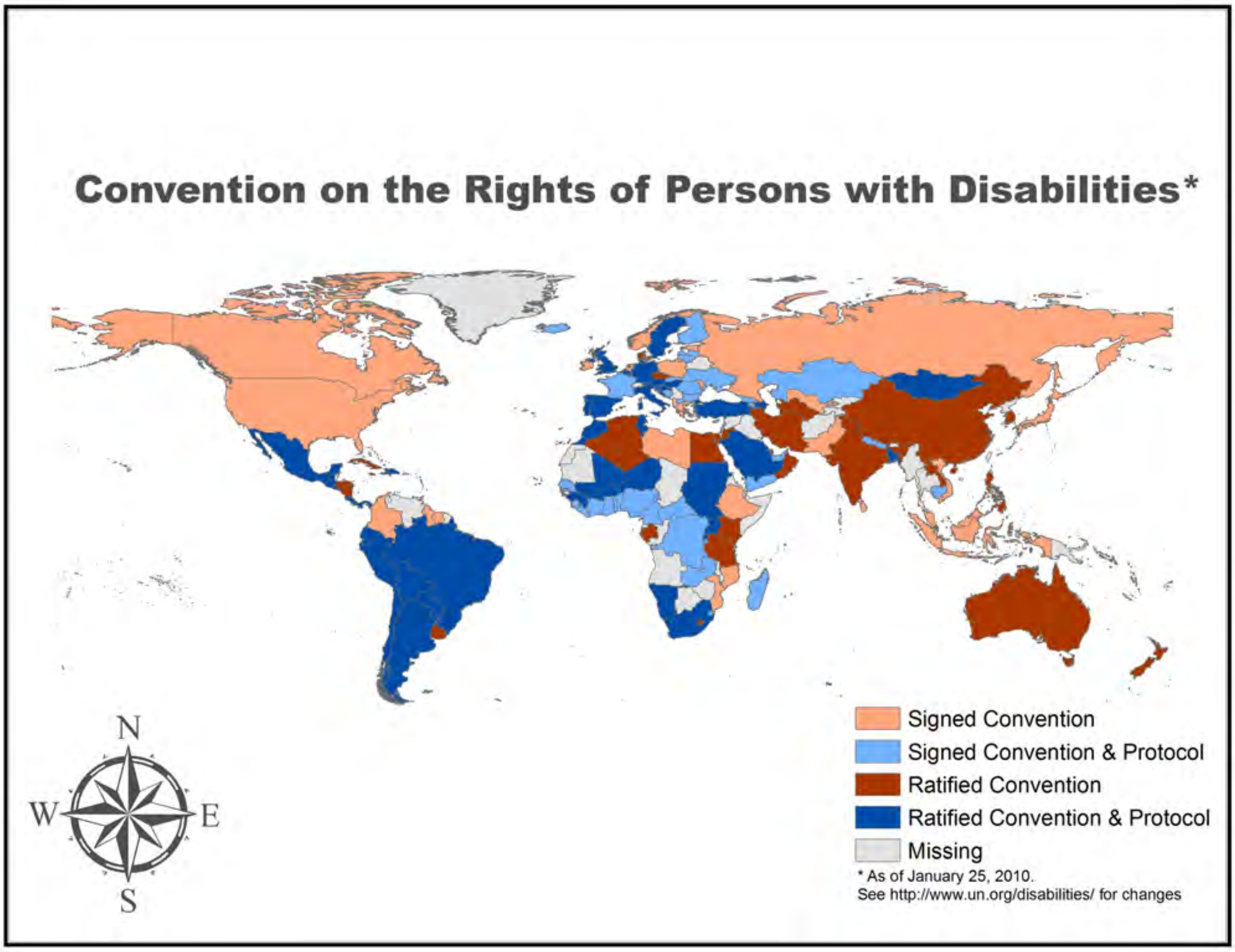

Figure 2: Convention on the Rights of Persons with Disabilities Signatories/Ratifications

survey via the internet. A unique code provided individual access for on-line completion, either in one session or saved for completion at a later time. On-line responses were immediately analyzed for real-time results.

Of the 102 Experts interviewed 96 received an invitation (Appendix G) to participate in the RAIT Survey and 54 people reacted to the themes via RAIT, a 56% response rate. Six interview participants did not receive an invitation to react to the themes via RAIT because of language barriers or because of the absence of a valid e-mail address at the time. Information about RAIT respondents includes the following, with additional details in Appendix H.

- The regions with the most respondents were Asia (24%) followed by the Middle East/North Africa region (20%) and Europe (19%). Other regions represented include Africa (11%), North and South America (9% each), Central America (6%), and Oceania (2%).
- Expert respondents primarily were affiliated with organizations or agencies that serve children and adults with all types of disabilities (54%), with 24% specifically serving children with all categories of disability.
- Experts were classified as advocate, practitioner, and researcher or any relevant combination thereof. Fifty-four percent were classified as advocates and practitioners and 33% as advocate only.
- 69% of RAIT respondents were female.
- RAIT respondents represented a variety of agencies with 59% from non-governmental organizations, 17% from government agencies, and the remainder from universities, faith-based and private organizations.

Results of the RAIT are presented in Appendix I and confirm the validity of the themes for children with disabilities in the Expert's country. Answers to specific items are utilized throughout the discussion of Project CHILD themes.

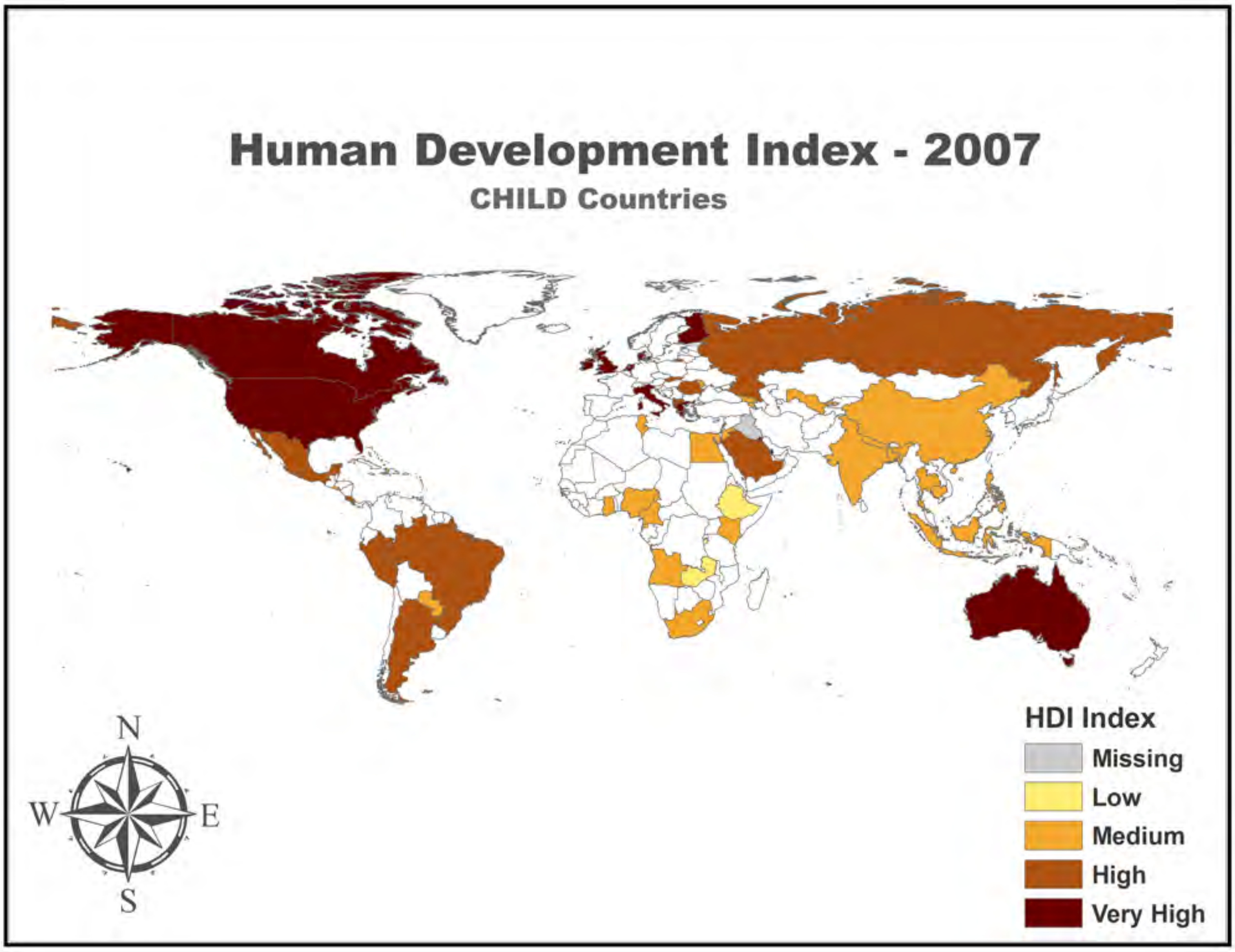

Figure 3: Project CHILD Countries' HDI Status by Geographic Distribution

PROJECT CHILD THEMES

After analysis of the 102 Expert interviews and RAIT responses, 11 themes emerged as significant. The consistency of these themes was quite compelling given the openness of the interview questions. These themes were identified based on the emphasis placed on each topic by the Experts and length of time topics were discussed in the Interviews. The 11 themes included in Project CHILD are:

1. *Cultural Views of Disability*
2. *Families of Children with Disabilities*
3. *Causes and Prevention of Disabilities and Availability of Health Services*
4. *Education of Children with Disabilities*
5. *Accessibility of Public Buildings, Transportation and Information*
6. *Transition to Adult Life*
7. *Statistical Data on Disability Prevalence*
8. *Funding for Disability Initiatives*
9. *Information Exchange and International Communication*
10. *United Nations and Disability Law*
11. *Environmental and Sociopolitical Factors that Impact Children with Disabilities and their Families*

The following discussion of each theme area includes information presented by Experts during the interviews. Quotations offer verbatim sentiments expressed by the Experts. Each quote includes the Expert's name and country, where confidentiality was waived, and the country only for those preferring confidentiality. Experts are listed by their country of residence in Appendix F. Brief descriptions of related Programs of Promise with their website or contact information are inserted, as are key facts that expand or clarify the theme discussion. The Bibliography contains a complete list of references.

1. CULTURAL VIEWS OF DISABILITY

Cultural views about disability are the beliefs and values that people attribute towards people with disabilities, whether positive or negative. Specific beliefs impact how families adjust to raising a child with a disability, as well as what types of services are offered. Each Expert was asked how children with disabilities are viewed in their country. Although most of the responses described negative viewpoints, a few Experts explained that in their culture all children, including children with disabilities, are viewed "as gifts from God" or other deity. Many described disapproving beliefs in the past, but cited more recent shifts to viewing disability as a natural part of life.

Evident in many interviews, the range of responses towards disabilities varies as much within countries as between countries, with cultural sub-groups holding different beliefs. While generalizing about beliefs is difficult, many significant similarities came to light during interviews. Views discussed towards children with disabilities and their families were mostly negative and included stigma, punishment or curse, helpless and dependent, and objects of pity. These views are often exacerbated due to a lack of knowledge about disabilities. Negative views, as Experts reported, often lead to prejudice and discrimination causing a substantial lack of opportunities for social inclusion for both children and adults with disabilities and have a significant impact on the family's functioning when raising a child with a disability.

Stigma

Experts from a variety of countries reported that many children with disabilities are unfortunately still viewed with shame or disgrace, although attitudes are changing. Over 68% of respondents to the RAIT Survey agreed that in their country having a child with a disability is often viewed as a stigma. Challenged by stigma, many well meaning parents keep their child with a disability hidden at home for fear that the child or family members will be ridiculed. Some experiences related to stigma for families of children with disabilities are described in the following passages.

> "Stigma is a huge problem that depresses parents; they're hiding their children."
>
> *Keti Melikadze, Georgia*

> "In most cases, children with disabilities are unwelcome in society because of different kinds of attitudes toward them."
>
> *Mesfin Taye, Ethiopia*

> "[Children with disabilities are] marginalized, often hidden."
>
> *Camille M. O'Reilly, Mexico*

> "They are usually kept in their house because their parents don't want them to go out because they may be afraid of letting people know that they have a child with a disability. Their overall quality of life is bad."
>
> *Wilaiporn Kotbungkair, Thailand*

> "In rural areas, deaf, blind, mentally retarded... are just hidden in the kitchens of their mothers."
>
> *Ondoua Abah Gabriel, Cameroon*

> "Most are neglected and often kept in-doors."
>
> *Jude Domosie, Ghana*

> "What I've seen a lot is that they're kind of hidden away and not even known about."
>
> *Cyle Nielsen, Paraguay*

> "Parents tend to be closed and ashamed."
>
> *Indonesia*

> "Some attitudes in the general community still stigmatize children with disabilities or see them as helpless and requiring 'charitable

> responses'. They don't see the capacity, only the disability."
>
> *Margaret Verick, Australia*

Many Experts explained that having a child with a disability not only hinders that child's future marriage prospects, but also the marriage prospects for other family members, especially siblings, thus adding to the stigma and the incidence of hiding the child.

> "Some parents still have the particular taboo that if they have a child with a disability they feel ashamed to show him around or keep him inside because they feel that this could affect the marriage of one of his sisters or her sisters for example…Now I think things are changing; slowly, but surely."
>
> *Mohammad Tarawneh, Jordan*

> "Of course, that is there too [hindered marriage prospects for other family members]."
>
> *James Mung'omba, Zambia*

> "It's easier for a boy with a disability to get married than it is for a girl with a disability to get married. So, people are frightened that if a girl has a disability, her children will have a disability as well."
>
> *Egypt*

Punishment or Curse

Another cultural belief widely discussed by Experts was viewing a child with a disability as a punishment for past sins or as a curse placed on the family. Findings from the RAIT Survey confirmed that 50% of Experts agreed that many people believe it is a punishment or curse to have a child with a disability, while 24% disagreed and 26% were undecided. This perspective is dangerous because of the accompanying practice of "curing the curse", which in some cultures often means harming or killing the child with a disability in order to rid the rest of the family of the curse. This punishment or curse view can also cause feelings of guilt especially for the mother, who often bears the blame for her child's disabilities. Several Experts discussed how the belief of disability as a punishment or curse manifests itself in their respective countries.

> "Kenya has 42 tribes and each one has a distinct way of looking at disability. Generally, where I come from it used to be that any child who is born with a disability ought to be thrown in the forest because it was viewed that this was a curse to the family…Currently we still have some communities that are a bit negative toward children with disabilities and may not consider taking them to school…So, culture is the biggest obstacle to delivery of these services."
>
> *Joseph Ayieko, Kenya*

> "They would say probably their parents committed some crime and this is a form of punishment, that's why they have a child with a disability. Usually parents and the family will withdraw from society."
>
> *James Mung'omba, Zambia*

> "There is a cultural obstacle; the label of 'handicapped' is a taboo. The individual with a disability is possessed by the devil; it's this belief that stunts the integration of individuals with disabilities into certain systems in our country." [translated from French]
>
> *Equatorial Guinea*

> "Also very peculiar to rural India, the inability of a child to speak or walk or reaching the desired milestones are attributed to "black magic", "evil forces", "envy of neighbors" or even God's curse and accordingly people, instead of seeking medical help, seek religious blessings and delay working on the required medical or early interventional help."
>
> *India*

> "People believe that they're cursed; that the family's been cursed. We found with one of our parents; she is so grateful that her child can come to our program because when she tries to sell food, people won't buy her food because she has a child with a disability and they think the family is cursed. When the child stays with us, people buy her food."
>
> *Reninca Hill, Haiti*

> "They are viewed like a burden on the family. Sometimes, it's even seen like a punishment from God. I had a mother telling me for example, 'I pray a lot, I don't understand why God sent me [a child with a disability]'. I had another mother telling me also that she had a husband with a lot of bad traits, so she could

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> understand why God sent him a child like that, but [she said to me] you're a good person, why did he [God] send you this [a child with a disability]."
>
> *Nada Khawaja, Lebanon*

> "If a child has a disability there's still a lot of blame towards the mother; that the mother was the cause or the reason for the disability."
>
> *Timor Leste*

Blaming the mother for the birth of a child with a disability is another unfortunate response. Some believe that the mother most likely did something during pregnancy to harm the developing fetus or that she or her family is cursed or being punished for past sins. Mothers especially need to be supported and empowered when they are raising a child with a disability. Current accurate knowledge and community awareness about the causes, prevention and treatment of disabilities are needed in many countries.

Helpless or Dependent

Another cultural view is that children with disabilities will always remain helpless and dependent. Over 70% of the Experts who responded to the RAIT agreed that this view of dependency was evident in their country. The consequences of dependency may include not assisting the child in accessing treatment, education, vocational training, career preparation, employment or independent living. It can also lead to patterns of learned helplessness for the child with a disability, contributing to lifelong dependence.

> "This population is viewed with low possibilities; low value perhaps. The professionals look at the things that they can't do; they do not value them related to the things that they can do."
>
> *Beatriz Zoppi, Argentina*

> "The population looks on [children with disabilities] with a traditional view in that they are not productive individuals. They are perceived as a burden, very insignificant. There has been progress made with the aid of seminarians, conferences, the "sensitivity" training and education; these are slowly changing people's views. But the perception that a person with a disability is still a burden

> persists in our society." [translated from French]
>
> *Equatorial Guinea*

> "[Children with disabilities are viewed] as poor people, useless, a burden of shame for their family."
>
> *Ondoua Abah Gabriel, Cameroon*

Children with disabilities need to be encouraged to reach their full potential, with their abilities identified and acknowledged. Too often, policies and practices are adopted without the input from the very people for whom they are intended. Indeed, a tenet of the disability rights movement that began in the 1960's was "Nothing About Us Without Us". While this movement ushered many adults with disabilities into the politically active disability rights sector, views and opinions of children with disabilities, are often ignored. Listening to a child with a disability, serves well to inform decision making and increase that child's independence. Many Experts discussed the importance of listening.

> "Another priority is having the voice of the child heard. The system is not very used to taking into account the wishes, the thoughts, the desires, and the experience of the child. The system often talks on behalf of the child; even the parents are talking on behalf of the child and I think that we could develop much more full inclusion and self respect and personal autonomy of the child [by listening to the child]."
>
> *Stig Langvad, Denmark*

> "There's a lot of interest in the country at the moment in trying to seek the voice of the child more effectively...The children's voice in our assessment and deciding on the provision are not truly solicited, and I think if we can find ways of doing that more effectively, and in a way that they're respected the same way that we respect other people's views, that would be a massive step forward."
>
> *Peter Farrell, United Kingdom*

> "In Finland we've done research where you ask children with disabilities what they think of themselves; what are their own opinions; how do they feel as a person with a disability; how they see that other people treat them and so

Meet Me Like a Human Being *(Denmark)*

Completed by Danske Handicaporganisationer (Disabled Peoples Organizations Denmark), this project embarked on the task of increasing awareness on issues faced by teens with disabilities. Teens were gathered to discuss issues specifically affecting them. The project clarified that children with disabilities have similar concerns and want their voices heard. Listening to the voice of the child with a disability brings the realization that they want the same things that every child wants.

More info: *www.handicap.dk/dokumenter/publikationer/meet-me/*

> on…That kind of research should be made.”
>
> *Aimo Stromberg, Finland*

It was often reported that when children with disabilities are given the same opportunities as typically developing children, they will exceed expectations and experience success. One Expert shared her personal story that highlights this point.

> “I was in high school when I was diagnosed with [a bone disease]. When I got the illness, my parents didn’t want me to go out because they said it would be very hard for me. So, for almost 10 years I stayed at home until I realized that I really wanted to continue my studies. My parents didn’t want me to come here to Manila but it is only in this city that there are some services for persons with disabilities. I really pushed that my dreams will come true, and luckily when I was confined again in the hospital, it was my [destiny] to come here to the Center. So, here in the Center I was able to continue my studies in secondary school and then up to college without the support of my family. The moment I went out from our home, my parents said that I am a rebellious one and for so many years they didn’t support me. It is only the Center that supported me until I finished college and it was only then that they realized that children with disabilities must also be given a chance. So, now they are advocating and telling other parents to support their children.”
>
> *Philippines*

This story illustrates the desire of children with disabilities for knowledge and inclusion and shows that with assistance and encouragement, children with disabilities can grow up and lead fulfilling lives.

Pity

Pity, or feelings of sympathetic sorrow, frequently describes views towards children with disabilities; verified by over 77% of RAIT respondents. Feeling sorry for a child with a disability may seem harmless, but pity brings unfortunate consequences. Similar to the beliefs of helplessness and dependence; pity places the focus on the disability and on what the child cannot do, rather than on what the child can do.

> “[Children with disabilities are viewed as a] burden of their family, pathetic, pity.”
>
> *China*

> “Children with disabilities are viewed in Costa Rican society with pity; though an effort is being made across the entire country to sensitize and inform the general population. There is still a lot of work to be done.” [translated from Spanish]
>
> *Costa Rica*

> “Most people would probably pity them and feel sympathetic to some degree.”
>
> *Russia*

> “They are objects of pity rather than to consider these children as equals like other children are.”
>
> *Susanna Tadyvosyan, Armenia*

> “If someone has a disability they’re automatically seen with pity, like ‘oh no, there’s nothing really for you when you grow up’. Not necessarily looking down on someone, but feeling sorry for them.”
>
> *Jamie Rau, Mexico*

Pity is detrimental. A child viewed with pity is at a greater risk of feeling self pity. Pity coupled with perceptions of helplessness can create self fulfilling prophecies of lost possibilities. Many Experts stressed that children with disabilities need extra encouragement and support to reach their full potential.

Lack of Awareness and Knowledge

The general public’s lack of awareness about disabilities was discussed by several Experts. Many people have a very limited and often incorrect understanding of disability, often due to misinformation and few positive personal contacts. Interaction seldom occurs in normal social settings because children and adults with disabilities are often excluded. In most countries, unless a person actively seeks out information their knowledge about disabilities is limited to learned beliefs, personal experience and media representation. Often awareness and a search for information rapidly increases when a family member or close friend experiences disability.

In accessing information, language barriers and low literacy rates are obstacles for many, as is limited access to current accurate resources. For parents, limited knowledge and inaccurate information can result in children not receiving services or delays in treatment. In other cases, incorrect information leads to a child receiving inappropriate or even detrimental services.

> "There was one girl in particular that had some sort of bone disease. Her mom got her medical treatment in Buenos Aires, so they were gone most of the school year. This little girl had a whole bunch of surgeries on all of her joints; I don't know what all they did to her exactly. So, she missed fourth grade. She came back and was able to enter into the fifth grade because that's how old she was. I remember the principal of the school coming to me and saying, 'this little girl is special ed, she's going to go to your class now'...I said to the principal, 'well she was gone last year'. I tried to reason with the principal that she was behind because she had to miss the whole year and she looked at me and said "But she has scars on her legs. She needs to go to the special ed room'. She was a perfectly smart little girl, she didn't even have a learning disability."
>
> *Paraguay*

Lack of knowledge can also contribute to prejudice, discrimination and hostility towards children with disabilities.

> "We once took a child with Hydrocephalus to the doctor and we went out of the car to go and find the doctor and when we got back there was a mob around the car just staring and jeering at the child. So, many children may never leave the back room of their house because parents just don't know how to integrate them into society."
>
> *Reninca Hill, Haiti*

> "A family with a disabled child is regarded with a kind of suspicion, that they have been cursed. Then there's the idea that the child is like that because that's the way God wants it, so you can't do anything about it. I'm afraid to say in many cases the child will be left to die...the first time he will get malaria, they won't treat it. Then, if the child dies then [the attitude is that] it's okay, it's meant to be like that."
>
> *Paul Caswell, Nigeria*

Best Buddies *(International)*

A positive program for people with intellectual disabilities, Best Buddies is dedicated to establishing a global volunteer movement that creates opportunities for one-on-one friendships, integrated employment and leadership development for people with intellectual and developmental disabilities.

More info: *www.bestbuddies.org*

Easter Seals FRIENDS WHO CARE *(USA)*

The FRIENDS WHO CARE disability awareness curriculum is designed to help children better understand what it means and how it feels to be a young person with a disability. This educational program gives students the opportunity to learn what is involved when someone has a disability and how they adapt to live life, go to school, or work as independently as possible.

More info: *www.easterseals.com/site/PageServer?pagename=ntl_friendswhocare*

Reports from Experts also revealed that misinformation is often given by the family's trusted medical doctors.

> "There is a story of a lady with a child with Cerebral Palsy and when this child was born she started going everywhere to receive information and support. She went to one neurologist and asked what happened with my child, what can I do, what will he be able to do in the future. This neurologist answered that the brain of her child was full of termites, so what do you expect from your child."
>
> *Fulvia V. Tomatis, Macedonia*

Examples show that lack of knowledge or misinformation impedes social integration.

> "I know of a mother in our church that has a 20 year old daughter that has the mental capacity of a toddler. She has been a quadriplegic for her whole life...Her biggest disappointment was just being let down by the whole society. I remember her telling me this one instance of when the child was a baby she took her to the reverend and asked him to baptize the child, and we usually baptize children with they are about 4 to 5 months old. His answer to her was one of 'I'm not sure if we actually need to do this because I'm not sure if the child will go to Heaven'. This was a huge disappointment for her. She has rarely brought the child to church over the years mainly because of the attitude of church members."
>
> *South Africa*

Cultural attitudes have a strong impact on family functioning and future outcomes for children with disabilities. Not only do appropriate services need to be available, but inclusion in the community is essential for change.

> "Services are only effective if parents believe in them."
>
> *Jamie Rau, Mexico*

When parents and service providers believe in success, outcomes are often positive. Fortunately, there are many Programs of Promise that work to empower parents and service providers to assist children with disabilities in reaching their full potential.

Positive Change and Increased Visibility

While children with disabilities were previously viewed negatively, current positive changes resonated with the vast majority of Experts. Changes included increases in awareness of disabilities and positive attitudes as well as visibility in the community.

Children with disabilities are becoming more visible. Previously hidden at home or placed in residential institutions, children with severe disabilities are now living with their families and integrated into schools and communities. Parents who were once ashamed now bring their children to public places and engage in social activities. This increased visibility and inclusion was discussed by many Experts.

> "During Soviet times disability was not visible. Most people thought that children and adults with disabilities did not exist. Now days it is more visible; not as fully as we would wish, but it is better."
>
> *Tako Tavartkiladze, Georgia*

The increased presence of children with disabilities in the community provides support for other parents who are fearful or have a child who is newly diagnosed. Previously, many families felt isolated and were unaware of services. The realization that they are not alone provides great comfort to both parents and children.

> "A Dyslexia center opened and outside people came in to provide training and even though the training was about dyslexia it brought about awareness of Autism and other disabilities. These types of things developing help bring about awareness to the public and help parents realize that there is somewhere for them to go to talk."
>
> *Jackie Butler, Antigua and Barbuda*

Families and community workers have spurred change in Peru, Paraguay, and Timor Leste.
In Peru, the presence of an elected federal government official with Cerebral Palsy has increased awareness of disability and provided a role model of a productive contributing member of society.

> "Also, we have here in the Congress one Senator with Cerebral Palsy. He is working in the Congress on the Commission for

Persons with Disability. He is promoting more campaigns and more conferences so people have more information about people with disabilities."

Maria Graciela Laynes Valdivia, Peru

"A guy who lives in my community showed up at my door and notified me of a family who he wanted me to meet. This family had a daughter who was 8 years old when I met her. The community she lived in was very small, yet her neighbors didn't know she existed because she was kept inside. She was born with Cerebral Palsy. Luckily, her mother loved her and recognized her personality even though she was not ambulatory and nonverbal. I showed up and began to work with her and throughout the month she was able to learn how to sit up on her own. I took her outside and the members of her immediate community began to learn about her, to not be afraid of her and to know that it was ok to ask questions. Somehow word spread to big people in the country. The President of Paraguay came to her town and presented her with a wheelchair. Within a few more months she had learned to steer her wheelchair with one hand. To see the effect she had on her community was amazing."

Paraguay

"We have one 3 year old girl with hydrocephaly who lives about 45 minutes to an hour from [a large city] on the coast and her father is of very modest means…They approached us independently because they had heard about us. They stayed for about a week or two and she is really weak through her legs and we did basic therapy with her and education with the family. When she went back the CBR workers gave some ideas to the father who constructed a little house for her with parallel bars and a seat that helps her pull to stand and another play area. She has her own therapy space… Because of her family support, her progress is amazing and she should be walking soon. Everyone from the community comes to observe her progress."

Timor Leste

Increased Awareness

Increased visibility leads to an increased awareness that children with disabilities exist in all communities and that they can fully integrate.

All children, including children with disabilities, have the right to be cared for by their parents, to the greatest extent possible.

United Nations Convention on the Rights of the Child, Article 7 (1989)

A new awareness of disabilities was discussed by most Experts.

> "We work with a child who is 8 years old. He lives with his biological family with his mother. Before we started working with him, his mother was providing basic care...She thought if she could feed the child and properly care for the child it would be enough. Then we started offering services based on the child's strengths and to develop his skills. His mother saw that the child could sit in an adaptive chair. The mother is now confident and satisfied that she can provide."
>
> *Jaba Nachkebia, Georgia*

Because this mother was unaware, the child was not getting needed services. Once they accessed services, both of their lives changed for the better. Other Experts commented on increased community awareness due to events in their respective countries.

> "The awareness is there so parents are bringing out their children for assessment. The awareness itself is good."
>
> *Agnes Kisila, Kenya*

> "There are some organizations creating awareness programs for the television. This is desensitizing people and increasing awareness."
>
> *Ferdausi Moula, Bangladesh*

> "More people have the opportunity to know that we have disabilities in Peru. The journalists, the TV programs, the people that work with publicity are working a lot and are supporting more campaigns to know about disability."
>
> *Maria Graciela Laynes Valdivia, Peru*

> "In general there is an increased awareness of different disabilities of children. This is particularly high in the cities. We can attribute this to a movie called Tare Zamin Par [http://www.taarezameenpar.com] by a famous Indian Actor named Aamir Khan that highlighted the life of a kid with Dyslexia."
>
> *India*

The importance of increased awareness in the general population is highlighted by one Expert.

> "Once people become aware that these childhood disabilities are not peculiar to their communities only, the shocks and disappointments that come with it are reduced."
>
> *Jude Domosie, Ghana*

Increased Positive Attitudes

With increased awareness and contact, attitudes change for the positive. On the RAIT Survey, approximately 85% of Experts agreed that attitudes toward people with disabilities have become more positive over the last 10 years. This corroborates what Experts stated in the interviews.

> "In Qatar, the attitude toward children with disability has vastly improved. Children are more visible in society."
>
> *Sameera ALQassimi, Qatar*

> "In China, more and more people realize that disability is not the choice of the disabled people. They will encounter a lot of inconvenience in life; people have therefore shown more understanding and give them more attention. More people have joined in the service for people with disabilities and provide appropriate support." [translated from Chinese]
>
> *China*

> "Attitudinal change is slow but increasing; the Chinese community has come to recognize disability as a human rights issue. There is still a long way to go."
>
> *Zhaoyang Chi, China*

> "As more people are reached and explanations offered about the cause of deformity and treatment opportunities, attitudes are gradually changing for those who get the message."
>
> *Jude Domosie, Ghana*

Although Experts agree that more needs to be done, these reported changes confirm that progress is occurring, new initiatives are making a difference, and there is a solid foundation for future growth.

2. FAMILIES OF CHILDREN WITH DISABILITIES

The experience of raising a child with a disability varies widely, with some families succumbing to the multiple pressures while others seem to thrive. Pressures arise from different fronts such as life threatening medical emergencies, numerous treatment regimes, social isolation, and high economic costs. Experts strongly suggest that support from extended family, friends and community is critical for any family raising a child with a disability. During the interviews, Experts confirmed that having a strong family is vital to successful outcomes for children with disabilities, which was verified by 96% of RAIT respondents.

Ideally, the family is a place of safety and protection; where every member, including those with disabilities, are valued and nurtured. Often, the reality is far from this ideal. Many families around the world lack the resources and social support necessary to provide this nurturing environment. Many Experts described the strain that having a child with a disability places on the family, the pressure to institutionalize, and the problems of abandonment and neglect.

Family Strain

Because so many families struggle daily to provide the most basic necessities, the added stress of the unexpected birth of a child with a disability makes life almost unbearable. Often, one parent is forced to quit their job to care for the child full time, thus reducing the already insufficient family income, and the family's situation spirals downward. The strain may also contribute to the separation of the parents, which when coupled with poverty and social isolation that is often associated with raising a child with a disability, places the child at increased risk for neglect, abuse and exploitation in many instances. The RAIT indicated that the vast majority of Experts agreed that raising a child with a disability in their country places a huge strain on the family (87%). Experts discussed situations that families face in their respective countries.

> "A lot of mothers with disabled children end up having to bring them up on their own, although this is not universal. Either way though, it is difficult to survive on one income with children for people who earn average wages."
>
> *Russia*

> "[Due to the complete lack of social/governmental support] caring for a disabled child is a real bother for the family and will even cause the family to break down."
>
> *Paul Caswell, Nigeria*

> "A lot of children are seen as being a burden on their family."
>
> *Jamie Rau, Mexico*

> "She [the mother] gives up her initial profession, the family has only one income... In case of mother´s illness or exhaustion there is very often nobody who can overtake her position and care for the child. She is unable to give her time to hobbies, to manage other things... she can´t have day off."
>
> *Mária Duračinská, Slovakia*

Without sufficient support from their communities, the significant strain of raising a child with a disability can lead to unfortunate family outcomes such as guilt and blaming, divorce, and loss of both income and independence. Much research, as well as anecdotal information from Experts, supports the many benefits a strong and resilient family unit has when raising a child with a disability, as well as buffering the impact on other children in the family.

Pressure to Institutionalize

In most countries, children anticipate being raised by their parents and living in the family's home. Because of the significant financial strain of having a child with a disability, often combined with little social support and acceptance, many families feel pressure to place their child into an out-of-home setting. Disability, alone, is not a valid reason to remove a child from the family. In many countries, parents are often advised that the best place for their child is in an institution where, they are told, the child will receive better care than they would at home. Not only are these parents advised by physicians to institutionalize their child, but they often face extreme pressure from their own family members to give up their child. However, out-of-home placement is reported to be decreasing in many countries. This is supported by the RAIT Survey where 50% of Experts indicated that there is no pressure to institutionalize children in their country, while for 19% this pressure continues.

> "Parents are often told, 'you should just give up your child' and I think you really need to work with families to help them look after their children."
>
> *Reninca Hill, Haiti*

> "We had siblings in our program who we removed from the state institution. Before we took them out we tried to reunite them with their mother, she was a very young single mother, two times. But, both times she took them back [to the institution] because of real financial problems and no support whatsoever...Finally, she was reunited with them again and we are monitoring very closely; trying to prevent any attempt by the mother to put the children into the institution again."
>
> *Keti Melikadze, Georgia*

> "Children are majorly placed in institutions. Basically, the child protection system was designed to remove children whenever something was wrong and take them away from the mainstream society and put them in institutions. The system is organized in such a way that the most likely thing that will happen to a child born with an easily identifiable disability is that he or she will automatically, from the maternity ward, be placed in an institution. His mother will be advised not to bond too much because, God forbid, she might want to keep the child."
>
> *Moldova*

> "The tendency is to tell parents of disabled children that it's better to send them to an institution and forget about them."
>
> *Sarah Hagnauer, Russia*

> "Some families are still looking for state placement due to the severity of the child's disability or their inability of dealing with the child."
>
> *Miriam Roman, United States*

> "The biggest reason is economical...They don't have the means to support these children at home."
>
> *Tako Tavartkiladze, Georgia*

> "In Russia we have delivery hospitals, and in these hospitals when a woman delivers a child and it's evaluated and if it has disabilities, the woman is pushed to give this child to the government. If she decides to do so, she can leave this child for government care and this child is then completely on government funding. He goes to special institutions and spends his whole life in special institutions. All the special treatment, education, rehabilitation for children who live in the institutions is provided there, but if child stayed with his mother, this [providing services] is the headache of his mother."
>
> *Russia*

While the deinstitutionalization process is underway in many countries and the number of children with disabilities living in institutions is declining, in other regions children remain in these settings, and still more are abandoned each year. Less developed countries did not often build large institutions, and a child's alternatives to his or her family or extended family were orphanages, adoption or simply being left to fend for themselves.

> "Some of these children are abandoned at public places and the parents become impossible to trace."
>
> *Jude Domosie, Ghana*

> "We've got one case where the family abandoned their 3 year old girl. The doctor said that the eyes could not be treated. So, that

> family left the girl at the door of the hospital. This girl was alone. Our organization took her and put her in a special school for the blind."
>
> *Birendra Raj Pokharel, Nepal*

> "There's another story of a 15 year old with Muscular Dystrophy and he has a wheelchair, but quite often when we go to see him, he's just on the ground and he won't have been showered for two to three days. He's got a lot of social issues because his father died and his mother remarried, but because he has a disability, she didn't want him so she gave him to the father's first wife to look after. She [father's first wife] works really hard to get the things they need: the water, the food, the firewood. So, you just find that he's just left outside and there are flies on him and he's not washed and just left there."
>
> *Timor Leste*

More Children Remaining with their Families

Efforts to keep children with their families whenever possible were supported by Experts everywhere. While pressure to institutionalize continues many Experts commented that with more support services for the family, coupled with deinstitutionalization efforts, children are remaining at home and accessing community services.

> "Community-based rehabilitation services have helped decrease the number of children with disabilities living in institutions."
>
> *Natia Partskhaladze, Georgia*

> "With the deinstitutionalization plan, there has been a twenty-five percent decrease from 2004 and four institutions have been closed."
>
> *Uzbekistan*

> "In the public care system for children, due to huge investment that was done by the international community...The child protection system contributed to the closing down of institutions and opened new family type houses and apartments."
>
> *Romania*

> "One quite striking story is of a young man who is 24 now. He had clinical death for about 17 minutes at 3 months old. His mother was told that he died and he actually came back to life. The doctors told his mother that he would basically remain a vegetable the rest of his life and there was no point in thinking about him, and that she should give him up. She refused and did everything she possibly could to support him. She got him walking and talking just finding individuals willing to help on her own."
>
> *Sarah Hagnauer, Russia*

Father Abandonment

Another form of separation is the father abandoning the family after the birth of a child with a disability or when his child is diagnosed with a disability. Many Experts cited father abandonment as a serious problem. Reasons for abandonment were often unspoken or vague; perhaps the stress or stigma of fathering a child with a disability is a factor. Whatever the reasons, being raised without a father only places the child and family at even greater disadvantage, with the entire responsibility of raising the child placed on the mother, older siblings or female relatives in multigenerational households. Experts discussed the consequences of father abandonment.

> "Frequently families can be broken up because of disability. I know a mother who gave birth to a baby with Clubfoot and with some other disabilities in the hospital and the husband just left her there in the hospital before she had even been discharged. He just left her and never came back."
>
> *Kenya*

> "I think a lot of women become single mothers because their partner leaves them because their child is disabled."
>
> *Russia*

> "There are a lot of cases in our office where families, especially the mothers, are depressed and most of the time they are abandoned by their husband."
>
> *Albania*

"Oftentimes, mothers carry the burden of care and search for treatment with little or no support from the fathers. Marriages get broken as a result of childhood disabilities."

Jude Domosie, Ghana

"In Mexico, it's very common for the father of a child with a disability to leave the family if the child is born with a disability. Culturally, the fault of the disability falls on the mother...The dad will leave and it's culturally acceptable; there's no shame on the dad at all. So, the majority of the families are single mom families with more than one kid usually."

Bree Lair, Mexico

"Consider a young family that has just been married and they are expecting their first born child. Then, it happens that the child they are expecting would have a disability. This has had quite a negative impact on some new families because based on the cultural practice and beliefs they will consider that marriage annulled. There are couples that separate because the child they were expecting is born with a disability. It is considered a bad omen and there have been many families broken up."

Joseph Ayieko, Kenya

"Generally, fathers leave those families because they don't like those children with disabilities, and mother tries to raise those children alone. She has to quit her job and she lives on some pension paid by the government that's around maybe $70 or $100...There is a boy with Autism whose father left the family. His mother had to quit her job and live on the pension, which was around $70 in 2005. On that money, she has to live, she has to eat, she has to feed this child, and it's impossible, but she manages to do so. Another problem for those lone mothers is that they feel sorry for themselves; they are isolated from society even from their friends. This is another problem; how to make those mothers feel better."

Russia

Because the positive presence of an involved father in the home can be critical for meeting the needs of a child with a disability, programs and services

that effectively engage fathers are essential. With knowledge and support for their role, more fathers may choose their family, as illustrated by the following story.

> "There was this family that came to me in 2003 when we started our hearing program in Kenya. When they came [initially], they had three deaf children (ages 8, 6 and 3)... Two years later the father came to me. He had gotten twins, a boy and girl. He brought them to me and I [tested their hearing] and did not find a lot of activity. So, I told him it was not a good result and we needed to go for another test... The result was that these two babies were profoundly deaf. When I told him, he didn't take it kindly. He wanted to hit his wife and said it was the wife that came with all these problems and he was ready to divorce. I had to call the hospital counselor and we took some time to calm the man the whole afternoon. We had to keep them in the hospital for the counselor to continue the session the following day. It went on like that, but [the father] could not come to terms that these twins were not going to hear. Surprisingly, he says no one in his family has a hearing loss and the wife says no one in her family has a hearing loss, but they are getting kids with hearing loss. So, it took a lot of time and we have put [the father] in one of our programs and provided the children with hearing aids at no cost. Slowly he has accepted that [due to the circumstances] he would not have any other child, but it was not easy convincing him."
>
> *Joseph Ayieko, Kenya*

Family Support

Clearly, raising a child with a disability places stress on the family. When that stress accompanies misinformation, poverty, scarcity of alternatives, and guilt and blame; results can include the separation of the parents, father abandonment, or out-of-home placement of the child. While all Experts affirmed that the vast majority of parents of children with disabilities love their child and seek their well being, several Experts described situations where the parents believed there was no other alternative except to give up their child. Most parents have other children to care for and with insufficient resources they have to make incredibly difficult choices when it comes to whether or not they can raise the child with a disability.

The Five Project Inc. *(China)*

The Five Project Inc. runs family support groups to bring families and parents together to support one another and share ideas. Their goals are to assist children and adults with autism, mental illness and/or developmental delay and their families in China through distribution of educational materials including a newly released DVD on autism.

More info: *www.thefiveproject.org*

Parental stress can be alleviated through various forms of support aimed at solidarity among parents, positive coping skills, stress management and positive parenting.

Risdal & Singer, 2004

Families need financial support such as pensions or stipends to cover the extraordinary expenses incurred. Other required supports include access to respite care, social support from friends and family, and help navigating the "disability system". Experts discussed the types of supports families of children with disabilities need in their countries.

> "It is difficult for a family to have a child with a disability because it is challenging the family to an experience they were not prepared for... It is difficult for them to find their way into the system...So, they are facing a lot of problems because they are not used to being in that position...The challenge of making sure your child is getting the necessary services and assistance is difficult."
>
> *Stig Langvad, Denmark*

> "They [parents of children with disabilities] need a higher level of support from the government. They need financial support, like monthly allowances so they can make an effort to take the child to different kinds of services to improve the situation of the child. Somehow, they are feeling that they are forgotten; that they are invisible and their problems are invisible in the society."
>
> *Dr. Vasilka Dimoska, Macedonia*

> "In Greece, the family still is a very strong component of social services...When the family is not able to support, then you need the organized community service; and there we have a very great, a very crucial deficit."
>
> *Yannis Vardakastanis, Greece*

> "The families and the parents need some programs providing them with the proper information, with the proper counseling from the beginning to prepare them for living with a child with a disability. Most of the time, they are not prepared, they are not trained, they are not counseled, they are not guided and later on they reflect that if there had been some training it would have made it easier to cope. They would have made fewer mistakes and would have had less stress."
>
> *Tako Tavartkiladze, Georgia*

> "Although there is some government subsidy for families of children with disabilities, the

Parent Training and Information Center *(United States)*

Parent Centers serve families of children with all disabilities (physical, cognitive, behavioral, and emotional) from birth to 26. Parent Centers provide a variety of services including one-on-one support and assistance, workshops, publications, and Web sites. The majority of Parent Center staff and boards are parents of children with disabilities, so they are able to bring personal experience and empathy when working with families.

More info: *www.taalliance.org*

Parent 2 Parent *(United States)*

Parent 2 Parent is a national non-profit organization committed to promoting access, quality and leadership in parent to parent support across the country. Parent to Parent programs provide emotional and informational support to families of children with disabilities most notably by matching parents seeking support with an experienced, trained 'Support Parent'.

More info: *www.p2pusa.org*

> amount of money that the family receives is so little compared to the huge expenses they need to get various services.”
>
> *Zhaoyang Chi, China*

> “[One of the three biggest priorities for children with disabilities is] strengthening the capacities of the biological family via material, psychosocial support and medical help.”
>
> *Vesna Samojlovska, Macedonia*

> “There is no grant, special income or other relevant tax incentives to parents and guardians of children with disabilities, especially with respect to medical and transportation requirements.”
>
> *Lancia Isidore, St. Lucia*

> “We don’t have any kind of respite care.”
>
> *Dr. Moussa Charafeddine, Lebanon*

Care Provision Following Parent Death

The greatest concern of parents of children with disabilities is “Who will care for my child when I die, or can no longer care for them?” In response to the interview question: “What are parents of children with disabilities the most concerned about?” Experts overwhelmingly replied that parents worry most about what will happen to their child when they die. Fear for their child’s future appears to be the number one concern of parents worldwide, which was verified by over 88% the RAIT respondents. Several Experts described this parental concern.

> “Where will my child go if I’m no longer there, especially for the more severe children…Who will take care of my child when I’m not able to do that anymore?”
>
> *Johannes Verheijden, The Netherlands*

> “Families of children with disabilities are under the nightmare of what will happen to our son or daughter after I am gone. [What will happen to] my own children with disabilities? What will happen to my 37 year old son and my 32 year old son? They are gentlemen now, they are big. What will happen to them when I will be away? This is a nightmare, which day and night follows me

Padres y Compadres *(Mexico)*

Padres y Compadres began with a mother’s realization that a therapy center was needed for children with disabilities. With the help of Push International, a therapy center was established where children could receive needed therapies while parents had the opportunity to work and learn. Parents learn how to perform the therapy exercises with their child so that they can replicate them on a daily basis at home. Many mothers are also employed at the center.

More info: *padresycompadresiap.org*

> and follows most of the parents of people with intellectual disability."
>
> *Dr. Moussa Charafeddine, Lebanon*

> "The first question that many parents of children with autism ask themselves as they get the diagnosis is 'What will happen to my child after we die? How can they survive in the society without our protection? Who will take care of them in the future?'"
>
> *Zhaoyang Chi, China*

> "It is a dark reality that after some years, parents are going to be too old to [take] care of kids. [Un]availability, or lack of long term residential options for kids, is a big concern. Lack of any government initiative in either funding for these programs or even conceptualization is a big concern for parents."
>
> *India*

In many countries, when parents die their children with disabilities have few desirable options and may be left to fend for themselves. Other options may include placement in a group home, government institution, or nursing home. Because plans for long term care are usually unsettled, parents continue feeling anxious about their child's future.

> "The biggest concern is what will my child do if anything happens to me, especially if they're severely disabled... For some of them, they'd like to get their child into some sort of institution."
>
> *Paul Caswell, Nigeria*

> "They are sent to institutions now [when parents die or can no longer provide care], but we are advocating for community-based group homes."
>
> *Moldova*

> "The biggest concern parents may have is the future implications of the disability. Because most children with disabilities in Thailand are kept at home, they have such limited opportunities to explore the general or typical society. So, it may be difficult for them to live independently in the future if their parents pass away... They go to institutions."
>
> *Wilaiporn Kotbungkair, Thailand*

Parents of children with disabilities have reported many positive effects including an expansion of tolerance for human differences and the appreciation of their child's contributions to the quality of family life.

Risdal & Singer, 2004

Auslan Coffee Shop *(Australia)*

Operated by Deaf Children Australia, Auslan Coffee Shop provides family members and care givers who wish to learn Auslan (Australian sign language) a relaxed and social way to practice and develop their signing. Each week for one hour a Deaf Auslan tutor will be at a coffee shop in local areas. Families are invited to join the tutor for coffee and a chat in Auslan.

More info: *www.deafchildrenaustralia.org.au/auslan_cofee_shop*

Other options included another family member providing long term care and support.

> "Some are entrusted to relatives… For the severely disabled children, that's a problem and it's really very hard for them when the parents are gone."
>
> *Philippines*

> "The biggest concern is what happens afterwards… Parents say, well I can look after this child now and for the next several years, but what happens when I get older and can't be there anymore; that's the biggest concern by far...They look around their relations and see if there's anyone else in the family that can look after the child later on; they try to use their extended family."
>
> *Sarah Hagnauer, Russia*

Some more developed countries have started programs for parents to create long term care plans and financial support for their children including the provision of independent living and community-based group homes unless another family member volunteers to provide care and support. Often parents assume that one of the child's siblings will take responsibility. However, families living in underdeveloped countries may have no options at all.

Strong Family is Important

The importance of the family resonated throughout the interviews. Most Experts explained that children with disabilities from strong families fare much better than those from unstable or fragile families. Many strong families whether they have access to needed services or not, possess resilience and determination in advocating for their child to secure the best possible outcomes. However, most families of children with disabilities find strength in access to social supports, resources and knowledge. The absence of supports can result in overwhelmed families preoccupied with acquiring basic needs. Experts shared stories of some very resilient and determined families.

> "Another family I know who lived out in the countryside had a son about 11 years old who is deaf. His mother really wanted something for him so I went in to try to find anything. The school couldn't take him in the local town because no one was trained to teach the deaf and we thought he should get somebody who

Special Needs Trusts *(International)*

Established in developed countries, Special Needs Trusts ensure that children or adults with disabilities are beneficiaries of property that is intended for their benefit, such as inheritances, and protect these assets for lifetime use. Legal trusts also protect people from losing access to essential government benefits.

More info: *www.wid.org/programs/access-to-assets/fact-sheets/special-needs-or-supplemental-needs-trusts*

Sibshops *(International)*

Sibshops acknowledge that being the brother or sister of a person with a disability is for some a good thing, for others, a not-so-good thing, and for many, somewhere in-between. They reflect a belief that brothers and sisters have much to offer one another — if they are given a chance. Sibshops are a spirited mix of new games (designed to be unique, off-beat, and appealing to a wide ability range), new friends, and discussion activities. The Sibshop curriculum is used throughout the United States, Canada, England, Ireland, Iceland, Japan, New Zealand, Guatemala, Mexico, and Argentina.

More info: *siblingsupport.org/sibshops* really knows what they were doing. So, we got him hooked up with [a special school for the deaf] that was about 45 kilometers away and arranged his mother to pay tuition in chickens and eggs or whatever they could bring to the school because they had no money. This boy is now healthy, happy, and able to read and write, able to communicate. It was a real ordeal [because of the distance], but the family kept up with it."

Cyle Nielsen, Paraguay

"There is a mother whose baby had a high fever when they were traveling to the south. He was in the hospital and acquired severe brain damage. So, the mother began to ask for services for early intervention because the child was 1.5 years old. She tried to get services, but sometimes when you have so many difficulties; people don't believe you can do anything. The mother was always very near her boy and she began to be very involved with the things that the professionals do to this child. So, she began to learn how to suck the mucous from his lungs…She wanted her child at this school because she said this was a right he must have…She began to be the guide for what her child needs. As she learned more and more about the disability, she could give more and more advice to the people around her…He has good communication because his mother was so conscious about the communication and the importance of it. She always said 'well if God gave me this child, I have to make him happy."

Beatriz Zoppi, Argentina

Interviews revealed that in many countries parents of children with disabilities are forming their own peer support groups. Because parents are forced to become strong advocates for their children, more experienced parents teach newer parents, and together they initiate positive change in their communities. As learned through the RAIT, the overwhelming majority of Experts (98%) indicated that it is necessary for parents to be strong advocates for their children with disabilities. While advocacy comes naturally to some, most parents need support to be successful. Indeed, 94% of RAIT Experts agreed that parents need training on successful advocacy.

When provided with current knowledge and adequate supports, families cope by managing stress and can then focus on meeting the needs of every family member.

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3. CAUSES AND PREVENTION OF DISABILITIES AND THE AVAILABILITY OF HEALTH SERVICES

Many disabilities are preventable. According to current public health reports, malnutrition, vitamin deficiency, poor hygiene, contaminated water, and inadequate prenatal care are some of the main causes of preventable disability. Implementing known public health, education and medical initiatives can greatly reduce or eradicate conditions that lead to permanent disability.

The causes of childhood disability discussed most by Experts were: harmful prenatal practices and birth trauma, interfamilial marriage, and disease. Poverty also emerged as both a cause and consequence of disability. When disability does occur, lack of outreach programs, cost and distance to travel are major obstacles for the families connecting to needed services.

> "A large number of disabilities in India are preventable, including those arising from malnutrition, accidents and injuries as well as medical issues during pregnancy or birth."
>
> *Dr. Chip Kingery, India*

Poor nutrition leads to early childhood stunting and, coupled with low stimulation, contributes to the poor cognitive and educational performance of over 200 million children under five years old who are 'not fulfilling their developmental potential'.

Grantham-McGregor et al., 2007

Prenatal Practices and Birth Trauma

Two interrelated causes of disability are harmful prenatal practices and birth trauma. Due to cultural beliefs and lack of information, many mothers engage in unsafe prenatal practices that can injure the developing fetus. While the following examples were discussed with Experts from Paraguay, similar types of potentially harmful prenatal practices occur throughout the world.

> "Paraguayans tend to be darker skinned with dark hair and [there is the belief that] if you drink beer when you're pregnant, you'll have a beautiful, blonde child."
>
> *Paraguay*

> "The medication that did exist was often expired...falsified stuff [medication], so you really don't know what you're getting."
>
> *Paraguay*

250,000 to 500,000 children who are vitamin A deficient become blind every year, half of them dying within 12 months of losing their sight.

World Health Organization, n.d.

> "Medication during pregnancy; the women have to be informed and educated for not using

> medication which will harm their unborn babies.”
>
> *Paraguay*

Many births in developing countries occur at home and are not attended by a knowledgeable physician, midwife or birth attendant. In some unfortunate cases, this can result in injury or infection causing disability or death for the infant, or the death of the mother. Experts discussed the consequences of harmful birthing practices.

> “I think that there are a lot of birth traumas that happen that result in kids having Cerebral Palsy (CP) and there’s no repercussion, there’s no malpractice, nothing like that. So, I think there’s a high prevalence of CP due to birth trauma…The stories that I know were treated by an ObGyn and they’re still practicing. I have a friend at our center that has a daughter who’s 4 years older than another kid who’s at our center and they were both served by the same OB who is still practicing who caused CP in both the kids.”
>
> *Bree Lair, Mexico*

> “Lack of awareness of prenatal programs [is a problem]; like mothers must get to a hospital early because some children are still being delivered within the home and many dangers can occur.”
>
> *Agnes Kisila, Kenya*

A community in the Western Cape Provence of South Africa reported the highest rate of Fetal Alcohol Syndrome in any overall community in the world: 65.2 - 74.2 per 1,000 children in the first grade population.

Viljoen et al, 2005

Cerebral Palsy is not caused by problems with the muscles or nerves, but rather with the brain’s ability to adequately control the body. Cerebral Palsy can be caused by injury or stroke, either during birth or in utero, although sometimes resulting from brain damage later in life. Symptoms usually appear in early childhood and generally do not worsen over time. Cerebral Palsy occurs in 2 - 2.5 out of every 1,000 live births.

Redline, 2008

Interfamilial Marriage

Interfamilial marriage was identified as a contributor to disability particularly in regions and cultures where it is the custom. Interfamilial marriage can cause or contribute to disability when close family members carry the same recessive genes that predispose their children to disabilities. Encouraging premarital genetic testing can assist couples in making informed decisions about choosing to have children. However, Experts on this issue said that even when presented with a relatively high risk of having a child with a disability, the majority of couples decided to marry and have children anyway. They described a cultural attitude of putting the situation in “God’s hands” and “submitting to the will of God”. Several Experts discussed their respective country’s policies on genetic testing before marriage, which is now mandatory in some regions.

> "You have to bear in mind the cultural factor in the region whereby you have close marriages that can lead to disabilities as far as the children are concerned…So awareness is a very important point."
>
> *Mohammad Tarawneh, Jordan*

> "We should consider that a lot of the genetic disorders, not only in Lebanon, but in all Middle Eastern countries are a result of marriage to relatives…This is very well known in the Arab region."
>
> *Dr. Moussa Charafeddine, Lebanon*

> "They have lobbied for premarital genetic testing, which is a must now in Kuwait…If there are any hereditary disorders, both people entering in the marriage would know what to expect …Yes there are many intermarriages, which do increase the chances that disability will occur…They can't tell them not to have children, they can only alert them to the risks… They would say it's up to God and take their chances…My cousin has Muscular Dystrophy and this is, of course, hereditary and they had four children and then the fifth was normal, the four previous died and if you argue with them about why did you have more children they would say, 'well look we have one perfectly normal and healthy child', so you can't deny them that right."
>
> *Rana F. Nasser, Kuwait*

> "In the Western world you have drugs and alcohol as a contributor; here we have intermarriages…Before you marry, you're very much pushed into doing analysis in order to know if you have any genetic problems or if you're compatible or not."
>
> *Maha Al-Juffali, Saudi Arabia*

> "There is a lot of mental retardation from genetic causes…We have obligatory genetic testing…We can only advise them, we can't tell them not to marry."
>
> *Dr. Mongi Ben Hammouda, Tunisia*

Whether one believes it is right or wrong to conceive a child knowing there is a higher than normal chance for disability, encouraging premarital genetic testing raises awareness and prepares parents for the probability that future

"Among traditional, social and family practices, is that of inter-familial or consanguineous marriages. These kinds of marriages play a major role in perpetuating disability through several generations."

Hissa al Thani, 2006

6 million people worldwide are blind due to Trachoma and more than 150 million people are in need of treatment.

World Health Organization, 2001

children may have disabilities. Additionally, many adults with disabilities, some genetic, choose to have children, because they have accepted their own disability and view disability as a normal part of human existence and not necessarily negative for their child, their family or society.

Disease and Infections

Experts also discussed disease and infection as causes of disability. Many causes are preventable through either access to clean water or vaccinations. Additionally, some diseases have been effectively eradicated in many developed countries. As an example, Polio, caused by a virus and eliminated 50 years ago though vaccinations in most developed countries, continues to result in disability among children in some parts of the world.

> "Polio too [is a cause of disability in children] because of a lack of vaccinations because of the ruralness of some places and they just don't have access. Polio is still alive."
>
> *Bree Lair, Mexico*

> "The other one [main cause of disability in Kenya] is poor immunization for under 5 years of age. Communities must take it seriously that children need to be immunized against the childhood diseases."
>
> *Agnes Kisila, Kenya*

Trachoma, which is a leading cause of preventable blindness, was also cited. Trachoma, caused by a bacterial infection in the eye, is most prevalent in areas marked by overcrowding, poverty and poor hygiene. While largely considered a disease of less developed countries, Experts in Australia discussed the prevalence of Trachoma in the indigenous community.

> "We still have in the indigenous community Trachoma as a blindness condition."
>
> *Glenda Alexander and*
> *Maryanne Diamond, Australia*

Prevention, timely intervention and disease management emerged as key priorities in reducing instances of disability, as the following story illustrates.

> "In a country like Paraguay, it has to be about prevention. If they had good health care to

Polio Eradication Project *(India)*

Using the child to child approach, health workers educated a group of older children about polio including information about causes, symptoms and prevention through vaccination. The children were assigned 30 families each to locate and encourage them to bring in their children for the polio vaccine. Because the older children were members of the same community, they were able to locate the families more effectively than the health workers, and were already accepted and trusted. The older children achieved a 100% success rate; with every family assigned to them bringing in their children for vaccinations.

More info: *www.indmedica.com/journals.php?journalid=7&issueid=83&articleid=1114&action=article*

The QuadPara Association *(South Africa)*

The QuadPara Association encourages motorists to wear their seat belts in order to prevent a spinal cord injury in the event of an accident. Every Festive season, people who are quadriplegics and paraplegics are deployed at gas stations on national roads encouraging motorists to Buckle Up (wear their seat belt) in order to reduce the number of spinal cord injuries from road accidents on South African roads. Motorists and motorcycle users are approached by people who are quadriplegics and paraplegics and asked to sign a pledge to Buckle Up or wear a helmet and in return they will receive free incentive items.

More info: *www.qasa.co.za/b_road.asp*

> start with…Taking care of all children from conception would prevent a lot of it…I do know that in [one area of Paraguay] one-third of the disabilities were meningitis caused…I know one mother whose child got a high fever, she went to the doctor who said, 'oh it's just flu' and she kept going back and going back. She finally took him into Asuncion trying to get services and they said, 'oh don't worry about it, we don't have enough beds anyway' and it turned out to be meningitis. Well, by that time her child was blind, can't talk, he can't walk, can't feed himself, he can't do anything. So, that's part of the problem, there's just not enough knowledge among the medical professionals…And you'll see people affected by polio. A lot of diseases that are ancient history in the United States cause a lot of problems in Paraguay."
>
> *Cyle Nielsen, Paraguay*

Experts confirmed that many cases of childhood disability are preventable and the incidence of disability could be greatly reduced through comprehensive prevention initiatives.

Early and Timely Medical Diagnosis

Many Experts discussed the importance and need for early medical diagnosis. Over 76% of RAIT respondents agreed that children with disabilities are not identified early enough in their countries. Generally, the more severe or visible the disability the earlier it is identified, such as Cerebral Palsy, Down Syndrome, Spina Bifida and some forms of blindness. Hidden disabilities, such as deafness, learning disabilities, mild intellectual disabilities and Autism, are often identified as the child grows and developmental milestones are delayed.

Methods of diagnosis were discussed during Expert Interviews. Many stated that children with visible disabilities are usually diagnosed at birth by medical or other experienced persons present. Traditional healers are also a source of diagnosis. In other cases, parents noticed that their child was not achieving appropriate developmental milestones and looked for an explanation, sometimes seeking help under difficult even desperate circumstances. Experts discussed some of the diagnostic methods utilized and ways services are delivered.

> "Parents bring their children to the local center to get a disability identity card…On the other hand, there are so many remote villages… Sometimes the human development officials will go to the house to visit and provide the disability identity card. Based on the identity card they can get services."
>
> *Birendra Raj Pokharel, Nepal*

> "The Ministry of Health has regulations according to special forms for disability diagnosis. Those forms are filled in primary health clinics. Mainly medical primary health care units can diagnose children with medical problems related to disability, such as development disorders, and physical disabilities, but unfortunately medical primary health care units cannot diagnose problems related to psychological disorders like Autism and Learning Disabilities for example. Those are diagnosed by NGOs."
>
> *Jaba Nachkebia, Georgia*

> "Eighty to ninety percent of babies probably are delivered in their homes, ten percent in a clinic or have a health care professional present for the delivery. For those ten percent, they will be screened at birth and some of them will then take their children to the clinic afterwards for vaccinations. Otherwise, it is word of mouth in the community."
>
> *Timor Leste*

> "It is usually the parents that will notice a problem. For my own cultural group, the parents will seek the public health care first. But, as I look at other groups, the first port of entry for seeking help when you notice a problem would be the cultural systems in place; whether you go to a traditional healer first in some cases."
>
> *South Africa*

While most Experts stated that parents sought answers from medical providers or others, depending on their resources some parents denied or ignored their child's disability until they no longer could.

> "Identification of disability is quite often the initiative of the parents. They see that the child is not developing in a normal way and go to seek services. There is not an elaborate system of identification of children other than

> incidental identification that happens because parents see a problem with child."
>
> *Samuel Kabue, Kenya*

> "[Parents] do not believe that their children are disabled and they tend to hide them and you probably come to know when it is so obvious and you can't hide anymore. But, ideally the children are taken to the hospital."
>
> *James Mung'omba, Zambia*

> "Children are diagnosed in the public hospitals where they then have to wait to get diagnosis. The diagnosis is delayed because hospitals don't know where to send the children for assistance."
>
> *Maria Aparecida Cormedi, Brazil*

> "Even though children have disabilities, they may not have the status of disabled, which means they would not have state insurance covering their needs. It is quite complicated to get disability status because the state decided the current system was corrupt…The family or the person with a disability has to apply for the status at the primary healthcare clinic and not all clinics can provide the diagnosis. Families have to pay for the diagnostic test and whatever is needed in order to get this checkup and many families are simply not able to cover the costs in order to apply."
>
> *Natia Partskhaladze, Georgia*

Another diagnostic issue is children being misdiagnosed or over-diagnosed, and the challenges associated with removing an incorrect label.

> "A person with Autism has problems in more areas like articulation, in behavior and so on. So, very often the diagnosis is not good. The doctor will diagnose them with a different kind of disability, not exactly Autism. These people have to be diagnosed by more specialists and they are diagnosed by using many different kind of [diagnostic tools], and after all these acts they are diagnosed as children with Autism."
>
> *Slovak Disability Council, Slovakia*

> "The system of diagnosis seems to be problematic…It can be quite difficult to lift the diagnosis once it is placed on a child."
>
> *Russia*

> "Labeling a child when they don't need to be labeled is unethical to me…What is happening is assessments are being done on children who have behavior problems for a whole range of social or familial reasons, and they are being given a diagnosis that is higher than necessary. So, they get the supports in school so they can learn along with their peers. We are suggesting that this is diminishing the needs of the other children with recognized disabilities who absolutely need supports to learn along with their peers."
>
> *Margaret Verick, Australia*

In most instances, the earlier the disability is diagnosed and intervention begins, the less impact the disabling condition has on the child's development. Early intervention requires recognition, medical or educational diagnosis, a treatment plan, and resources and providers to deliver services to the child. For many children, due to the type and severity of the disability, their social and economic circumstances and access to services, intervention is delayed until school age or later, or may never occur at all. Experts discussed many concerns about the delay in diagnosis.

> "There are a lot of undiagnosed children and most parents can't afford to take their child overseas to have them diagnosed. There are assumptions of possible Autism, or possibly this, or possibly that. Parents just want a diagnosis so they can have a prognosis…Very often a child is not brought to the forefront until problems have already occurred."
>
> *Jackie Butler, Antigua and Barbuda*

> "I have an Autistic son who is now 23 years old. I took my son to the doctor and was told that he was rude. I was determined that he was not rude and knew something was wrong with him. I brought him to the United States to have him diagnosed. That is when I learned about Autism. There are a lot of people here that have their child and no one ever tells them what is wrong with their child."
>
> *Name and Country Withheld*

> "In the cases of cognitive disabilities, when disability is not visible, they [medical doctors] hesitate to make the diagnosis because they don't have the tools to diagnose the child with cognitive impairments…Therefore, these children remain undiagnosed."
>
> *Tako Tarvartkiladze, Georgia*

> "People with physical disabilities and sensory impairments are not detected until school… For the disadvantaged ones that do not attend school; they have no other system of identification."
>
> *Kenya*

The stigma associated with disability can also hinder a family from seeking a diagnosis from medical or other care providers.

> "There are a lot of people here with mental health difficulties that don't identify as having a disability because of the stigma that is attached. This could often happen in childhood as well. Because there is a stigma to mental illness you may not even have parents seeking assessments of their child if they think it is a mental health issue."
>
> *James McClean, Ireland*

Availability and Access to Medical Care and Habilitation Services

In many areas of the world, basic health care services are grossly inadequate or simply unavailable to the general public including children with disabilities. In those areas, habilitation services are almost certainly absent as well. According to the RAIT, 55% agreed that children with disabilities do not have adequate access to health care services. In areas where general health care services are adequate, often habilitation services continue to be unavailable; 68% of Experts agreed that children with disabilities do not have access to adequate rehabilitation or habilitation services. However, nearly 30% of RAIT respondents indicated that children with disabilities in their country do have access to habilitation services.

Ideally, intervention and habilitation services begin immediately after diagnosis. Often,

however, immediate access is not the case. Emotional support and educational services needed to address the parent's shock following the confirmation of their child's disability are often unavailable. Services to engage parents in becoming treatment partners are mostly non-existent. However, one Expert described efforts to support parents in his country.

> "We focus more and more on the emotional support from the diagnose phase. What we try to do is set up a structure in the health care system that is a kind of net for parents to catch them at the moment of the diagnostic of their child. It's just at the starting point, but I hope in the next five to ten years it will be implemented and it will be a regular service that we provide."
>
> *Johannes Verheijden, The Netherlands*

Obstacles to receiving adequate medical and habilitation services include: services not available, little access to necessary services when they do exist due to the distance and cost, few trained medical professionals, social workers and rehabilitation therapists, and limited awareness of disabilities and services.

In many countries there are entire geographic regions with few or no disability related services. Experts described the obstacles to receiving health services for children with disabilities in their respective countries.

> "In the hospitals they have no medicine. They have the doctors, but they don't have the money to buy medicine. So, it's very hard that day by day the parents have to buy medicine for their children."
>
> *Maria Graciela Laynes Valdivia, Peru*

> "Moldova didn't even have social workers until last year.
>
> *Moldova*

> "My center is serving a 1.5 million population; we have only one psychologist that is working for psycho-social support."
>
> *Dr. Awring Kadir, Iraq*

> "Diagnosis, screening, early intervention, education, family support for children with Autism are very rare in China. Even when

Health services should be available as close as possible to people's own communities, including in rural areas.

United Nations Convention on the Rights of Persons with Disabilities, Article 25, 2006

> there are, most of them [services], except diagnosis, are provided by non-government organizations, which are often established by parents of children with Autism."
>
> *China*

> "The services for children with disabilities in Paraguay are insufficient because there are very few institutions which feel responsible for any kind of service, and in general there is no support from the government."
>
> *Paraguay*

Even when there are adequate services available in some regions of a country, they are often not accessible to rural families. Many Experts from very different regions of the world agreed that services are often absent in rural areas. Others explained that families often do not have money for transportation or travel expenses.

> "We have only five centers in five districts and there are sixty-four districts. There are some other NGOs too, but not all people are being reached in the country."
>
> *Romela Murshed, Bangladesh*

> "In the capital, I think the movement is getting better; but if you go outside the capital, we still have a lot of work to do in that area."
>
> *Mohammed Tarawneh, Jordan*

> "There is no incentive for professionals to be located in remote, rural areas of the country."
>
> *Romania*

> "In some country [rural] areas I think that parents would find it very difficult to locate any services at all and would be encouraged to send their child to a residential institution; either as a boarding school and retain their parental rights, or even possibly giving up their parental rights leaving them in a specialized orphanage for disabled children."
>
> *Russia*

> "I would say in bigger cities services are better. In smaller cities or rural areas, this is disaster. I think that majority of women who live in

Jibon Tari Floating Hospital *(Bangladesh)*

The Jibon Tari Floating Hospital provides general health services and specialized clinical or surgical services addressing disability in the remote, very poor, riverine areas and off shore islands of Bangladesh. The pontoon-based hospital boat has an air-conditioned operating area with a three bed postoperative room, 12 bed in-patient ward, one x-ray and one laboratory together with accommodation facilities for doctors, nurses, visiting volunteer surgeons and other support staff. The boat carries a tent capable of accommodating up to 150 outpatients in places where appropriate facilities are not available.

More info: *impactfoundationbd.org/ongoing_program.html#jibon*

The Royal Institute for Deaf and Blind Children Teleschool *(Australia)*

Teleschool offers a model for service delivery to families in rural areas who have access to a television in their own homes. In areas where it is often not practical to send out a therapist due to the vast distance, this model provides an alternative means to interact and consult with a therapist. Parents are sent a bag of therapeutic items they can use and are able to consult live via TV with a therapist on how to effectively work with their child using the items in the bag.

More info: *ridbc.org.au/services/teleschool.asp*

Lifeline Express *(International)*

The Lifeline Express is a mobile train clinic that provides on-the-spot diagnostic, medical and advanced surgical treatment for preventive and curative interventions for children and adults in inaccessible rural areas where medical services are not available. Lifeline services also leave behind a much greater awareness of health issues and concepts with the communities. At a higher level, the Lifeline Express promotes awareness of disability, encourages both the Government and NGO sector to get involved, and encourages media awareness.

More info: *lxenglish.com/lxenglish/index.html*

Ronald McDonald House Charities *(International)*

Ronald McDonald Houses around the world offer families a way to stay together, in close proximity to the treatment hospital, and be comfortable and cared for during their stay. Families are stronger when they are together, which helps in the healing process. By staying at a Ronald McDonald House, parents are close to their child, can better communicate with their child's medical team and can keep up with complicated treatment plans when needed.

More info: *rmhc.org*

rural areas or in small cities don't have any choice but to give this child to the government."

Russia

"We still don't have very good quality health services especially in the rural communities. Also, in the rural areas, we didn't have Kindergartens, we didn't have daycares, and we didn't have some special elementary schools; that is the problem for me. We have a network of services in the urban areas, but in the rural areas that's a big problem."

Slobodanka Zdravkovska Lazova, Macedonia

"The services are not really geographically distributed; the majority of them are located in the cities. There are some services, but they are not generally accessible to children with disabilities in Egypt."

Egypt

"The services for children with disabilities in Armenia are not really accessible for many children. They are concentrated in the capital and children in rural areas are lacking services there. Medical and rehabilitation services; they lack these services. Their parents are obliged to take them to the capital to benefit from these services...The country is very centralized and if there are services, they are the responsibility of the national government and the communities don't have the budget for these services for children."

Susanna Tadyvosyan, Armenia

"China has large number of children with disabilities, the vast majority of them spread out in the economically backward and not easily accessible rural areas. The relative small number of special schools and rehabilitation agencies are not wide scale and are unevenly distributed; these factors affect early intervention, education, and rehabilitation results."

China

For so many families in rural areas, the cost and logistics of traveling to the cities for services remains insurmountable. Families are often faced with significant travel expenses including bus or train fare, as well as lodging and food costs while their child receives care.

> "Even to travel from up-country to Nairobi costs a significant chunk of money for a family on a very low income. Travel expense is enough to make it out of their reach, let alone the cost of the hospital services. The services are centered in the main towns and there are only about six or seven big towns in Kenya that would have any kind of disability services."

Kenya

> "Health care is available, but they have no means to get there physically."

Wilaiporn Kotbungkair, Thailand

> "How could she get this spastic, full-grown, man on a bus to get services?"

Camille M. O'Reilly, Mexico

In some cases, families are forced to relocate in order to access needed services.

> "A boy I work with is now 7 years old. He's a blind boy in my school here in Buenos Aires. He was born in [a rural area in] a state very far away from Buenos Aires. There, he had a family, a beautiful house; his grandmother was near his home. But, when he was born, he had many, many, many health issues and in [the place where he was born] they don't have a children's hospital. So, when he was one month [old], his family decided to move to Buenos Aires. They came here, they took him to the children's hospital and he got all the health services that he needed and the early intervention services and the education. But, for his family, it's really difficult to be here because here they don't have the work that they had there and they are alone, only the father, mother and his brother. There, they had all the family, grandparents, aunts, uncles, cousins. This is the situation that many, many families move to Buenos Aires in, but this is not their natural environment. This family is doing a lot for their son. [They are] not only moving but they have different kind of work that they don't like. His mother is doing everything for him. When he was born the doctors said he couldn't do anything, but now he is talking a few words and he is walking."

Delia Góngora, Argentina

More services are needed for children with disabilities in rural communities. The RAIT verified this with 93% of Experts agreeing that there is a great disparity in services between rural and urban areas. With few resources of time or money, many parents are unable to travel to urban centers to access even minimal services for their children.

Cost of Services

Poverty and disability are highly correlated. Cost of services is a major obstacle for many parents attempting to access services for their child. For far too many families, the cost of needed health care, habilitation and specialized education for their child is unaffordable. Many Experts discussed how families cannot pay for services or the travel costs to get to the provider. This was verified by RAIT responses with 68% of Experts indicating that the cost of disability services is too much for many parents to pay. However, almost 25% disagreed, which may indicate that financial support is available in some countries.

> "There are plenty of blind schools and only five percent of blind children go to school. Some schools are only half full or less because people can't send their children to school because it will cost them money."

Paul Caswell, Nigeria

> "[One of the main obstacles is] lack of money. As you know, the rehabilitation process is very, very expensive...Poor people, like those in Palestine, are suffering from not being able

to provide their children with rehabilitative services due to lack of money and the expenses of rehabilitative services."

Mohammed Al Araeir, Palestine

"If you have resources as a family, you can probably get services privately. Otherwise it's not very good."

Camille M. O'Reilly, Mexico

In many cases, in the time it takes parents to save the money needed for services, the child's condition worsens and opportunity for critical intervention is lost.

"I spoke with a lady who came with a child who has Hydrocephalus and Spina Bifida. This baby is now 8 months old. The baby was born at home and the mother noticed a protruding sac located low down on the spine, which is a Spina Bifida presentation. She went to her local hospital and they said 'we don't know what this is; we'll send you to the biggest hospital in Kenya'".

So, she managed to save the money to come to the big hospital in Nairobi, which is a long way from where she lives. She went to that hospital and they told her to come back with 5,100 Shillings for treatment. So, she went home and went about raising the money by asking all her family and friends for a loan or to donate. She took the baby back to the big hospital and they took her 5,100 Shillings; then told her that wasn't enough and she needed to come back with another 7,000 Shillings.

All this time the child is not being treated for anything, so they've got an open sac on his back and a very 'floppy baby'; the baby is about 4 months old and still hasn't had any treatment. So, she went back home because she didn't have the money they were asking for. When she got home, the sac burst with the spinal cord in it; it was all very nasty, the child became unconscious. So, she took him to a local hospital again in her home town. They did first aid; kind of patched it up, did dressing and referred her on to the hospital she'd been to before. He stayed at the local hospital for about one month and was unconscious for a week.

Before this, he had been developing and was able to smile and laugh and those kinds of things, but once the sac burst, he went back in his developmental progress and he's still not even smiling. So, she raised the 7,000 and went to the big hospital again. They did an x-ray, which cost 4,000; they told her she needed to buy a shunt for the Hydrocephalus for another 5,000 and that she needed to pay more for admission and medication. She didn't have this money of course, so she went home again and used the remaining funds she had for family food because she has four other children staying with cousins while she was trying to get this baby treated.

She was home about a week and the child's head started to swell. She went back to Nairobi and found a Medecin Sans Frontiers clinic that referred her to another hospital that specifically treats children with Spina Bifida and Hydrocephalus. So, she went up there and they gave her free treatment and medication as well as folic acid for her next pregnancy. He was admitted for five days and the head started to get smaller and he's now following up there."

Kenya

To eliminate needless suffering, deteriorating medical conditions and lost potential, effective treatment needs to be available, accessible and affordable to all children with disabilities and their families.

Qualified Service Providers

The unavailability of qualified service providers is a major obstacle discussed by Experts. Some talked about the lack of professionally trained staff in their countries, while others identified staff's lack of current knowledge about disabilities and treatment approaches. Over one-half of RAIT Experts agreed (53%) that in their country medical doctors do not have current information about disabilities; 28% disagreed. With too few trained staff to provide health and habilitation services, effective service delivery becomes impossible. Many Experts from disparate regions discussed this problem in their respective countries.

> "We don't have a speech therapist and we don't have an occupational therapist."
>
> *Jackie Butler, Antigua and Barbuda*

> "Some professions do not even exist in this country."
>
> *Natia Partskhaladze, Georgia*

> "In one county out of the 47 there is only one neuro-psychiatrist. There is no other trained person there to deal with this issue. So, that doctor needs to see all the cases all the time and it's impossible."
>
> *Romania*

> "We don't have enough professionals. Most of the professionals live and work here in Lima."
>
> *Maria Graciela Laynes Valdivia, Peru*

> "We have limited human capacity and professionals."
>
> *Tako Tavartkiladze, Georgia*

> "[One of the main obstacles to delivery of services to children with disabilities is a] lack of trained professionals."
>
> *Wilaiporn Kotbungkair, Thailand*

> "An even greater obstacle is insufficient staffing, and relatively small number of people receiving professional training in this area; there are not enough to provide the necessary services for many children with disabilities."
>
> *China*

> State Parties undertake to promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.
>
> *United Nations Convention on the Rights of Persons with Disabilities, Article 4, 2006*

Smile Train *(International)*

The Smile Train is a successful program empowering local surgeons in developing countries to deliver safe, high quality surgery year round. Each year over 10,000 surgeons are trained to perform cleft lip and palate surgeries. By providing free equipment, education and training and on-going financial support, Smile Train is helping very poor, but very proud communities become self-sufficient one smile at a time.

More info: *www.smiletrain.org*

> “There are not enough professionals to work with the children and their families.”
>
> *Miriam Roman, United States*

Many Experts talked about the inadequate training and antiquated skills of direct service providers. Examples were cited of poorly trained staff who lacked the necessary knowledge to effectively administer medical therapies and habilitation services to children with disabilities.

> “Generally in the medical sphere the situation is very difficult in terms of disability. Medical doctors don’t know how to address this issue. So, parents end up running around to one medical doctor after another and it’s very expensive for them.”
>
> *Keti Milikadze, Georgia*

> “The doctors aren’t educated in disabilities at all during their training...I took a child to the doctor with a sore foot and the doctor had never seen a child like that before [spastic Cerebral Palsy].”
>
> *Reninca Hill, Haiti*

> “A pediatrician that I interviewed told me that when she graduated from the medical school in 2001, a five-year program, they had not learned or even heard about Autism at school. The first time she heard of it was from her colleague who has a son with Autism.”
>
> *Zhaoyang Chi, China*

Canon Triest International Institute
(Belgium)

Canon Triest brings in young men from different countries to give them a background in Special Education. These participants then return to their respective countries and either further their education or begin providing services. This particular model has a religious basis; however, the concept can be applied in a secular settings as well.

More info: *www.iictriest.org*

Ineffective Outreach

Several Experts explained that even when services are available, families are often unaware of them. The majority of respondents to the RAIT (62%) indicated a lack of awareness among parents of services for children with disabilities in their countries. Several Experts discussed the need for referral systems and disability networks to link families with services.

> “There’s no real referral system...It’s more word of mouth.”
>
> *Reninca Hill, Haiti*

> “A referral system should be in place, otherwise

parents are left alone and children do not receive the services they need."

Fulvia V. Tomatis, Macedonia

"Many children don't receive services due to lack of outreach and understanding of services."

Miriam Roman, United States

To utilize the services that do exist, a comprehensive outreach and referral system needs to be in place so when a child is first diagnosed service providers can make recommendations and parents know the child's options. Outreach programs and publicity campaigns are an excellent way to increase awareness among parents, service providers, people with disabilities and communities about services for children with disabilities in their area.

Positive Outcomes

Although there are many tragic stories about children who did not get services, there are also success stories about families who were able to access needed services and the positive outcomes that resulted for both the child and family.

"One boy came to me at the age of four with Cerebral Palsy. We are a school with mental disabilities, moderate to severe, and he was not. He was normal IQ, but he had severe physical disabilities…At that time I had a physiotherapist and she decided to take that child and work with him…We're going to make him walk first and then we're going to make him hold and write with his foot. By the time he was 10 years old, he was walking and writing with his foot and doing beautiful pottery with clay. I remember the day that he walked in his walker to his dad and then the Friday after that his father took him to the Mosque. He [the father] came to me and said 'thank you thank you…I took him to the Mosque and he repeated everything we did and he was so calm and so good that everybody in the Mosque accepted him and I'm going to take him now every other day."

Maha Al-Juffali, Saudi Arabia

"Two twin-sisters, born in 1989 lived with their family. In 1990 they were categorized as children with severe disabilities in their development because of Down Syndrome. One of them had problems with her heart. They

were placed in the institution for children with disabilities for twelve years, and in 2002 through the process of deinstitutionalization they were placed with a foster family. They are still there now. With the efforts of the foster family, a surgery was performed on the heart of one of the twin sisters and she is now in good health conditions. Now they are at the age of 20, they are well accepted in the foster family, have gained cultural and hygiene habits, have learned to live independently in their everyday life and are surrounded with much love from the family."

Vesna Samojlovska, Macedonia

"We helped to open a Sunday school [non religious] to help prepare children for school. It was in a town with quite a high number of children with disabilities…Different teachers would come and do activities with the kids each week and there was support offered to the mothers. This little boy would go to the school and he couldn't walk. By going to this school he started seeing other children because before that he was basically sitting at home and the father left the family after the boy became disabled… After a year of attending the school, he started walking and he started smiling. He went from a boy who couldn't even speak to you to start talking and reading some poems and being really an active boy. The school did a fundraiser and got some money together for his mother to take him to the hospital for a needed procedure."

Uzbekistan

"A boy with Cerebral Palsy was born in a family of poor economic background. He grew up believing that his disabilities were for the economic and social curse and burden for his family. As a result, his parents often perceived him to be worthless. He was unable to defend himself and often left alone at home. He was undervalued by those around him, which made him particularly vulnerable to be physically and emotionally abused. When he was 3 years old, his parents brought him to our rehabilitation center. He was then assessed by the pediatrician and psychologist. He was diagnosed with Cerebral Palsy, he could not stand up or communicate, but he was intelligent. Then, he was admitted to special school. As he could not speak, nor hold a pen or sit he was provided regular physiotherapy

The Bangladesh Protibondhi Foundation – Distance Training *(Bangladesh)*

Parents of children with Cerebral Palsy bring their child to the center where they are assessed and trained on how to do exercises with their child using what they have at home. They are sent home with manuals with very little text and detailed pictures illustrating these different exercises and activities. The manuals are designed for parents with low literacy rates to follow. Parents are asked to return every 3 months for follow up assessment. Studies have shown that this model is as effective as therapy provided in a center (McConachie et al, 2000).

More info: *www.portageproject.org/7th_conf/sC_bangladesh2.htm* and speech therapy in school and home. Gradually, he was trained to read and count. He received a special wheel chair from the government that helped him to move properly. Now he is relaxed, sleeps better and is positive to life. He can use the toilet and dress and feed himself independently.

Another important outcome of his achievement is that he draws and paints beautiful pictures by mouth. His learning experience changed the thinking and attitudes of teachers and parents. He participated in many art competitions and got first prizes. He became a role model among children with disabilities as well as children without disabilities."

Name and Country Withheld

"We have one girl who is 2 years 5 months who has two Clubfeet. Her mother didn't know why her child had feet different from other children. One day her mother went to the market and met a person with a disability who is getting rehabilitation. She told this mother 'please bring your child to that [rehabilitation] place'. So, after she heard about that, she brought her child to that center and now she has confidence that her child will be like the other children because they said that they can treat her child. After the surgery, she comes to the center every week to follow up. Now her child can walk the same as the other children and the mother has new hope."

Cambodia

"The story of a mother I worked with and her son is a compelling one. She assists her husband in their subsistence farm and does some petty trading as well. This is her seventh child, and the second in a row to have Clubfoot! The mother comes from a small village in Ghana. Her sixth child had Clubfoot, was treated at [a large regional hospital], discharged and is now playing around like any normal child. No trace of disability! This was the child that gave his mother sleepless nights and loss of appetite for several weeks after her birth. She used to wonder what might have caused this. 'Were my or my family's sins so many that God decided to punish me? Why me?' These were questions that constantly agitated her. She and her husband were both devastated. Luckily someone saw the child and directed them to [a large regional hospital] where he received treatment.

> One out of every 750 children around the world suffers from clubfoot, a congenital deformity that severely twists the foot downward and inward, making walking difficult or impossible.
>
> *Cure International, n.d.*

> ‘So when this seventh child came with Clubfoot, it became a normal disease like fever to me’, the mother said. This mother knew where to go to and without streaming tears, took immediate steps to consult at the [special clinic] at [a large regional hospital]. Her child has had four serial casts, and she’s more than confident he will be totally healed like her brother. This mother could not hide her joy as she expresses her gratitude to the sponsors who now make this treatment free of charge for her. She lamented her struggle in raising money for the treatment of the other child three years ago.”
>
> *Jude Domosie, Ghana*

These stories illustrate the many achievements of children with disabilities who were given appropriate supports and services. Experts stressed the importance of awareness, availability and access to medical, habilitation and educational services that offer children the opportunities to reach their full potential.

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4. EDUCATION OF CHILDREN WITH DISABILITIES

The year 2015 targets the date for achieving the United Nations Millennium Development Goal of Universal Education for All (UN, 2000). This UN initiative documents the worldwide need for basic education. Recent international organizations and publications champion the right of all children, including children with disabilities, to a quality education. The strength of the education theme expressed by all Experts is noteworthy given the open format of the interviews with no specific questions probing education as a topic. Experts reflected that although progress is slow and more needs to be done to ensure quality, several countries have educational policies targeted for children with disabilities reaching their full potential.

When asked ‘What in your opinion are the three biggest priorities for children with disabilities in your country?’, almost everyone identified early intervention and quality educational services for children with disabilities. However, Experts expressed many concerns including exclusion from school, accessing early intervention services, offering a continuum of quality educational options and ensuring an adequate supply of well prepared and qualified teachers.

> 140 million children don’t attend school, a majority of whom are girls and children with disabilities. Among them, 90% live in lower middle-income countries and over 80% of these children are in Africa. There are countless others within the school system not receiving quality education.
>
> *UNESCO, 2005b*

Early Educational Intervention

Early intervention, in most cases, minimizes the lifelong effects of disability; while delaying intervention often leads to more profound impacts. Over 80% of RAIT Experts agreed that their country experiences a lack of services for infants and young children. The importance of early educational intervention is well documented throughout both early childhood and special education literature. The right mix of school-based services increases the likelihood that children with disabilities will reach their full educational potential, thus improving their overall quality of life. Generally, the earlier the intervention begins, the greater the possibility for remediation to occur, placing children with disabilities on a more equal footing with their peers. Expert comments focused on the lack of access and availability, and the poor quality of educational services. They also emphasized the importance of early detection and intervention.

> Early childhood provides the best opportunity to foster developmental gains in children, as 80% of the brain’s capacity develops before the age of three. Gains are highest for those with the maximum disadvantage.
>
> *UNESCO, 2009*

> “First of all, early detection and early intervention [should be a priority]. This is

extremely important and should be a top priority for each country to have a kind of early detection and early intervention."

Dr. Moussa Charafeddine, Lebanon

"Children should be able to access services in a timely manner; in their own communities that are culturally responsive services...They should have access to early childhood programs as the first tier to education."

Debra Mayer, Canada

"The most important intervention should start at birth."

Fulvia V. Tomatis, Macedonia

"Earlier services are not as good as they could be, particularly in the area of mental health."

Peter Farrell, United Kingdom

"Early intervention in general is delivered in the school."

Paula Rubiolo, Argentina

Experts pointed out that unfortunately most children with disabilities do not receive intervention during early childhood, with services often delayed until elementary school. Many learning disabilities or mild cognitive impairments, which manifest later in childhood, are not diagnosed until the child reaches primary school. Too often identification and diagnosis requires the child to fail in school before intervention occurs.

Separate Special Schools Versus Inclusive Education

Almost all Experts interviewed discussed their country's efforts to provide some level of inclusive education. According to UNESCO, inclusive education is based on the right of all learners to a quality education that meets basic learning needs, while enriching lives (UNESCO, 2005). The goals of inclusive education are to provide quality education programs, to end discrimination and foster social cohesion by including children of all ability levels in the same classrooms, with specialized instructional methodologies and needed supports. Some countries are just beginning this process, others, such as Italy report well developed systems. In Italy virtually all special schools were eliminated in the 1970s; today

The Shafallah Center for Children with Special Needs *(Qatar)*

The Shafallah Center serves children age three through young adulthood. Their early intervention program is designed for children aged three to five years and includes a state of the art center-based preschool / kindergarten. The program not only emphasizes educational and therapeutic services according to the individual strengths and areas of need for each child; it also offers a wide array of social play situations and activities of daily living. Upon reaching the age of six, the students are transferred to other units or other school programs, according to the type and severity of their disabilities.

More info: www.*shafallah.org.qa*

> Only 56% of all young children with disabilities worldwide have access to any preprimary services.
>
> *UNESCO, 2009*

Italian children with disabilities are educated with supports in inclusive settings alongside their typically developing peers.

As the interviews progressed, the complexity of implementing inclusive education began to unfold. While there is a growing body of knowledge in support of inclusive education, there remain many obstacles including reluctance from both teachers and parents. Of particular interest were descriptions of cases where parents of typically developing children were unwilling or refused to have their children educated alongside children with disabilities.

At the same time, many parents of children with disabilities expressed reluctance to move their children from familiar special schools to the inclusive environment of mainstreamed classrooms. Reluctance often results from fear, due to parents being previously convinced that their children could only receive targeted services at their special school including all support services and therapies, teachers specifically trained in disabilities, accommodations of equipment and technology, social acceptance by staff and the friendship of peers with similar abilities. Often it is these same parents who were instrumental in advocating for the creation of special schools for their children when no programs existed. So, their reluctance to transfer their children to mainstream inclusive schools is understandable.

The majority of Experts interviewed described their countries' educational system as a mix of both segregated and inclusive schools.

> "There is pressure to provide services that are one hundred percent inclusive and there is pressure to supply a healthy specialized or segregated sector and as a result the government doesn't know which way to turn… On the one hand they have to meet their budget and on the other hand have to meet the needs of the families who want totally different provisions, so they end up with a mixed economy of inclusive and special provision."
>
> *Peter Farrell, United Kingdom*

This statement illustrates that even when inclusive education is available, many parents choose to send their children with disabilities to special schools or classrooms. While each family has reasons for their choice, one often stated in support of separate programs is the belief

The Sparkle Effect *(United States)*

The Sparkle Effect is aimed at bringing together typically developing children and children with disabilities. This program started with a high school cheerleading squad welcoming children with disabilities to cheer with them during high school sporting events. They now provide guidance for other high schools who would like to include children with disabilities in to their existing cheerleading squads

More info: *www.thesparkleeffect.org*

Early Intervention Program for Infants and Toddlers with Disabilities *(United States)*

The Early Intervention Program is a federally mandated, state operated program in the United States, which allows each state to direct the program according to their unique needs. They serve children with suspected or documented disabilities from birth through age three and their families. This model differs from center-based programs in that therapists visit the child in their natural environment (childcare facility, home, etc.) and provide needed services with the intention of teaching caregivers how to do various therapies and skill development activities with the child on daily basis.

More: www.*ed.gov/programs/osepeip*

that both the quality of education and level of supports are inferior or non-existent in inclusive environments.

> "I don't think there's a real choice. Theoretically there's the option to send your child to a mainstream school, however many families would think that's not an option because that school wouldn't be able to meet their child's needs and often it's a huge struggle to get appropriate levels of support in education at school."
>
> *Stephanie Gotlib, Australia*

> "There are special schools, but often the parents will put their child in a normal school until the teacher gets to the point where she says 'no, I can't look after this kid'. At that point the child will be often pulled out of school altogether unless the parents have money and can send the child to a special school."
>
> *Kenya*

> "Most families who keep children with disabilities have to invite teachers into their homes because there are not many special schools."
>
> *Russia*

Teacher expertise and the quality of education play a critical role in parental decisions on where to educate their child. However, in many developing countries, parents truly have no choice. In some cases, Experts described inclusive education as the only option because special schools are too far away for families to bring their child. In Slovakia, if a child lives within reasonable distance of a special school, that would typically be the family's first choice; but if the distance is too far and the disability relatively mild they attend a regular school in their community. In many countries, it seems that inclusion remains an option only when the child's disability is mild and can be easily accommodated.

> "It's [inclusive education] relatively easy to do with people with single physical disabilities or mild cognitive disabilities. Once you get into more complex cognitive disabilities it's very hard, but I think it would be fair to say that the progress toward social inclusive education has

> been strong particularly over the last decade, but there's still a way to go."
>
> *Ron McCallum, Australia*

> "There was a 2008 decree covering inclusive education…Not all children with disabilities can benefit because they set some criteria like the IQ has to be above a certain level, the child cannot have more than one impairment, and so on."
>
> *Egypt*

It is also difficult to determine if references to inclusive education refer to adherence to the specific model, or simply the presence of children with disabilities in the classroom or school without specialized instructional methodologies and essential supports.

> "In our educational system there is integration principle, not inclusion principle. A child can be integrated into the educational system after he or she adapts to the majority."
>
> *Maria Duracinska, Slovakia*

Another obstacle that Experts commented on was the reluctance of parents of typically developing children to have their children educated alongside those with disabilities.

> "Parents of children without disabilities think that it's to the disadvantage of their child to be in a class where children with disabilities are because they think that the education is slowing down."
>
> *Stig Langvad, Denmark*

> "One mother came in [to the school] last week and said 'Oh, there are children with disabilities here. I want to take out my child.'"
>
> *Nada Khawaja, Lebanon*

> "The parents of healthy kids who attend those schools are quite often not willing to have their kid's classmates be children with disabilities."
>
> *Natia Partskhaladze, Georgia*

> "We had cases in some Kindergartens where some parents of typical children moved their children to another Kindergarten…We need to consider them [children with disabilities] not as a problem, but as a resource."
>
> *Fulvia V. Tomatis, Macedonia*

These comments describe the belief that inclusive education benefits the child with disabilities to the detriment of typically developing children in the classroom. Proponents argue that inclusive education meets the educational needs of all children. Additionally, the awareness, acceptance, and understanding of differences, and opportunities to interact with children of all abilities are of paramount importance when creating positive attitudes toward disability.

> "My youngest son went to a really excellent inclusive day care center when he was a little boy and right through school had kids with disabilities in his classroom. He came home in the twelfth grade to tell me 'oh mom, guess who's president of our high school?'…He told me it was this kid Sam…A boy with Cerebral Palsy, doesn't speak, uses a voice synthesizer, has an aide in the classroom to help him, he uses a wheelchair and the student body elected him president of the high school. I think this is because this is the generation that's grown up experiencing inclusion and the fact that he uses a wheelchair and voice synthesizer doesn't matter."
>
> *Debra Mayer, Canada*

Proponents believe that strong inclusive education systems are vital for full social inclusion to occur. Children with disabilities who are instructed in special schools or classrooms, especially residential placements, miss the opportunity to interact with typically developing children and typically developing children miss the opportunity to interact with them. Integrating children of varying backgrounds and ability levels throughout childhood leads to greater understanding and acceptance.

> "The earlier they [children in the community, both typically developing and with disabilities] see each other as playmates and friends, the easier it is all the rest of the way in life."
>
> *Elizabeth Bauer, United States*

> "[I would like to see programs grow that are engaged in]bringing youth together with and without disabilities to talk about things that

> interest youth and to do things publically together; not only for the youth to get to know each other, but also to challenge barriers to social activity."
>
> *Jamie Rau, Mexico*

While there remain barriers to inclusive education in many countries, such as teacher preparation, financial resources, acceptance by teachers and parents, physical access to all areas in school buildings, and negative attitudes; a variety of evidence supports the effectiveness of quality inclusive education, and its implementation is a priority in such disparate countries as Peru, Armenia, and Italy.

> "Now in Peru, we are living in a time of inclusion. Everybody talks about inclusion, the Ministry of Education talks about this and we have the law, but it's not enough. Inclusion is in Lima, but in other cities, no…The community needs time to learn more about inclusion."
>
> *Maria Graciela Laynes Valdivia, Peru*

> "Children have access to mainstream education and get better education than in special schools…The number of children with disabilities in higher education has increased due to this approach [inclusive education]."
>
> *Susanna Tadyvosyan, Armenia*

> "We have a good view of children with disabilities because since 1977 we have full inclusion in schools."
>
> *Luisa Bosisio, Italy*

> "We have been noticing when students [with disabilities] have the opportunity to be in the regular classroom with proper support, they are performing better on their tests."
>
> *Elizabeth Bauer, United States*

> "[I would really like to implement a program of] ensuring inclusive education in normal school for all children with disability, in all parts of Albania."
>
> *Albania*

> "Educators are being taught inclusion as the norm and are entering the classroom expecting it."
>
> *Debra Mayer, Canada*

Debra Mayer went on to describe how these teachers often meet resistance from some school administrators who are set in their ways and reluctant to shift to total inclusive education. However, as more new teachers enter the classroom expecting inclusion, acceptance will grow.

Through talking with Experts, the implementation of inclusive education and all of its complexities became apparent. Additionally, on the RAIT, 60% of Experts agreed with the statement, "Schools do not include children with disabilities in the regular/general education classroom", while one-third disagreed. Effective inclusive education needs to be consistently implemented over time with programs and best practices shared. Simply placing children with disabilities into general education classrooms with few supports and a teacher who is not yet prepared for full inclusion provides very little benefit.

Quality of Education

Many Experts discussed the poor quality of education for children with disabilities. On the RAIT Survey 72% of Experts agreed that the quality of education for children with disabilities remains inadequate in their country. One of the main reasons cited for poor quality was the low educational expectations for students with disabilities by teachers, parents and their communities. The cultural view of children with disabilities as helpless and dependent thwarts efforts to increase educational quality. Educating children with disabilities needs to be viewed as a worthwhile investment. One Expert explained how some believe that educational services are not a priority for children with disabilities.

> "Many services are very medicalized. Problems relating to education are really not seen as part of the arena of problems of children with disabilities."
>
> *Romania*

Others talked about how low expectations for children with disabilities remain a problem in many countries.

> "There is an extremely low expectation of kids with disabilities and that's reflected in their educational opportunities, the programming, curriculum and their opportunities and resources."
>
> *Stephanie Gotlib, Australia*

> "[One of the three biggest priorities for children with disabilities is] high expectations and access to the general curriculum."
>
> *Elizabeth Bauer, United States*

> "I've also heard of children with Cerebral Palsy being given tests to see if they're capable of being educated and when they're not able to hold a pen to learn to write, they can be classified as uneducable or put in [inappropriate] classes."
>
> *Russia*

> "I know a guy with Autism who lived with his mother. Initially the government believed he could be taught; he had the ability to learn. So, in that case he had a teacher who would come to his apartment and teach him. But, then there was a review of his ability to learn and he was classified as a non-learner and then the appearance of this teacher discontinued. Then, his mother had to pass a lot of government officials, a lot of bureaucracy, in order to start his education again."
>
> *Russia*

> "Most of people, still ask questions like 'Why teach those silly children?'"
>
> *China*

35% of children not attending school have disabilities.

Fewer than 2% of children with a disability are enrolled in school.

Over 90% of children with disabilities in Africa have never attended school.

UNESCO, 2005a

Due to low educational expectations for children with disabilities coupled with the belief that education will afford little benefit; the quality of education for children with disabilities remains dismal in many parts of the world according to several Experts. One of the main purposes of education is to prepare children for adult life so that they become independent and contributing members of their communities. However, if the belief persists that children with disabilities will make little contribution; there is no motivation to provide any level of education. In many countries, children with disabilities are not taught skills that will benefit them as adults. Experts from several regions of the world described the quality of the education system for children with disabilities in their respective countries.

> "Unfortunately the special schools that I've come across are not really that helpful in progressing children [with disabilities] forward like you would expect. They're more like a daycare arrangement."
>
> *Kenya*

> "A lot of the facilities that provide special education and even inclusive settings provide a very low quality of education. So children are hardly ever able to move up from one level to the other."
>
> *Samuel Kabue, Kenya*

> "Schools are still too ready to blame the family and the child for the problem that is emerging and still are not willing enough to look to themselves for the problem."
>
> *Peter Farrell, United Kingdom*

> "[One of the biggest obstacles is the] mandated, scripted teaching that allows for no variation whatsoever."
>
> *Paraguay*

> "Educational settings and educational opportunities are very limited for children with disabilities, especially children with multiple disabilities and intellectual disabilities and also for children with sensory disabilities."
>
> *Tako Tavartkiladze, Georgia*

This lack of quality and little concern about the education of children with disabilities has led to some unfortunate outcomes as described by some Experts.

> "We have a lot of dyslexic children. They keep them in the schools and they're not learning anything. They take the parents money and don't do anything with them. They keep them there until they reach 12 or 13 and then there is nowhere else for them to go because after 12 or 13 is secondary school and you have to do an exam to go into secondary school and they cannot pass the exam. What will they do with these children? They just stay at home. They get in trouble and they become hard criminals."
>
> *Name and Country Withheld*

> "Sometimes services are delivered to a less degree than needed. If you need assistance in school for fifteen hours a week, sometimes they would give you ten and would write it in the book that they gave you fifteen, when in reality they did not."
>
> *Stig Langvad, Denmark*

> "I have heard in some places of diabetics being educated with Down Syndrome children simply because they're all classified as disabled, which obviously isn't very satisfactory for either side."
>
> *Russia*

> "Another story I know very well is of a child who is blind and he was abandoned at birth. He spent 2 years of his life in the orphanage and without being with intellectual disability he was sent to the institution of people with intellectual disability. He spent there 7 years just being fed with a bottle and not receiving any kind of treatment or rehabilitation…He was normal intelligence, but after having spent seven years in such a place, he developed intellectual delay and when he was 9 years old he was the first child who came out of that institution. He was put in a foster family and started to attend a school for visual impairments and there he had to learn how to eat normal food, to eat with a spoon and then to perform in a different way. Now he's a child of 18 and he can write and read Braille. He plays accordion and piano and he loves music. He's still living with this foster family. His life is much better than he would have had living in that institution. But still he suffered a lot and he's still suffering."
>
> *Fulvia V. Tomatis, Macedonia*

> "It is an incredibly intolerant education system and whoever cannot keep up gets weeded away."
>
> *Moldova*

Even in countries that have comparatively well developed education systems for children with disabilities, there are lingering doubts about the quality of these educational programs.

> "As we speak, the government has expressed concern in a number of reports on the quality of education of children with disabilities; in particular they're not reaching the standards you'd expect them to reach and there needs to be improvement."
>
> *Peter Farrell, United Kingdom*


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Children with disabilities are far more likely to reach their full potential and live independent lives if provided a high quality education. Several studies as well as personal accounts have demonstrated that the investment in education for all yields high returns.

Teacher Preparation

Comprehensive teacher preparation is integral to quality of education. One indicator of effective education is the presence of universities within a country that offer teacher education programs providing a steady supply of qualified teachers. If a country relies on importing teachers from other countries or sending their students abroad for training, they will likely experience a shortage of well-prepared teachers. Also important are credentialing and continuing education requirements that help to ensure excellence. Many Experts spoke about inadequate teacher training.

> "The training of teachers who have skills in special needs education is still very low...There are many good students who go through the [university programs here], but they don't learn how to teach these children."
>
> *Samuel Kabue, Kenya*

> "I would say the government is trying it's level best to have the teachers trained...Trying to orient the teachers on basic skills to handle children with disabilities, but what I would love to point out is that those are just basic skills. Many times we have found out that those skills are based on only one category of disability...So, we see those kinds of gaps with those who have been trained on handling children with disabilities."
>
> *James Mung'omba, Zambia*

> "The teachers [in the special education institutions] are not very qualified...They bring them because it doesn't cost a lot."
>
> *Nada Khawaja, Lebanon*

> "Teachers still need lots and lots of training on special needs, special education, teaching strategies, and so on. No teacher training, no service quality."
>
> *China*

> "There is a lack of adequate preparation of teachers in order to include these children [with disabilities] and a lack of specific educational materials for each disability, as well as [a lack of] programs of social consciousness to the educational community."
>
> *Mexico*

These Expert comments combined with RAIT results, where 85% agreed that there are not enough specially trained teachers for children with disabilities, strongly indicate that ensuring sufficient numbers of highly qualified teachers is an international priority. Many also believe that today's well-trained teachers know how to achieve effective inclusion of all children in their classrooms though they often lack support from school administration and have too few resources and materials in the classroom. High quality teacher preparation is an essential component of excellence in education; and attaining an effective inclusive educational system is a significant step towards full, lifelong social inclusion for all children.

Exclusion from School

Of critical concern are children with disabilities who are excluded from opportunities to attend school. Four frequent reasons given were: parents did not believe their child would benefit, children were hidden at home for social reasons, the school building was not physically accessible, or the administrators or teachers refused to admit children because of their disabilities.

Many Experts discussed concern over the low rates of school attendance for children with disabilities in their respective countries.

> "Quite a low percent of children with disabilities are able to access the schools or attend mainstream schools, and though the number of these kids is increasing, it is still not very high...Most schools are not ready to accept children with disabilities... They do not have enough resources, they are not accessible, and the teachers are not ready to work with kids [with disabilities]."
>
> *Natia Partskhaladze, Georgia*

> "In the countryside, even if there is a school in the area he [child with disabilities] will not expect to go to school because he would be totally stigmatized and the family would not want him to go to school. If he were in the city, if the family is from the middle class, then one hundred percent chance they would go [to school], but families in the lower class I don't think the child would go because of the expense."
>
> *Mesfin Taye, Ethiopia*

> "A lot of children come from very poor homes and that can affect whether they go to school or not."
>
> *Samuel Kabue, Kenya*

> "I would say only about five percent of children with disabilities have any kind of special education at all."
>
> *Paul Caswell, Nigeria*

> "Sometimes, children with disabilities are refused enrollment in a public school, and the excuses from schools usually are that they are

90% of children with disabilities in developing countries do not regularly attend school.

United Nations Factsheet, 2006

> short of professionals or a child's disability is too severe, and so on."
>
> *China*

These remarks were mirrored by the RAIT where 69% of Experts worldwide agreed that many children with disabilities do not attend school at all. Efforts also need to focus on increasing parental awareness of the advantages of education for children with disabilities. Parents believing that their children would not benefit from an education resonated throughout many Expert interviews.

> "I went to visit a family in a very rural area of the country and realized that they had a young daughter who was always banging her head against the wall in a back room and injuring herself. The girl, who seemed to have mental health issues, would yell for no reason and the parents kept her hidden at home. I told the mother to send her daughter to an NGO to try to get some services for her and the mother said, 'Why bother, she is just going to stay home with me anyway'."
>
> *Bakary Sogoba, Burundi*

> "Parents have problems sending a child with disabilities to school because they believe that they are unproductive, that they cannot accomplish anything." [translated from French]
>
> *Equatorial Guinea*

> "Before, parents won't take the child with disabilities to school because they think that the child can't study or learn, but now, some parents are taking their child to school."
>
> *Cambodia*

> "I have a colleague and one of her upper limbs is paralyzed. When someone that doesn't know her sees her, they don't see her disability. But, at home her parents did not want her to go to school; not because they didn't want her to learn, but because they were afraid that outside of the confines of their home she would have suffered mockery from society and the other school children. She stayed home until the age of 14 and only started school at that time. Can you imagine starting your first class at 14?" [translated from French]
>
> *Equatorial Guinea*

Even when parents show extreme commitment to their child's education, other obstacles often arise that prohibit the child from participating. The following story graphically illustrates the importance of accessible schools, as well as the need for mobility aids and accommodations such as wheelchairs and ramps, in many parts of the world.

> "The school buildings are old and have lots of stairs, which make it impossible for children with mobility limitations to even get in the building, so most children with disabilities are either kept at home or are sent to institutions. There have been cases though of very dedicated parents carrying their child to school every day and staying with their child to carry them from class to class."
>
> *Moldova*

Although there were no specific questions asking about gender discrimination, some Experts identified gender discrimination for participation in school and other disability services. Many Experts talked about the preferential selection of males with disabilities over females with disabilities.

> "The girls are still much more deprived and they are not sent to the schools. The enrollment rate of the boys with disabilities is more than the enrollment rate of girls with disabilities...Still we have to focus more on the education of girls with disabilities."
>
> *Birendra Raj Pokharel, Nepal*

5. ACCESSIBILITY OF PUBLIC BUILDINGS, TRANSPORTATION AND INFORMATION

Physical access to buildings, walkways, public transportation and information are critical issues for children and adults with disabilities. Overall, access to buildings, such as schools, medical facilities, government buildings, stores, religious facilities, and housing, remains an enormous barrier to attaining disability services, education and independence. In response to the RAIT Survey, over 81% of Experts agreed that building accessibility is a major concern in their country and 87% agreed that public transportation is not accessible to many people with disabilities. Access to information was discussed as well.

A number of Experts talked about inaccessible school buildings, which prevent many children with physical or some sensory disabilities from receiving even a basic education. Building inaccessibility occurs in all countries, but it was specifically identified by Experts from Uzbekistan, India, Mexico, St. Lucia, and Slovakia. Lancia Isidore from St. Lucia illustrated this issue in the following story, which points out how accessibility barriers impact children with disabilities, preventing them from reaching their full potential.

> "A 16 year old boy lives in an isolated area of St. Lucia. He was vibrant from a young age. After entering school he progressively lost the use of arms and legs resulting from Muscular Dystrophy. He continued his education using a wheelchair. Upon completion of grade five, his condition had progressed so that he could no longer sit for more than thirty minutes. He is still capable of using his mind and wanted to continue his education. However, the secondary school is housed in a two level structure. There are ramps that will allow access to classes only on the first floor. Due to this inaccessibility he was forced to stop attending school. His family is poor and even if the school could have accommodated him, there are no hydraulic vehicles available for his use, therefore this young man, who is eager to continue his education, is forced to remain at home."
>
> *Lancia Isidore, St. Lucia*

> "When a building is being constructed, we should consider people with disabilities. Those kinds of things are coming. It is still very rare, even the UN building in Ethiopia is not accessible for people with disabilities."
>
> *Mesfin Taye, Ethiopia*

Public transportation is frequently inaccessible to children or adults with some physical or sensory disabilities for independent mobility. Roads and sidewalks are difficult to maneuver in places such as Antigua and Barbuda. In Mexico, curb cuts when present are randomly located with no continuity. Since many people in rural areas rely on bus or train services to travel to cities, inaccessible vehicles and stations make it especially difficult to utilize disability services that may only be available in urban areas. Experts described instances of parents carrying their child with a disability from place to place, even to classes inside a school building; a situation that clearly stops when the child grows too heavy for the parent to carry. At that point, even routine medical visits become difficult and education or work options limited or non-existent.

Access to information was another concern described by Experts. People with disabilities are further marginalized when they cannot access information or media available to others in their communities. Samuel Kabue of Kenya commented that the adaptive equipment needed for many people with disabilities to use computers, including the internet, cost more than the computer itself, thus taking it out of reach for many of the people in need. An Expert from South Africa discussed how news programs in his country had sign language interpretation so that many people with hearing impairments had access to media information. This Expert went on to say that other countries, including many developed countries, do not have this provision. National efforts are needed to ensure that information is disseminated through a variety of methods such as printed material, television, radio or the internet, and that both the skills and technology that provide access to information sources and the media are available to children with disabilities and their families.

Assistive Technology

A specific obstacle discussed by several Experts is the unavailability of necessary assistive technology, which aids people in accessing both information and their environment. Use of assistive technology facilitates accessing schools, moving independently in the community, or hearing media announcements. Technology like wheelchairs, hearing aids, eye glasses, and computer programs improve the quality of life for many children, and often make the difference between isolation and independence. Unfortunately, even simple and inexpensive devices are not available to many who could benefit and 66% of Experts confirmed on the RAIT that it takes a long time for children with disabilities to get the assistive devices they need.

> "It costs up to three years' salary for some of these families to buy a wheelchair for their kid who is going to outgrow it in two years."
>
> *Bree Lair, Mexico*

> "[Access to] mobility aids are a problem for them [children with disabilities]."
>
> *Philippines*

> "I met a man in his late 20s who lived with his elderly mother who had taken care of him his whole life. He had an inappropriate wheelchair and spent most of his time in a homemade diaper lying on the ground on a pile of blankets."
>
> *Camille M. O'Reilly, Mexico*

> "Despite years of public intervention, a growing disability rights movement and one of the most progressive policy frameworks for persons with disabilities, only a few disabled people have access to aids and appliances."
>
> *Dr. Chip Kingery, India*

> State Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities by facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost.
>
> *United Nations Convention on the Rights of Persons with Disabilities, Article 20(b), 2006*

Access for All *(Sri Lanka)*

The Access for All campaign was launched in the immediate aftermath of the tsunami, which devastated large parts of coastal areas in Sri Lanka in December 2004. The campaign aims to promote the inclusion of all persons with disabilities and their needs in the tsunami relief, reconstruction and rehabilitation work in Sri Lanka.

More info: *www.cbm.org/en/general/CBM_EV_EN_general_article_75271.html*

120-130 million persons with disabilities need wheelchairs.

Only 10% have access to one.

Ding, et al., 2005

In some countries programs provide assistive devices that are affordable or free for children with disabilities. However, more needs to be done to ensure that all children who could benefit from assistive technology are evaluated and receive services at little or no cost. Instances were also reported where inappropriate or ill fitting assistive technology devices actually harmed growing children. Because children grow and their needs change, children require assistive devices that fit and are appropriate for their developmental stage.

6. TRANSITION TO ADULT LIFE

Transition between childhood and adulthood is often stressful for the adolescent with a disability and their family. Throughout the interviews, Experts identified transition, usually around ages 15 to 21 depending on the culture, as an area of concern. Many Experts discussed the overall shock families experience when they realize there are no mandated services for adults with disabilities. Adult services refer to specialized programs and supports that assist the person with achieving employment, living independently, and participating as a citizen in their community to the greatest extent possible. The most common services include: post secondary education, vocational training, accommodations and supports in the workplace and access to housing, transportation, and recreation.

In more developed countries services are delivered through government agencies and non-profit organizations such as vocational rehabilitation, mental health services and centers for independent living. Even though the Expert interviews had only one question about the expected future for children with disabilities, everyone stressed the importance of transition to adulthood and the limited services available in their country.

Few Adult Services

Experts talked about the lack of services available for adults with disabilities. Results of the RAIT showed that almost 95% agreed that transition services from secondary school to adult life are not adequate. In many less developed countries specialized transition or adult services are non-existent. Quotes from South America, Eastern Europe, North America, the Middle East, and Central America highlight the breadth of the issue.

> "This is a big problem. We have no programs for adults in Brazil. I think parents are concerned about this problem for adult life. This is the most important point we have to change; to have more attention to programs for adults."
>
> *Maria Aparecida Cormedi, Brazil*

> "When a person with disability becomes an adult and the parents become older and older, this person again will lose support, will lose autonomy and independence and need again other different kinds of services to go on to have an independent life as much as possible. This is a big issue in Macedonia now and so far there has been little intervention to tackle the problem and most of the interventions are promoted by associations of persons with disabilities or parents of people with disabilities and developed at local level, not in the system of social care."
>
> *Fulvia V. Tomatis, Macedonia*

> "One of the things that I have observed since we have had the entitlement to public education, families don't recognize that there is no entitlement to services once the student leaves public education. They are in a comfort zone."
>
> *Elizabeth Bauer, United States*

> "Programs for adults with disabilities are very, very few. There is plenty for young ones, still not enough, but for adults very little is available. This is a number one priority."
>
> *Nada Khawaja, Lebanon*

> "When referring to individuals with cognitive disabilities or Cerebral Palsy, the opportunity is reduced even more, since educational programs and vocational development is provided until 21 years of age. Afterwards, the individual must return home since the labor sector does not present suitable conditions to receive them, and they are not prepared to participate in the labor force." [translated from Spanish]
>
> *Costa Rica*

> "This [transition] is the biggest problem because they have to go back to social service establishment or they have to stay home with their family members. This is the biggest problem because we don't have enough social service establishments and these establishments very often don't work."
>
> *Slovak Disability Council, Slovakia*

Vocational Training

Experts expressed concerns about the inadequacy of vocational preparation and training. They confirmed this on the RAIT with 74% agreeing with the statement, there are few or no vocational training opportunities available for youth with disabilities.

© Dennis Thern / Star of Hope

> "This is the biggest problem. We need a lot of vocational training. That is the problem. There is no transition from school to vocational training."
>
> *Nada Khawaja, Lebanon*

> "Few children finish their education and go on to vocational training."
>
> *Ferdausi Moula, Bangladesh*

> "They can leave the special school and go to the vocational school…But, this is for a person with a mild disability and most of the students who work for vocational schools are high functioning."
>
> *Paula Rubiolo, Argentina*

Experts also described the inadequacy of vocational training programs in their respective countries.

> "Vocational training is not adequate and if they get vocational education there is no sustainable plan for how they can use their skills. There is no further planning…If they get some self-employment training; there is no revolving fund to be provided by the government [for a] small industry business."
>
> *Birendra Raj Pokharel, Nepal*

> "One of the biggest priorities is the need to strengthen vocational training."
>
> *China*

Marketable job skills needed to obtain employment are lacking in many vocational training programs, while for the majority of young adults there is a total lack of appropriate vocational options.

> "The services that existed were kind of sporadic and weren't planned; there was absolutely no specialized training and [the services] were really condescending. One of the big projects was making curtains of drinking straws and that would be what they did every day. It wasn't teaching a trade they could go out and sell."
>
> *Paraguay*

> "Vocational training, there has only been one disability specific training and that was for people with physical disabilities only and that

> was only men and that was last year and they do only carpentry training…There is little vocational training.”
>
> *Timor Leste*

Higher Education

A transition concern with lifelong social and economic implications is the low number of young adults with disabilities accessing college or post high school education or being encouraged to do so. Sixty-eight percent of RAIT Experts agreed that children with disabilities were not encouraged to pursue higher education in their country, while 24% disagreed. This is not surprising given many children with disabilities are denied the opportunity to attend even primary school and often when they do the quality of their education is poor. There are many issues that prevent people with disabilities from exploring or completing higher education, which vary depending on the country. Experts encouraged more effort, advocacy and dissemination of successful program models.

> “It is difficult for these children to enjoy or benefit from preschool education and higher education.”
>
> *China*

> “There is meant to be some supports, but it is the elite few that get to go to university.”
>
> *Stephanie Gotlib, Australia*

> “It [exclusion] also applies to higher education; those few students who can further their studies find themselves discriminated against. What’s worse, higher education is not fully available for people with disabilities who cannot take it as part of their social inclusion like any other person.”
>
> *Graciela Ferioli, Argentina*

> “I think research needs to be done on higher education and access for people with disabilities.”
>
> *Jamie Rau, Mexico*

Many people with disabilities are very capable of attaining higher education degrees, especially with adequate support, accessible buildings and the requisite educational foundation. Too often they are not encouraged to apply or when they do,

Vocational Training in Nigeria *(Nigeria)*

This program equips people with disabilities with useful skills needed to establish their own micro business. One example of their work is the story of a boy and a bar of soap.

“There is a boy who has cerebral palsy quite badly and when he was about 12 years old we helped him with one bar of soap, which he cut up into pieces to sell and bought two bars of soap and so on. Now he has quite a big shop and he has got a taxi and he has got some motor bikes…He has gotten married and his wife is expecting a child now.”
Paul Caswell, Nigeria

More info: *cbm.org/en/general/CBM_EV_EN_general_article_45191.html*

> While the number of students with disabilities in higher education has increased, those who benefit most are already the most socially advantaged.
>
> *Barnes, 2007*

are not accepted by the university or college. This limited access to higher education has lifelong employment and income implications; people with baccalaureate degrees generally earn more than those without, and report higher job satisfaction. A country investing in education and increasing participation in higher education for all children, yields significant positive social and economic returns.

Employment for People with Disabilities

Most children and adults with disabilities have the same dreams for independence, a meaningful life and the desire to be a contributing member of society as those without disabilities. Employment is critical to independence for most people. Many regions of the world lack employment prospects in general, which is even more pronounced for people with disabilities. Even with vocational training or university degrees, many adults with disabilities are not meaningfully employed. Experts made various comments regarding the importance of employment for people with disabilities.

> "If they have any capabilities to work, they work with their father or mother."
>
> *Ferdausi Moula, Bangladesh*

> "We have state of the art education services at the Shafallah Center, and we are just beginning in the area of supported employment."
>
> *Sameera ALQassimi, Qatar*

Encouragement and support from family members plays a vital role in their obtaining employment. When parents believe their child can succeed, that positive attitude is passed to the child.

> "One of the great examples you can give to parents of a child with disabilities is to show them an adult of the same disability who is gainfully employed."
>
> *Ron McCallum, Australia*

Some governments have taken proactive steps encouraging businesses to employ people with disabilities. Unfortunately, the lack of implementation and enforcement of these regulations often renders these attempts inadequate.

> "There is a rule that obliges companies to integrate and recruit disabled people. This is

What's Next? *(United States)*

What's Next is a mentoring program that brings together young people with physical disabilities and adults with similar disabilities who are living active, successful lives. They provide each mentee with a mentor who is matched by functional ability, gender, personality, and ethnicity whenever possible. Once matched, mentors and mentees enjoy one-on-one time within a social group environment and by phone and email. They get together for fun, sharing of experiences and presentations on topics ranging from independent living, managing personal attendant services, Social Security benefits, and Department of Rehabilitation programs.

More info: *www.whatsnextsd.org*

> The International Labor Organization estimates that 386 million of the world's working-age people have disabilities. Employers often mistakenly assume that persons with disabilities are unable to work.
>
> *United Nations Factsheet, 2006*

about one percent now, but we are fighting for it to be five percent."

Dr. Mongi Ben Hammouda, Tunisia

"Their disability associations were able to legislate a law concerning disability [and] creating equal job opportunities…These things are coming and the disability organizations are working very hard to push the government…To bring the law into practice takes a lot of time."

Mesfin Taye, Ethiopia

"We have the program of Saudization. The Interior Ministry is asking us to please employ more Saudis. If you employ one Saudi disabled, in your institution or in your factory or wherever, no matter what disability they have, it's as if you have employed four Saudis."

Maha Al-Juffali, Saudi Arabia

Maha went on to explain that because of this policy, many times the Saudi person with a disability is only hired so the business can achieve their quota for Saudization. Often the Saudi person with a disability is paid a wage, but not given the opportunity to actually work. This is an issue that her program, Care Center, is trying to combat by ensuring that the businesses are actually encouraging the Saudi person with a disability to have meaningful job responsibilities. Although not specifically mentioned in the interviews, this scenario undoubtedly occurs in many other countries with similar initiatives. Most people with disabilities want to be contributing members of society, so to be given a job with few responsibilities and low expectations is demeaning.

"One of our students complained that although she was a teacher aide, she had nothing to do. We then gave her specific responsibilities; she did a great job and is much happier."

Sameera ALQassimi, Qatar

Other governmental programs offer specific supports to increase employment opportunities. Two respondents from China and one from Russia discussed options available in their respective countries.

"China now has specialized higher education institutions where people with disabilities can receive special education. Individual colleges and universities have specialties offered to people with disabilities whereby upon graduation they can enter direct employment and participate in social activities." [translated from Chinese]

China

"According to the Regulations on Employment of the Disabled by the State Council, the Chinese government has the responsibility to establish social welfare enterprises of diverse types to help create job opportunities for those who are able to work. The concentration approach refers to job placement of people with disabilities in "welfare workshops" where workers with disabilities should account for at least thirty-five percent of the entire staff body. However, the future of children with Autism is desperate; very few schools are willing to accept Autistic children and the employment opportunities for this group of people are very limited."

Zhaoyang Chi, China

"A number of charities are working to open up the labor market. As I understand it, there are fewer opportunities now than under the Soviet system to actually work because the Soviet system had workshops for the blind and for other people with disabilities to do some kind of work."

Russia

Specialisterne *(Denmark)*

Specialisterne creates jobs for people with Autism Spectrum Disorder (ASD), who may experience difficulty in getting and keeping a job. They offer a 5-month occupation clarification component that includes training. Participants' options for potential employment in the corporate sector are assessed using Specialisterne's experience with the requirements of the business community. This program capitalizes on the detail oriented skills often associated with ASD that can be applied to business situations.

More info: *www.specialisterne.com*

> In developing countries, 80% to 90% of persons with disabilities of working age are unemployed, whereas industrialized countries employ between 50% and 70%.
>
> *The Washington Times, 2005*

Independent Living

Due to the civil rights perspective and resulting political action of the Independent Living Movement, many countries now offer funding and supports for adults with disabilities to live as independently as possible in their communities. In some countries these services are organized into Centers for Independent Living. Where available, specific skill training for independent living begins in adolescence and continues as needed, which can be lifelong. Concerns expressed by Experts were the availability of housing options, physical accessibility and accommodations, and social supports.

> "Non availability or lack of long term residential options for kids is a big concern. Lack of any government initiative in either funding for these programs or even conceptualization is a big concern for parents."
>
> *India*

> "We need community living. We don't have this in Lebanon. It would be great to see this implemented in Lebanon."
>
> *Nada Khawaja, Lebanon*

> "We have to move from residential institutions to community-based living; to organize independent living centers, to organize centers with protected living for people with severe disabilities in society. We have not made this move in Greece yet, but this is what we try to do."
>
> *Yannis Vardakastanis, Greece*

As many independent living initiatives are nonexistent or inadequate, Experts discussed the need for programs teaching life skills, especially as people transition from institutional settings to their communities.

> "There is only one pilot of this kind of project [group home], again initiated by an NGO, and this home is supported by international money. However, the government has in its plan to take funding to subsidize this home for sustainability...In the future we would like to use this as success story to show the government that not only this center has to be supported by the government, but also this is the best way to take children out of institutions

> and create group homes in the general community."
>
> *Susanna Tadyvosyan, Armenia*

> "The ongoing deinstitutionalization process primarily at the moment is targeting the adults. There is a project by the government for opening independent living units for people with disabilities."
>
> *Macedonia*

> "There are several what they call focused living, you can live independently and have assistance whenever you need it...There are groups of people that are living with a number of staff that come along and take care of them. There are a number of independent houses..."
>
> *Johannes Verheijden, The Netherlands*

As the development of independent living alternatives is very new in some countries, Experts hope that efforts will be expanded.

> "Many across the globe will come to accept that disability is not inability and that the disabled

Assistance Dogs Australia *(Australia)*

Assistance Dogs Australia trains Labradors and Golden Retrievers to help people with physical disabilities. These dogs undertake everyday tasks such as opening doors, pressing the button to cross the road, and picking up dropped items, but most of all they offer a form of confidence and independence to people accessing the community.

More info: *www.assistancedogs.org.au*

> child can be helped to become more productive and support himself or herself."
>
> *Jude Domosie, Ghana*

One unique discussion regarding independent living occurred with an Expert from Australia. The Expert talked about the backlash from parents who were reluctant to assist with their child's independence.

> "While we are doing better with education, there is still more work to be done with transitioning from the education services to what happens afterwards. I know that is an area of high anxiety for parents and there is often competing interests, where rightly or wrongly, parents that have had a good experience with their child's support through the education services and will often resist the kind of move to independence...This can be very confronting for a parent who feels responsibility for their child."
>
> *Australia*

While achieving independence is the ultimate goal in many cultures and families, a few Experts emphasized that independent housing in adulthood is not pursued where people value multigenerational households. Pursuing or forcing independent living programs in cultures that do not value these outcomes is inappropriate. However, independent living is more than housing, and includes education, employment, transportation and access to relationships in the community. Globally, independent living needs to be an option guaranteeing transitioning youth with disabilities similar opportunities for independence as their typically developing peers.

Safety and Protection

Concerns about the safety of and the need to protect children and adults with disabilities were expressed during most interviews. Many Experts stated that parents are concerned with the safety of their child, especially their daughters, and that this may be a reason for limiting their independence at all ages. Stories from around the world of abuse and exploitation perpetuate these fears.

> "Parents particularly worry about the safety of their daughters. This often leads them to prevent their child from participating in any type of employment. One concerned father

Project Search *(International)*

Project SEARCH serves people with disabilities through innovative workforce and career development. Through this process they educate employers about the potential of this underutilized workforce while meeting their human resource needs. Project SEARCH provides employment and education opportunities for individuals with significant disabilities. The program is dedicated to workforce development that benefits the individual, community and workplace.

More info: *projectsearch.info/apps/*

> came to me saying his daughter, although well cared for at home, was extremely sad and cried all the time. He was concerned about her safety, but agreed to let her attend the Shafallah Center. She has done very well, is happy, and even progressed to become a teacher aide."
>
> *Sameera ALQassimi, Qatar*

> "Women are more exposed than men. Women with disabilities need specific protections and their situation is more difficult." (translated from French)
>
> *Equatorial Guinea*

> "They [children with disabilities] are also especially vulnerable to neglect, physical abuse, sexual violence, exploitation and they lack recognition of their equal humanity by their families and communities. They are less likely to obtain preventive care, police intervention or legal protection."
>
> *Dr. Chip Kingery, India*

Children with disabilities are manipulated or exploited in many situations and then not always believed when reporting.

> "I do want to mention one that I have encountered about a person with mental disability who was sexually violated while going to fetch water and gave birth to a child with mental disability. She is now 17 years old…This is very common…Even yesterday we dealt with a girl who was sexually violated… The police insisted that they needed evidence from the girl with the intellectual disability without the support of her parents and it was very difficult. Her statement was very weak… The girl was able to talk about this person who has been continuously violating her and exploiting her and now the secondary sign of exploitation, the pregnancy that now informs everyone that something bad was happening to her."
>
> *Kenya*

Parents of children with disabilities face the challenge of balancing their growing child's need for independence with their parental instincts to keep their child safe.

Violence rates against children with disabilities are at least 1.7 times greater than for children without disabilities.

United Nations Factsheet, 2006

Women and girls with disabilities are particularly vulnerable to abuse. A focused 2004 survey in Orissa, India, found that virtually all of the women and girls with disabilities were beaten at home, 25% of women with intellectual disabilities had been raped and 6% of women with disabilities had been forcibly sterilized.

United Nations Factsheet, 2006

In some cultures, persons with disabilities are raped in the belief that this can potentially "cure" an HIV-positive individual.

Groce & Trasi, 2004

Low literacy levels and a lack of HIV prevention information in accessible formats (e.g. Braille) make it all the more difficult for persons with disabilities to acquire the knowledge they need to protect themselves from HIV.

Groce, 2005

Persons with disabilities experience all of the risk factors associated with HIV infection and are at increased risk because of poverty, severely limited access to education and health care, lack of information and resources to facilitate 'safer sex,' and an increased risk of violence and rape.

International Affairs Directorate, 2009

Sex Education and HIV Prevention

With the current HIV/AIDS pandemic, it is vital that all youth receive adequate information about sexual health including information on their rights over their own bodies, safer sex practices, and HIV/AIDS and sexually transmitted infections (STI) education. Often youth and young adults with disabilities are not provided with sexual health information because of the misconceptions that they will not be interested in having sexual relationships and/or that no one would be interested in having sexual relationships with them. However, it is well documented by Experts that these beliefs are false and a lack of information about human sexuality can lead to harmful outcomes such as girls with disabilities being raped, unintended pregnancies, and the transmission of sexually transmitted infections including HIV. Many Experts mentioned that parents are very concerned about the future sexual behavior of their children.

> "One of the most common [concern of parents of children with disabilities] is their sexuality, when they grow up to a certain age, and how to deal with it."
>
> *Macedonia*

> "Parents are concerned about their child's future sexual behavior." [translated from Spanish]
>
> *Costa Rica*

> "Parents of children with disabilities are concerned about how to deal with the issue of sexuality of these children."
>
> *Vesna Samojlovska, Macedonia*

One Expert from South Africa described how even though human sexuality education including HIV/AIDS education in schools is compulsory for all children; it is often not taught as mandated.

> "We had at our school one period in the morning for the whole school [to teach sex education], but people try if they can to avoid it and do some other work because they say they are just uncomfortable teaching it."
>
> *South Africa*

While there are many model programs around the world that address the issue of human sexuality among people with disabilities, more needs to be done to stop the spread of HIV/AIDS. One Expert from Australia describes their program.

> "They [an association for persons with Cerebral Palsy] had a wonderful program for sexuality and actually employed a [sexual health educator] to talk to families, to talk to persons to help them understand."
>
> *Margaret Verick, Australia*

When young people with disabilities and their families are educated about sexuality they can make informed decisions that reduce their risk for negative outcomes such as sexual violence, unintended pregnancies and decreasing their risk of contracting a sexually transmitted infection.

Intellectual Disabilities

During numerous interviews Experts stated that a child's future depends on the type and severity of their disability. Many agreed that those with cognitive or intellectual disabilities are afforded the fewest opportunities. RAIT responses confirmed this with 68% of Experts agreeing with the statement "Children with intellectual/cognitive disabilities have fewer opportunities than those with other types of disabilities". Experts from Australia, Denmark, Kenya and Kuwait each expressed the difficulties experienced by children with cognitive disabilities.

> "One of the areas of growing importance is the area of cognitive disabilities...When it comes to the profoundly disabled children we need to do much more work. There are still some in residential care and I think we need to make greater strides."
>
> *Ron McCallum, Australia*

> "When you have cognitive difficulties it becomes much more difficult for you to be a part of the employment system or even to be fully included in society."
>
> *Stig Langvad, Denmark*

> "I would say that for other groups with disabilities it has been easier...But, with intellectual disability it has been a bit difficult with stigma."
>
> *Kenya*

Disability and HIV/AIDS *(Uganda)*

The program on Disability and HIV/AIDS of the National Union of Disabled Persons of Uganda (NUPDIPU) currently focuses on increasing access to HIV/AIDS prevention. They also provide care and treatment services to people with disabilities with emphasis on providing information to HIV/AIDS service providers about disability issues to influence service utilization.

More info: *www.nudipu.org.ug/aids.php*

> “There are services for physical disabilities. Music, art and recreational activities for people with intellectual disabilities are lacking.”
>
> *Rana F. Nasser, Kuwait*

Several explanations may account for persons with intellectual disabilities having fewer opportunities. One is that as societies become more economically and socially complex, higher order intellectual skills are needed. Another reason often expressed is that people with intellectual disabilities may be less adept at advocating for themselves. One positive outcome is that many strong advocacy organizations have evolved throughout the world that empower children with disabilities through self-advocacy skills, involve their families, and if needed, assist or advocate on their behalf.

7. STATISTICAL DATA ON DISABILITY PREVALENCE

A critical issue impacting childhood disability is the lack of current, reliable and valid statistical and demographic data. Indeed, almost every Expert expressed this concern. The challenges resulting from inaccurate information about the actual number of children with disabilities impacts every level of service delivery and makes planning problematic. Experts from many countries, including Georgia, Macedonia, India, the USA and Egypt stated that the lack of data is one of their biggest concerns, as well as the inaccuracy of the data that do exist. Below, one Expert responds when asked about the main obstacles to the delivery of services to children with disabilities.

> "First and key is an absence of data. In order to be able to design services, you need to know about your target group; the specifics of the target group and their needs. We don't have that. But, this will be changed with the census in 2012 when, for the first time, Macedonia will have a module within the census targeting specifically persons with disabilities; so we will be able to show for the first time how many people with disabilities are living in Macedonia because until now we were working with estimates."
>
> *Macedonia*

With inaccurate data about disability prevalence, service providers do not know how many children and families remain unserved. Prevention efforts are also thwarted because there is little information regarding the impact of public health and medical initiatives. Additionally, funding sources struggle to provide adequate budgets when they are unsure of the magnitude of needs.

Agreeing on a basic definition of disability, types of disabilities and degrees of severity is paramount to accurate statistical reporting both within and across countries. Many Experts discussed the need for a uniform definition of disability, the absence of which contributes to unreliable data.

> "Data related to disability among adults and children varies from one source to another. Lack of reliable figures regarding children living with disabilities and the different types of disabilities they face has been an obstacle in planning and making adequate interventions. This illustrates the insignificance accorded

Chicago Disability Complete Count Committee *(United States)*

As part of a larger campaign targeting historically undercounted groups, the Chicago Disability Complete Count Committee is launching a multi-tiered initiative to get people with disabilities involved in the 2010 US Census. Among its efforts are distributing flyers, visiting institutions and social centers where people with disabilities routinely congregate and broadcasting announcements.

More info: *2010.census.gov/partners/national-complete-count-committee*

> to the lives of disabled children. There is a need for more accurate data collection and for harmonizing definitions of disability in government surveys and the Indian census."
>
> *Dr. Chip Kingery, India*

Even countries with comprehensive national census initiatives experience problems due to non-specific questions that neglect key issues. The following experience reveals the need for a uniform definition of disability in order to collect accurate statistics.

> "We still do not have a comprehensive census of disability in America. There has been a lot of talk about doing a census...There are a lot of numbers out there. There are a lot of estimates and extrapolations...but there has never been a real count of people with disabilities in America or a serious effort to define that. In Census 2000, there were three questions on the short form. Do you have a disability that prevents you from using public transportation? I put no. Do you have a disability that prevents you from working? I put no. Do you have a disability that limits your choice of housing? I put no. Do I have a disability? Absolutely! Does the Census Bureau think I have a disability? They don't have a clue. We have no reliable data on disability anywhere in America."
>
> *Duncan Wyeth, United States*

In answering the RAIT Survey, almost 75% of Experts agreed that there are no reliable or valid data pertaining to children with disabilities in their country. Efforts to evaluate the effectiveness of prevention, eliminate causes, or assess the impact of current services are hampered by this lack of data. The question that needs to be answered is: Are all children with disabilities receiving the type, amount and quality of services they need?

8. FUNDING FOR DISABILITY INITIATIVES

Insufficient funding for disability initiatives resonated throughout the Expert interviews. Funding sources include government/public funds, non-governmental organizations, charities and faith-based organizations, corporations and private donors. However, when one source falls short and the other entities fail to fund the difference, programs and people suffer. Exactly, 70% of Experts agreed on the RAIT that there is an overall lack of funding for disability programs, while 24% disagreed. Many discussed insufficient government funding for children with disabilities.

> "There is a lack of financial means on national and local levels to provide services for the needs of children with disabilities. Policies and legislation in Albania do not provide financial support to NGOs. They are operating with donor funds to maintain sustainability."
>
> *Albania*

Financial Crisis

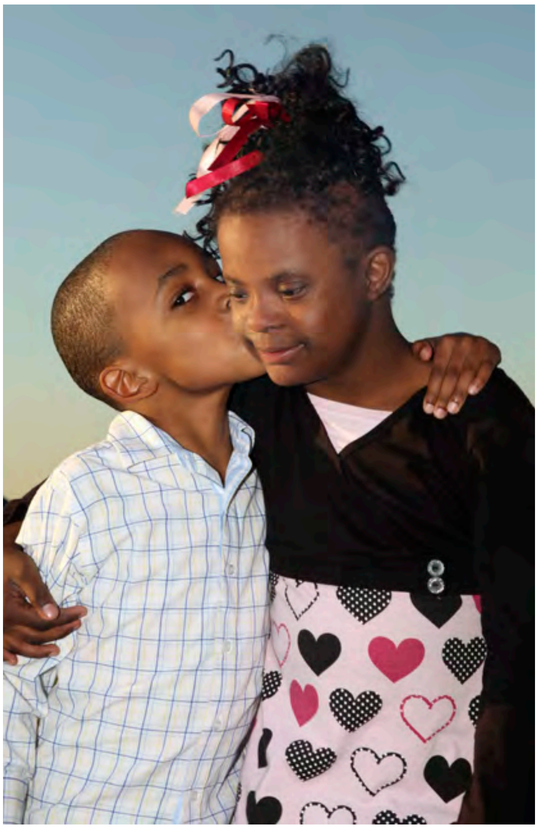
With the current worldwide financial crisis causing even greater economic strains, Experts concluded that while there is the interest to serve children with disabilities and their families, financial resources are grossly inadequate. As one Expert summarized, "The coffers are bare". Experts from such diverse places as Ireland and Armenia spoke about the impact of their country's declining economy on services for children with disabilities and their families.

> "We have one big problem here in Ireland and that is that we are in a severe recession. So, while there was hope that services were going to improve, they have taken a backward slide very, very quickly."
>
> *James McClean, Ireland*

> "The economic crisis has had an impact on the poor people in our country and, among the poor; the majority are families of persons with disabilities. Unfortunately, due to crisis, many programs have been stopped and many initiatives that were going on now are delayed until we see what will happen after overcoming the economic crisis...In the coming two to three years, I don't expect any major changes to happen in the field of disability rights in Armenia."
>
> *Susana Tadyvosyan, Armenia*

Most Experts concurred that while some government funding is currently available it falls far short of meeting the needs of children with disabilities and their families. Experts confirmed this shortage when answering the RAIT with 81% agreeing. With declining government funding and the increase in the number of children with disabilities, Experts discussed the support offered by charities and faith-based organizations and the establishment of non-profit entities by groups of proactive parents to secure additional funding.

> "The pro-activity, participation and encouragement of several non-governmental organizations, in partnership with parents whose children have disabilities, is a new and effective way by which the needs of children with disabilities are currently being addressed. People, no longer waiting for the Government to act, instead are taking upon themselves to work for the cause of children with disabilities. This is indeed heartening, and we can only hope that such groups and movements increase in number and their efforts are met with success."
>
> *Dr. Chip Kingery, India*



Seventy percent of Experts agreed on the RAIT that disability services are not a priority for government or public funding in their country. While every country experiences financial constraints, Experts stressed that services for children and adults with disabilities and their families need to be moved higher on their country's priority list for funding.

Unfunded Mandates

One critical consequence of inadequate national funding is that disability laws become unfunded mandates. Numerous Experts stated that laws are in place, but there is no money for implementation or enforcement, to which 57% of RAIT respondents agreed, and 28% disagreed. Critical services that are affected by reduced funding are often those that children and families need the most.

One Expert from Russia said that the cost to their government to institutionalize a child with disabilities is over $700 per child per month. Yet, if the child stays with the family, the government only pays the family $75 per child per month to offset expenses. This stipend given to families is drastically insufficient. If the government were to give the family 50% of the cost to institutionalize the child it would reduce the economic pressure on the family, save public money, and keep more children at home.

Financial Management

In several countries mismanagement and corruption prevent funding from reaching its intended recipients. Corruption in some governments and organizations was a concern expressed by Experts.

> "Diverting of funds…I know from personal experience that there really wasn't much desire to do anything. There was talk about doing things and there are a lot of photo opportunities, but nothing really happens."
>
> *Camille O'Reilly, Mexico*

> "One obstacle is the corruption and the political instability."
>
> *Dr. Awring Kadir, Iraq*

The consensus of Experts is that adequate and sustainable government funding, rather than a patchwork of provisional resources is necessary for both preventing disability and reducing its impact. This is necessary to truly address the needs for services for children with disabilities and their families. An additional positive factor includes increased collaboration among governments and the private and non-profit sectors.

9. INFORMATION EXCHANGE AND INTERNATIONAL COMMUNICATION

Experts discussed the need for more information about disabilities, the desire to learn about programs and services in other parts of the world, and modifying the successful practices of others to fit their situations. In spite of this desire, over 61% of RAIT respondents agreed that service providers are unaware of programs serving children with disabilities in other countries. Experts expressed eagerness to learn about programs, services and the issues that faced children and families elsewhere. Some Experts even suggested the creation of a centralized online database of disability related information that is easily accessible and organized in a user friendly format.

> "We should always study what happens elsewhere; not to copy, but to try to learn and to adapt it to our situations. Therefore, international communication and cooperation is absolutely necessary in a globalized world to really develop solidarity, support, ideas, knowledge, experience, you name it... Development of the internet can be of great importance to parents and children."
>
> *Yannis Vardakanstanis, Greece*

> "I would like to see a more established vehicle for information exchange. The more we know about how things are working in other areas, the more change can occur."
>
> *Debra Mayer, Canada*

The majority of Experts readily obtained information through the internet. In responding to the RAIT survey, over 77% of Experts agreed that the internet was an extremely useful tool for providers to get up to date information about effective programs and services for children with disabilities and 75% agreed that it was likewise useful for families. Furthermore, 98% of RAIT respondents indicated that they use the internet to seek out new information regarding disability descriptions, treatments, programs and services. Recent estimates report over 1 billion computers in the world, 1.8 billion internet users and over 3 million cellular phone sold each day; all of which continue to increase each year (Worldometers, 2010). Although not universally available, the internet and other computer-based technology holds great promise, as tools for information

Article 32, the UN CRPD (2006) recognizes the importance of international cooperation and communication, which have the potential to greatly improve the quality of life for children with disabilities around the world.

Creature Discomforts *(United Kingdom)*

Creature Discomforts is an awareness campaign from Leonard Cheshire Disability. The goal of this campaign is to change the way society views people with disabilities. The campaign includes various animations viewed on different media outlets. Each animation depicts actual experiences of people with disabilities. This unique approach teaches acceptance and that anything is possible with access to services and adaptive equipment.

More info: *creaturediscomforts.org*

dissemination and communication; providing immediate access with relative ease and low cost.

> "The internet is really important. In the last few years, we have improved the lives of people with disabilities because of the internet. We get information about other countries. We get information about the rights of people with disabilities. We can learn how people with disabilities are advocating for themselves. We get information about work being done around the world. Other countries have solved some of the problems. If they can do it, we can do it to. The internet is very important."
>
> *Delia Góngora, Argentina*

> "Knowledge spread through the internet has effectively disseminated information to those who need it most."
>
> *Dr. Helen McCabe, China*

> "I think it has had a profound effect...The internet has been a great advantage to we persons with disabilities and to children with disabilities."
>
> *Ron McCallum, Australia*

> "Why do a printed booklet when you can put it all on the internet?"
>
> *Stephanie Gotlib, Australia*

Experts discussed both the almost universal availability of the internet, and its absence in critical locations, especially in rural areas without electrical service. They also acknowledged that while the internet is a very valuable tool for families, many low income and isolated families lack both access to equipment and technical skills. Nearly 67% of RAIT respondents agreed that most families do not have access to the internet. However, with the availability of the internet rapidly expanding and the upsurge of its new users, tapping its worldwide potential for instant and direct communication and access to information is critical for children with disabilities, their families, and service providers.

Positive Influence of Programs from around the World

Another positive change includes the sharing of information among countries. Approximately 74% of Experts responding to the RAIT agreed that information about programs from other countries has positively impacted services in their country. With the continued expansion of the internet, there is quick access to massive amounts of information, including descriptions of various disabilities, disability organizations, and programs and practices that are having positive impacts in other countries.

Service providers also share information by accessing experts from other countries to provide instruction about effective methodologies.

> "We have a partnership with Partners of America who send down people to do training workshops. These kinds of situations can be a positive opportunity for people to visit and see what is out there and what is available. If people can bring in training that can be the biggest plus."
>
> *Jackie Butler, Antigua and Barbuda*

> "In the school where I am working, we have some support from international programs, which is very important to get more information for teachers because they can be trained about new technologies and new methodologies."
>
> *Paula Rubiolo, Argentina*

One Expert described how families working abroad are communicating what they learn to others in their homeland.

> "Thanks to the domination of Indians in the Global IT landscape over the past ten years,

> many Indian families moved to US, Australia and Europe for long term assignments abroad. They see how disability is treated in their respective geographies and try and pass this to their families back home. This is surely helping improve things back in India."
>
> *India*

Overall, sharing of information among countries brings about positive change for children with disabilities and their families. Models, best practices, and Programs of Promise with strong potential for successful implementation can be exchanged for the benefit of all. Utilizing current technology, such as the internet and distance learning strategies, exchange is accomplished immediately and cost effectively. Service providers, parents and children with disabilities are increasingly active partners in international information exchange.

10. UNITED NATIONS AND DISABILITY LAW

The United Nations (UN) plays an integral role in promoting the rights of children with disabilities throughout the world. When speaking about the United Nations, most Experts cited the critical impact of the UN's 2006 Convention on the Rights of Persons with Disabilities (CRPD) on these children and their families and the changes it is creating.

Arabic Rap Video *(Middle East)*

An Arabic rap song entitled *Difference is Natural* was commissioned by the Office of the Special Rapporteur on Disability in 2006. Performed by young persons with different types of disabilities and featuring a popular Arabic rap artist, this song is helping raise awareness of the abilities of persons with disabilities. A clip started airing on Arabic television stations devoted to pop music and popular youth culture in 2006.

More info: http://www.*youtube.com/ watch?v=ylFwcdNfVhE*

> "Slowly changes are coming. Argentina signed the Convention related to the rights of persons with disabilities from the United Nations. I think this is a big step to move forward."
>
> *Paula Rubiolo, Argentina*

Experts also discussed the influence of the United Nations in general on children with disabilities. Over 60% of RAIT respondents agreed about the UN's positive impact. Many attributed the UN's influence to the legal framework provided by the CRPD and UN support of non-governmental agencies.

> "UN agencies were also supporting the activities the [NGOs] were performing at that time. The UN played a big role."
>
> *Dr. Awring Kadir, Iraq*

While many laws protecting disability rights are in place, their enforcement is still lacking in several countries. The development of the UN's Standard Rules was based on knowledge gained during the Decade of Disabled Persons (1983-1992). The purpose of these Rules was to ensure that people with disabilities exercised the same rights and obligations as others. These Rules provide guidelines for increasing awareness, medical care, rehabilitation, support services, accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion (United Nations, 1994). The appointment of a Special Rapporteur to monitor the implementation of the Standard Rules was stipulated.

> "Revealed in the Global Survey, 12 years after the adoption of the *Standard Rules* no single country has yet succeeded in fully implementing them."
>
> *Hissa Al Thani, 2006*

In an ambitious attempt to assess the implementation of the UN's Standard Rules, a 2006 Global Survey was spearheaded by the former Special Rapporteur on Disability, Sheikha Hissa Khalifa bin Ahmed al-Thani, (Qatar) (South-North Center, 2006). The 2006 Global Survey concluded that while the intention to implement laws was in place, an overall lack of political support often resulted in poor enforcement. One Expert discussed barriers to implementation of disability policies.

> "Lack of awareness about their special necessities and failure to enact and follow policies that are implemented for their well being are the most important obstacles we face today. India falls short in implementation and in accountability of public funds devoted to disability, and lacks resources and strong monitoring mechanisms. Poor enforcement of the existing legislation means that disabled people in India continue to be discriminated against in terms of access to basic services and opportunities."
>
> *Dr. Chip Kingery, India*

Most Experts discussed multiple reasons for the slow implementation, including corruption and insufficient funds. In confirmation, almost 80% of RAIT respondents agreed that current laws and policies are not always put into practice, while 56% agreed that the laws are not enforced due to inadequate funding (28% disagreed and the remaining nearly 15% were undecided).

Overall, the consensus is that the United Nations has been extremely influential in many countries, especially those with little national disability policy. However, there is still much work to be done to ensure that once adopted, laws that positively impact people with disabilities are funded and enforced.

11. ENVIRONMENTAL AND SOCIOPOLITICAL FACTORS THAT IMPACT CHILDREN WITH DISABILITIES AND THEIR FAMILIES

While conducting research for Project CHILD, several circumstances and events that impacted prevalence of disability or services for children with disabilities emerged. Often they develop randomly or without warning throughout the world and result in multiple hardships for large populations of people, while in some instances they have been occurring throughout generations. Many of these events cause immediate injury or death, or environmental hazards and the spread of diseases that also culminate in trauma and lifelong disabilities. Those discussed by Experts include disaster, poverty, government instability, and armed conflict and violence.

> “When the ground shook in Port-au-Prince, Haiti, on January 12, the magnitude 7 earthquake left behind an estimated 4,000 to 6,000 instant amputees in a land where there’s little mercy for disability.”
>
> *Aleccia, 2010*

Disasters

Disasters, whether man-made or natural, cause huge upheavals in any country. Resources become scarce or are reallocated while all efforts focus, at least temporarily, on the rescue of survivors and the recovery of the deceased. Not only are many children disabled due to injuries as a direct result of disasters, but many suffer permanent disability as a result of the aftermath from malnutrition, infectious disease, and psychological trauma caused from witnessing such a traumatic event. Recent earthquakes in Haiti, Chile and China have brought attention to the devastation caused by natural disasters bringing about a greater awareness of both the effects of disasters on children with disabilities as well as disasters being a cause of acquired childhood disability.

> “‘[During 2004’s Hurricane Katrina in the United States] Disabilities were generally placed into one large category, without consideration for the unique needs associated with each type of disability. Emergency planners often decided what people with disabilities needed without consulting those people,’ the report by the National Council on Disability said. ‘This practice further alienated people with disabilities and increased their vulnerability during disasters.’”
>
> *Hudson, 2009*

Disasters often expose the lack of Disaster Response Plans contributing to unfortunate outcomes. Too often forgotten in disaster and crisis planning are people with disabilities who experience devastating consequences including death.

> “We are looking into that [disaster plan for persons with disabilities]. Here in the center, we are coming up with ideas on disaster management for persons with disabilities. We are planning on how we can go about it. With our experience [during 2009’s Typhoon Pepeng] what we need now is to have a plan.”
>
> *Philippines*

While disasters are devastating for the communities impacted, there are instances of unintended positive outcomes - increased services for people with disabilities. Rebuilding efforts provide a good opportunity to increase accessibility for persons with disabilities. Some Experts discussed how past disasters, causing increased numbers of people with acquired disabilities, resulted in public awareness and more funding for disability services.

> "This network of services has been developed in Armenia after the earthquake and with support of many countries. Quite good rehabilitation centers have been established in Armenia."
>
> *Susanna Tadyvosyan, Armenia*

> 20% of the world's poorest people are those with disabilities, who tend to be regarded in their own communities as the most disadvantaged.
>
> *United Nations Factsheet, 2006*

Poverty

Poverty is well documented as both a cause and consequence of disability. An estimated 80% of people with disabilities live in developing countries where poverty rates are high and people with disabilities are often the most disadvantaged. Due to added costs and limited financial support, families of children with disabilities in many countries are less likely to achieve as adequate a standard of living as families of typically developing children. If a family is on the verge of poverty, the costs of raising a child with a disability can force them into dire poverty, which then permeates every aspect of their lives. Living in poverty plays an unfortunate role in the lifelong outcomes of many children, particularly children with disabilities.

> Overall, poor prospects for education and employment combined with the intense stigma that people with disabilities often face will drive them in to poverty.
>
> *Braithwaite & Mont, 2008*

> "A very important issue is the number of children with disabilities and their families living in poverty."
>
> *Jaba Nachkebia, Georgia*

> "There is a high percentage of families who have a child with a disability and are in a very bad economic situation. This is mostly because of the child with a disability. The mother has to care for the child and she cannot go in labor market to find a job and make an impact in the family budget."
>
> *Dr. Vasilka Dimoska, Macedonia*

> "They are concerned about the health of their

> children, feeding their children and trying to keep them healthy."

Reninca Hill, Haiti

> "[Parents want] to find a surrounding with sufficient medical aid and nutrition because at home they are usually not able to provide these, especially for those who need special diets. Normally, the families are not capable of providing well-balanced nutrition to their children for the lack of financial means."

Paraguay

> "The poverty levels in our country are quite high and act as an obstacle for services for children with disabilities. It is very, very difficult, and sometimes you find that families are misinformed and others tend to have bigger family sizes. They produce a lot of children and can't cope with them."

James Mung'omba, Zambia

Families of children with disabilities who are living in poverty suffer greatly and often have little hope for the future. These children are often more disadvantaged than their peers due to lack of education and a low overall quality of life. With too few resources, and no universal education, families are forced to make impossible decisions such as choosing who among their children receives an education.

> "They [large families] have to choose who to send to school, and when it comes to that, a child with a disability is always the least considered."

James Mung'omba, Zambia

> "A lot of children come from very, very poor families and that may affect their ability to go to school...They [children with disabilities] are the first to drop out of school when the resources are not available at the family level."

Samuel Kabue, Kenya

> "In general the majority of African families, and particularly in Equatorial Guinea, are sixty to seventy percent poor. So, in order to integrate and respond to the needs of those that are disabled, families face financial difficulties and economic problems. Parents that are confronted with these economic problems "throw" away the disabled individual." [translated from French]

Equatorial Guinea

Parents are often separated while one parent strives to earn money to support their family.

> "Moldova has two specificities in the region. The first is incredibly serious poverty and second is incredibly high migration rates. There are estimates that more than thirty percent of the working population of Moldova is working abroad."

Moldova

Families in poverty have less access to affordable health care, clean drinking water, and adequate nutrition, with little knowledge about how to prevent or lessen the impact of disability.

> "One thing [that is a cause of childhood disability] is malnutrition and poverty... Malnutrition is a risk for all children with disabilities and also poverty; these are the main things."

Afroza Sultana, Bangladesh

Poverty intensifies disability. Consumed with acquiring the basic necessities for survival, parents combating extreme poverty are much less attentive to the higher order needs of their children. With economic stress on their family, parents are often forced to leave their children unattended while they focus on providing food, shelter and safety. Lack of parental supervision and nurturing also contributes to dismal outcomes.

> "I think that it's important to mention for Moldova the prevention of childhood injuries. The parenting styles are very outdated and the country's very poor. There seem to be extremely high rates of injuries and deaths among young children that are caused by lack of parental supervision; burns, falls, and these contribute to a higher rate of disability in Moldova than in the neighboring countries."

Moldova

> "I also have seen a couple of instances in rural areas where mothers who go to work feed children with hyperactivity and other

> disabilities milk mixed with sedative so that they are calm and sleep for long hours till mothers return back from work, which is a six to eight hour stretch.”
>
> *India*

Government Instability

Government instability and its impact on disability services emerged as a topic of discussion during Expert interviews. With governmental unrest, the continuation or expansion of services is uncertain. Also, drastic changes in a country’s government can result in temporary suspension of services.

> “We hope for the best, but the political situation in Romania is very fluid and if we were having this conversation one week ago probably my answer would have been different, but our government just resigned yesterday. So, you have a clear commitment one day and the next day you don’t know if all of the priorities will be adopted by the next government.”
>
> *Romania*

> “The big one has to be the fall of Communism, which resulted in the collapse of the existing services.”
>
> *Russia*

For every 1 child killed as a result of armed violence, 100 are left with permanent disabilities.

Office of the Special Rapporteur on Disability, 2007

Warfare, Armed Conflict and Violence

Government instability can lead to armed conflict or warfare, which greatly impacts the lives of all people including children with disabilities and their families. Instability often results in disruption or termination of services, while open conflict also causes an increase in the number of children and adults with disabilities.

> “The ongoing conflict means that things haven’t been stable and that disability is not a big priority for the government.”
>
> *Timor Leste*

> “Many of these disabled people are considered heroes because many in Palestine are suffering from disabilities due to the occupation… They can expect to be marginalized due to the occupation and siege. Even if we succeed to rehabilitate them at the end what is the

While violence and armed conflict lead to disability, persons with disabilities are also more likely to experience violence due to their disability.

Office of the Special Rapporteur on Disability, 2007

> future…We, as Palestinian people, have the ability to overcome many of the obstacles in our life because we are used to obstacles…We have more people with disabilities in the Gaza Strip…This changed the direction of services for disabilities because we have to focus on those newly disabled people.”
>
> *Mohammed Al Araeir, Palestine*

> “One child with Down Syndrome was 5 years old when the war started. He was at home with his family. Unfortunately, his home was bombed by a military airplane. He was killed with his father at the home. Fortunately, his sister, brothers and mother are still alive…He was receiving our services since he was born. He moved from step to step, from one program to another. He was one of the good children with Down Syndrome in the integration program in the kindergarten. One of the children in class with him was my daughter. When we started back to school my daughter went to her class. She missed him like her peers in class. The children were told by their teacher that he was killed in the war. She came home and tells me of his death. We began to communicate with his family after that and to help support his family.”
>
> *Mohammed Al Araeir, Palestine*

To flourish, all children need to live and grow in secure safe environments. However, many of the world’s children experience violence and conflict every day, permeating every aspect of their lives; threatening their well-being and resulting in disabilities for many.

Adding to the problem, during periods of conflict, immunization, prevention, and intervention programs are often suspended causing further disease, disability and death. A few Experts discussed how violence impacted disability in their respective countries.

> “I know a lot of people become disabled due to landmines that are still in the country.”
>
> *Angola*

> “At this time, Nepal is in a transition phase. We passed through the armed conflict but there are so many land mines remaining. And most of the survivors, children with disabilities, are

> not getting education. They are not getting better health service. So, these children with acquired disabilities, due to mine explosions, are the priority. There is no rehabilitation center. There is no means of continuing their education and they are much more deprived."
>
> *Birendra Raj Pokharel, Nepal*

> "I know many stories of families affected by disability, especially those living in the south of Lebanon with the violence from the Israeli war. You cannot imagine how fierce it was."
>
> *Dr. Moussa Charafeddine, Lebanon*

> "The El Salvador war left many people disabled and pushed the government to start helping people."
>
> *El Salvador*

There are many circumstances that impact children with disabilities and their families. Violence and conflict remain a leading cause of disability in many parts of the world. To decrease the impact of injuries, victims of violence and armed conflict need timely medical and effective rehabilitation services. Often, when nations and governments are faced with armed conflict and political strife issues like disability rights and services seem less important. All resources are redirected to support the war effort. However, when a country is in turmoil and the incidence of disability increasing, protection of disability rights becomes even more critical for children with disabilities and their families.

Unique Occurrences Around the World

When interviewed for Project CHILD, Experts discussed specific policies, beliefs, or practices that they thought were exclusive to their country. These specific beliefs affect a variety of socio-cultural nuances from overall view of disability to how services are delivered.

> "First of all, the family planning policy says that most couples should have one child. There are tons of exceptions and one of the exceptions is that if your first child has a disability, you can have a second child...What ends up happening is that some families choose to have a second child...However, it's really interesting because everyone else only has one child. So, this is really unique where Chinese families who have a child with a disability have it in their minds that this is their one child and so they work and work and put all their effort in fixing or changing this child and it takes them a long time to accept, number one, that their child is always going to have a disability, and number two, that they could have another child."
>
> *Dr. Helen McCabe, China*

> "We have a big problem with language in Lebanon. Parents teach their child either French or English before teaching Arabic, and for any child when faced with two to three languages you can expect a delay. So, you can imagine the difficulty faced by a child with a disability. We are an Arabic country, resources need to be made available in the native language."
>
> *Nada Khawaja, Lebanon*

While every region may have unique cultural beliefs about disability, those discussed were by Experts from Asia, Africa and the Middle East. While these circumstances may occur in other places; specifics regarding unique cultural beliefs on disability were not mentioned by Experts from other regions.

It is interesting to note that when Experts were asked to describe issues regarding childhood disability that are unique to their country, the majority of them struggled with the question and often replied that they did not believe there was anything unique about their country with regards to children with disabilities and their families. This reaction further highlights one of Project CHILD's key discoveries: In the arena of childhood disability there are many more similarities around the world than there are differences.

Children with disabilities and their families around the world share similar needs, hopes, fears and dreams for the future. These similarities offer a common ground for pursuing a mutual disability agenda on an international level.

ACTION STEPS AND CONCLUSION

Action Steps

1. Cultural Views of Disability

Cultural views about disability encompass the beliefs and values attributed towards people with disabilities, whether positive or negative. Specific beliefs impact how families raise children with disabilities, the types of services available, and anticipated lifelong outcomes for these children. Reported views of disability varied throughout the world and showed that all cultures held a range of beliefs. Although Experts acknowledged that attitudes toward disabilities were changing and becoming more positive, the majority of views and practices discussed during the Expert Interviews were negative, likely because most Experts were seeking change. Predominant negative views toward children with disabilities described by Experts were that having a child with a disability is a stigma, the child represents a punishment or curse on their family, and that they would always remain helpless and dependent. Many felt these negatives views resulted from a lack of current and accurate information, and limited social inclusion of children with disabilities.

Awareness and education are keys to fostering acceptance; changing negative beliefs about children with disabilities to viewing disability as a natural part of human existence. Efforts to increase public awareness about disabilities need to be expanded in most countries so that children and adults with disabilities are perceived as valuable members of society with similar needs and aspirations as others. While much has improved, more needs to be done to educate people about the causes and prevention of disabilities, and the rights of both children and adults with disabilities. With increased awareness and visibility of people with disabilities, many Experts noted dramatic improvements in attitudes and behavioral practices over the past 10 years. Those who would continue the momentum of positive change that is occurring need to:

1.1 Promote social inclusion in all aspects of life from the time a child is first identified with a disability through family awareness and support, followed by integrated and community-based childcare programs, high quality educational options, and social and recreational opportunities;

1.2 Enhance awareness, identification and access to treatment options by utilizing communication technology and media to educate the public about disabilities, including prevention, available services and portraying positive images; and

1.3 Increase the general public's knowledge about disabilities through the use of available technology such as radio, television, newspapers, internet, teleconferencing and text messaging, to cost-effectively educate people in diverse and remote locations.

2. Families of Children with Disabilities

Across cultures, the ideal family provides a place of safety and protection where every member, including those with disabilities, are valued and nurtured. However, with so many families around the world coping with multiple challenges such as poverty and the lack of basic necessities, having a child with a disability often exacerbates the situation beyond what the family can bear. Even with the best of intentions and love for a child, the added pressure associated with raising a child with a disability without adequate supports often leads to the breakdown of the family including, in some cases, pressure to institutionalize the child, neglect, abandonment or separation of the parents.

Information gathered during Project CHILD supported the many benefits a strong family has on raising a child with a disability, and the importance of providing families with the resources needed to keep families intact and increase their resiliency. Targeting specific services to meet the needs of both mothers and fathers leads to shared responsibilities and reduced strain on the family. The question of what will happen to the child with a disability when the parent dies or can no longer provide care, especially in cases where the disability is severe, is a constant source of anxiety for families throughout the world. Those who would strengthen families of children with disabilities in order to promote positive outcomes for both the family and child need to:

2.1 Provide financial assistance, respite care and plans for lifelong care to alleviate the stress on families and help ensure that more children with disabilities remain living with their family, in their homes and communities;

2.2 Implement inclusive intervention services that target the whole family, with specific services for parents, siblings, and the child with a disability; and

2.3 Allocate or redirect funding from supporting large residential institutions to family support and community-based residential and care alternatives.

3. Causes and Prevention of Disability and the Availability of Health Services

The worldwide need for disability prevention and health care services reverberated throughout Project CHILD. The limited availability and poor quality of health care and habilitation services for children with disabilities were key issues. Experts also discussed several preventable causes of disability including harmful prenatal practices and birth trauma, interfamilial marriage, and disease. Critical early diagnosis is not occurring in many regions and even where diagnostic services are available, inadequate referral systems prevent access to services and intervention. In cases where families are aware of services, the travel requirements and cost of services often remain insurmountable obstacles.

In many regions, Experts discussed the lack of current and accurate knowledge of medical professionals and other service providers and the subsequent negative outcomes of inaccurate diagnoses and inappropriate or nonexistent treatment plans. Related to this obstacle are the low numbers of trained professionals available to serve large populations in many areas. Without high quality, knowledgeable service providers even the best designed intervention programs fail. Those who would increase prevention efforts and improve health outcomes need to:

3.1 Concentrate on eliminating preventable causes of disability through raising awareness, education, and direct public health initiatives such as vaccination and clean water initiatives;

3.2 Establish outreach and referral networks that connect children and families with needed services consisting of partners such as hospitals, clinics, child care centers and schools to ensure that parents know where to go when they have a child with suspected disabilities;

3.3 Implement early screening procedures to identify various disabilities at onset or at the earliest age possible;

3.4 Extend services for early diagnosis of childhood disabilities to all areas of a country;

3.5 Develop decentralized service delivery and reallocate funds to rural communities to equalize access to services using itinerant staff, mobile clinics, and telecommunication in remote and sparsely populated areas;

3.6 Alleviate direct costs to families through stipends, supplements for travel and fees for services based on ability to pay;

3.7 Provide on-going professional development training for physicians and other service providers on disability related issues through continuing education programs, conferences and telecommunication; and

3.8 Increase efforts to recruit and retain knowledgeable direct service providers.

4. Education of Children with Disabilities

Education emerged as a multifaceted theme during discussions with the Experts. In addition to general concerns over the quality of education for children with disabilities, topics included early intervention, inclusive education, teacher preparation, and exclusion from school. While the importance of early educational intervention was almost universally recognized by the Experts, the lack of these services remains a concern for children around the world resulting in missed opportunity for critical skill development. Inclusive education, as a formal methodology, emerged as a topic of discussion by Experts in most regions of the world. However, many barriers to inclusion still need to be overcome, ranging from inaccessible school buildings to negative attitudes of both teachers and parents.

Other concerns focused on the poor quality of education for children with disabilities, the need for appropriate and relevant curriculum, and creating an adequate supply of well prepared teachers. Also, expectations for success of children with disabilities need to emphasize what a child can do rather than what they cannot do, thus increasing beliefs in the benefit of formal education. Those who would achieve quality education for all children with disabilities need to:

4.1 Ensure early intervention services for the child that occur in the child's natural environment and begin as early as possible;

4.2 Provide educational programs and access to school for all children with disabilities;

4.3 Offer parents the opportunity to choose the type of quality education they believe is best for their child whether inclusive education or specialized segregated education or some combination; while providing parents with the knowledge to make this decision;

4.4 Expand teacher preparation programs to insure an adequate supply of highly qualified teachers; and

4.5 Create and implement international standards for the education of all children.

5. Accessibility of Public Buildings, Transportation and Information

In every community there are physical barriers and obstacles that prevent children with disabilities from leading full and independent lives. Reports from all regions of the world noted that physically inaccessible buildings prevented many children with mobility and some sensory disabilities from attending school, receiving medical services, and participating in their communities. Traveling to needed services was also difficult or impossible due to inaccessible buses, trains, taxis, pedestrian walkways, private automobiles, and inadequate signage. Learning and communicating were hampered by unusable information sources such as books, television and the internet, which remain inaccessible for many people with disabilities. While a variety of assistive technology equipment and devices empower many people with disabilities with accessing both the environment and information sources, many more lack the opportunity to obtain necessary assistive devices.

Making high quality and meaningful lives possible for children with disabilities requires a multifaceted approach. Although some aspects are expensive, others can be achieved at a relatively low cost. Increased accessibility and barrier-free design not only benefit children with disabilities, but everyone in a community. Those who would ensure full inclusion for all need to:

5.1 Ensure that all children with disabilities receive an evaluation for potential use of assistive technology and accommodations that could increase their access to their physical communities, information sources and communication;

5.2 Implement standards of Universal Barrier Free Design in new construction and re-modeling existing buildings to meet these standards; consulting with people with disabilities in order to ensure that their needs are being met;

5.3 Provide barrier–free public transportation through accessible stations and vehicles;

5.4 Facilitate access to the environment by using such varying innovations as signs with universal symbols, Braille labels, ramps and curb cuts, and accessible restrooms; and

5.5 Disseminate information through media offering accommodations such as books in Braille, sign language interpretation and closed-captioning for television shows, news articles on the internet and adaptive technology for computer users with disabilities.

6. Transition to Adult Life

Most children with disabilities have dreams of independence and meaningful adult lives. Often transition between childhood and adulthood is stressful for the adolescent and their family. Parents are fearful about what independence will look like for their child as they see typically developing peers making employment, housing, relationship and other adult choices. Many experience shock when they realize that even in countries with well-developed services for children there are no mandated services for adults with disabilities. Parents and adolescents believe they have no place to go, no one to talk to, and nowhere to turn for help. Parents also face the challenge of balancing their maturing child's need for independence with parental instincts to keep their child safe.

Adult services entail specialized programs and supports that assist a person to pursue higher education, achieve employment, live independently, and participate in their community to the greatest extent possible. Some people need lifelong supports. Although independent living options are the goal for most youth, diverse cultures view independence in adulthood differently, such as living in multigenerational households. In more developed countries services are delivered through government agencies and non-profit organizations such as vocational rehabilitation, mental health services and centers for independent living. In less developed countries services for adults with disabilities may be non-existent. Actions to ensure a future of financial and social autonomy for children with disabilities as they reach adulthood need to:

6.1 Establish a user-friendly system of adult services that assists adolescents and young adults in their transition to employment and independent living to ensure their success to the greatest extent possible. Ideally services include assistance with access to and provision of supports for success in such varied areas as: higher education, vocational training, employment, housing, transportation, recreation, medical and psychological treatment, personal care attendant services, social relationships and community and political participation;

6.2 Create programs with safety nets that reasonably ensure the success of youth and adults with disabilities as they access life in their communities;

6.3 Develop a range of employment and vocational preparation options since earning a wage is so critical to independence;

6.4 Recognize the potential of children with disabilities and encourage opportunities for attaining higher education degrees when appropriate;

6.5 Build mentor programs where successful people with disabilities serve as role models and coaches for youth, as many children have little or no knowledge of the range of career and life possibilities they might achieve;

6.6 Involve people with disabilities in the planning of independent living programs, offering maturing children increased involvement in personal choices as they approach adulthood; and

6.7 Support the basic independent living tenet of people with disabilities, "Nothing About Us Without Us."

One specific concern expressed by Experts was limited education about human sexuality and sexually transmitted infections (STI) for children with disabilities. Lack of knowledge can lead to negative occurrences such as victimization, contracting STIs, or unintended pregnancies. Additionally, HIV and safe sex campaigns often fail to include young people with disabilities because of the misconception that they will not be sexually active, leaving many misinformed and vulnerable. More services are needed to ensure that relevant information about human sexuality and related issues are proactively taught and are in accessible formats for people with disabilities. Those who would increase education about human sexuality need to:

6.8 Include information about human sexuality and STI prevention in schools or health programs and certify instructors to effectively teach the content;

6.9 Provide human sexuality materials in accessible formats such as Braille, large print, closed captioning, sign language interpretation, movies and DVDs, and computer technologies; and

6.10 Safeguard girls and women with disabilities through education and laws that protect their rights as they are especially vulnerable to sexual exploitation.

7. Statistical Data on Disability Prevalence

The need for demographic and statistical data on disabilities including accurate counts of people with disabilities, causes, types, and severity resonated throughout discussions with Experts. Further, policy makers need to be accurately informed by reliable disability data to ensure adequate representation, appropriate budget allocations, and that interventions are effectively reaching intended populations. However, even where disability data are collected, accuracy is often disputed or in doubt. Regardless of these problems, creating a centralized archive of national level disability data for each country would aid in establishing a baseline for future comparisons for that country, region, and internationally.

Disabilities have no political boundaries. As a result, facilitating data documentation endeavors on an international level requires the cooperation of all nations. Such efforts need the assistance and sponsorship from national governments and large international organizations such as the World Health Organization or the United Nations. Utilizing sophisticated data management capabilities of diverse data sets is also necessary. Through the utilization of an international data system, analyses would become increasingly meaningful over time as trends regarding the status of people with disabilities were reported, monitored, and acted upon. Those who would implement national and international disability data systems need to:

7.1 Develop international standards for defining disabilities and measuring their prevalence in order to fully understand the magnitude of disabilities worldwide and the social and economic impact of related issues;

7.2 Include valid disability measures in the collection of national census data for all countries;

7.3 Calculate accurate counts by country of the international prevalence of disabilities, as well as data on disability types and levels of severity; and

7.4 Utilize international statistical data to combat the causes of disability, coordinate multi-national prevention efforts, and measure impact over time.

8. Funding for Disability Initiatives

Insufficient funding for disability initiatives was widely reported by Experts from around the world. An overall lack of resources for current programs, expansion of services, and implementing mandates exists everywhere. Many programs are now operating on reduced funds, thus jeopardizing the much needed and already scarce prevention and treatment services. Compounded by the current financial crisis that has slowed the world economy, providers are searching for alternative sources of financial support that are often non-existent. Also, financial mismanagement reported within some organizations and governments keeps funding from reaching those for whom it was intended. Those who would secure adequate funding need to:

8.1 Ensure continued government funding by allocating funds in support of current policies on disabilities;

8.2 Evaluate current expenditures and reallocate where possible to fund effective disability initiatives;

8.3 Diversify and create new funding sources through disability awareness campaigns, public education, political lobbying, and combining public, private, corporate, and faith-based funding;

8.4 Adhere to standard accounting procedures to provide transparency and guard against financial mismanagement; and

8.5 Seek international partners for cross border funding and disability collaborations.

9. Information Exchange and International Communication

The international sharing of information results in new knowledge about programs, services and successful interventions that can be modified to address unmet needs in other countries. With the emergence of the internet and its current 1.6 billion users worldwide, more information is now available and can be accessed faster than ever before. Service providers and parents can search for current disability information and effective treatment methods. Families can connect through disability support groups instantly. Providing access to the internet and related technologies for families and service providers of children with disabilities is critical in today's world.

While the importance of information sharing is stressed, barriers to exchange were also a recurring topic during Expert interviews. Disability information is often hard to locate, and adaptive computer equipment needed by some to access information can be more expensive than their computer. Also, access to the internet is not universal, especially in rural communities and for low income families. However, with the rapid expansion of technology and the internet, it is the most efficient way to connect those who want information about disabilities with those who have information about disabilities, and to communicate with the broader disability community. Those who would increase international communication exchange need to:

9.1 Increase the availability of adaptive equipment to make all forms of information and technology accessible;

9.2 Expand internet access to rural areas and low income families;

9.3 Develop worldwide internet communication systems that facilitate dialog through directly connecting people: family to family, child to child, service provider to service provider, and children to successful mentors with similar disabilities.

9.4 Create a user friendly international electronic database of information related to children with disabilities readily available through the internet. This database would include categories such as: disability descriptions, treatment options, programs that work, personal success stories, websites and email addresses of experts and organizations, research results, effective advocacy, future conferences, and interactive "chat rooms" generating dynamic dialog; and

9.5 Promote cross border sharing of information by using varied media outlets for families, teachers and health care providers to learn about intervention strategies from their counterparts in any part of the world.

10. United Nations and Disability Law

The influence of the United Nations' policies is evident in many countries, especially for promoting the rights of children and adults with disabilities. The UN's Convention on the Rights of Persons with Disabilities (CRPD) provides a legal framework for many countries that are working to improve the overall quality of life, human rights, and services for children and adults with disabilities. Several governments are amending their current laws and creating new policies to reach the goals set forth in the CRPD. Although in many countries the public will exists to enforce disability mandates, the funds are not available to do so. To ensure enforcement of policies, adherence to the CRPD or other framework, and to improve outcomes, countries need to:

10.1 Increase enforcement and provide funding for current laws and policies;

10.2 Conduct an international evaluation of disability laws and policies to assess the level of CRPD implementation on a periodic basis;

10.3 Share successes and barriers to implementation of disability laws and policies to provide guidance for struggling countries; and

10.4 Design an assessment that governments can utilize to self-monitor the current status of implementation and impact of their laws and policies, and measure change over time.

11. Environmental and Sociopolitical Factors that Impact Children with Disabilities and their Families

Factors that increase the prevalence of disabilities and reduce available services include disaster, poverty, government instability, and armed conflict and violence. These critical and far reaching events, especially natural disasters and acts of violence, often occur without warning and seemingly at random throughout the world. Others such as generational poverty and warfare are chronic in many countries. In all of these circumstances, disability and death rates dramatically escalate due to injuries, malnutrition, and the spread of disease, while resources become even more scarce.

Poverty is a well documented cause and consequence of disability. An estimated 80% of people with disabilities live in developing countries where poverty rates are high. In these countries, children with disabilities are among the most disadvantaged. However, families of children with disabilities in all countries are more likely to live in poverty, with less access to health care, disability services, adequate nutrition and education.

To flourish, all children need to live and grow in safe environments. However, countless numbers of the world's children experience disaster, hunger, disease and violence daily, too often resulting in disability and death. Countries and their communities need to mitigate the impact of these events, which disproportionately affect children, especially those with disabilities. Those who would reduce negative outcomes of environmental and socio-political events need to:

11.1 Create Emergency and Disaster Response Plans and prepare for disasters to the extent possible ensuring that people with disabilities are included in the planning process;

11.2 Include procedures in Emergency and Disaster Response Plans that protect the safety and ensure continuation of medical and social services to children with disabilities in times of upheaval;

11.3 Develop cooperative agreements between nations and international organizations that provide for emergency responses to prevent disabilities where natural disasters occur, such as the immediate provision of medical care, safe and sanitary housing, nutritious food, clean water and family reunification;

11.4 Address poverty worldwide through united proactive efforts and proven strategies to ameliorate its impact on children with disabilities; and

11.5 Support international peace efforts to reduce the incidence of violence, armed conflict, and warfare.

Conclusion

Countries around the world are making great strides in recognizing the rights of people with disabilities. In many of these countries, the United Nations plays an instrumental role in creating a legal framework that assists governments in developing or adopting policies which ensure the rights of their citizens with disabilities. Often, these policies are only applied to adults, as in many regions children are considered property having few, if any, rights while children with disabilities are legally invisible.

To learn more about children with disabilities around the world, Project CHILD's *Voices from Around the World* reached across national boundaries, conversing with those who work directly with these children and their families. What was discovered is that wherever these conversations occurred, when talking about children with disabilities and their families, there are more similarities than differences.

Upon having a child with a disability, families sought to understand, "Why?". They looked for explanations through the teachings of their culture, searched for assistance and information, and discovered or created solutions to their specific problems. Whether in Egypt or Argentina there emerged common bonds of caring coupled with intuitive problem solving. Families responded in creative and loving ways, trying to improve the lives of their children. These responses were sometimes unusual or seemingly strange to those of different cultures, but sincere nonetheless.

Discovered during Project CHILD and presented in *Voices from Around the World* are the experiences and knowledge of the 102 Experts interviewed, the Programs of Promise identified around the world, and stories of family resilience. Also apparent is that people around the world must engage, collaborate, teach and learn from one another if they are to remove barriers and improve the lives of children and families impacted by disability.

The answers to many questions and complexities of childhood disability can be found by facilitating conversations among parents, families and children with disabilities; service providers, teachers, physicians, policy makers and community members from all nations. Indeed, today's communication technology makes these conversations possible and information, even at the family-to-family level, increasingly accessible.

Project CHILD's *Voices from Around the World* seeks to continue the work of advancing the rights of persons with disabilities by facilitating this global dialogue. Great accomplishments have been achieved and the journey ahead is ours to embrace.

UNITED NATIONS TIMELINE

United Nations established	1945	
	1948	Universal Declaration of Human Rights
Declaration on the Rights of the Child	1959	
International Covenant on Civil and Political Rights	1966	International Covenant on Economic, Social and Cultural Rights
	1969	Declaration on Social Progress and Development
Declaration on the Rights of Mentally Retarded Persons	1971	
Declaration on the Protection of Women and Children in Emergency and Armed Conflict	1975	Declaration on the Rights of Disabled Persons
	1981	International Year of Disabled Persons
World Programme of Action	1982	
	1989	Convention on the Rights of the Child
Tallinn Guidelines for Action on Human Resources Development	1990	
	1991	Principles for the protection of Persons with Mental Illness and the Improvement of Mental Health Care
Vienna Declaration	1993	Standard Rules on the Equalization of Opportunities for Persons with Disabilities
Mr. Bengt Lindqvist appointed Special Rapporteur on Disability	1994	
Beijing Declaration	1995	Copenhagen Declaration
	2000	United Nations Millennium Declaration
Sheikha Hissa Khalifa bin Ahmed al-Thani appointed Special Rapporteur on Disability	2003	
	2006	Convention on the Rights of Persons with Disabilities (CRPD)
CRPD entry into force	2008	
	2009	Mr. Shuaib Chalklen appointed Special Rapporteur on Disability

INTERVIEW QUESTIONS

Project CHILD
Children and the International Landscape of Disabilities

1. Overall, how would you describe in general the services to children with disabilities in your country?
2. In your opinion what are the three biggest priorities for children with disabilities?
3. How are children with disabilities viewed in your country?
4. What future can a child with disabilities expect in your country?
5. What past events in your country have changed the direction or scope of services to children with disabilities?
6. What changes, if any, are occurring now?
7. Please describe the major laws or policies that impact the delivery of services for children with disabilities.
8. In your opinion what are the key obstacles to delivery of services for children with disabilities?
9. What is going particularly well in the delivery of services for children with disabilities?
10. How are services delivered to children with disabilities?
11. What issues are parents of children with disabilities the most concerned about?
12. What issues should research and program evaluation address?
13. Who provides services to children with disabilities in your country and how are they funded?
    a. Does the Government provide funding for programs?
        i. Religion / Faith-based
        ii. Non-Governmental Organization
        iii. Foundation / Charities
        iv. Corporate
        v. Other
        vi. Combination of any of the above
14. What programs for children with disabilities would you really like to implement?
15. Describe some issues regarding childhood disability that are unique to your country.
16. How has the internet influenced advocacy for children with disabilities in your country?
17. Can you tell me about “one family’s story”?
18. How could the quality of services for children with disabilities be improved through international communication and cooperation?
19. Who else could I talk with about childhood disabilities?
20. What else would you like to add, that I haven’t asked?

KEY INFORMANT CONSENT FORM

Project CHILD
Children and the International Landscape of Disabilities

A. Purpose

The Public Policy Research Institute at Texas A & M University and the Doha International Institute for Family Studies and Development are conducting a study of the status and needs of families of people with disabilities around the world. The reason for this interview is to learn about the best practices, programs, and policies that exist regarding this issue. We are asking you to participate in this interview because you may be able to provide us with valuable information that can be included in this study.

B. Procedures

If you agree to be interviewed, this is what will happen.

1. During the interview, a staff member will ask you questions about the following issues:
    a. current status of identification, treatment, and impact of policy on families of people with disabilities;
    b. cultural and national responses to families of people with disabilities including their identification, treatment and opportunities for assistance, types of assistance needed and available, educational provisions, and situational impacts of varying policies upon the families of people with disabilities;
    c. Programs of Promise and best practices regarding disabilities and family policy;
    d. other potential study participants
2. Notes from the interview will be recorded on paper and/or audio.
3. You can refuse to answer any question at any time. If you do not answer a question or want to end the interview there will not be any penalty to you.

The interview is completely confidential if you so desire. Or you may waive confidentiality and have your responses to questions attributed to you. At the beginning of your interview, you will be informed that your responses can remain confidential. At the end of your interview you will be asked if you want to retain or waive confidentiality. Your response will be documented by the interviewer.

C. Discomforts and Risks

There are no physical risks to you by participating in this interview.

D. Benefits

There are no direct benefits by being in this interview. The information you give us may help us have a better study.

E. Compensation

You will not be paid for the time you spend taking part in the interview.

F. Persons to Contact

This study is run by Dr. Charles D. Johnson at the Public Policy Research Institute (PPRI) at Texas A&M University, at 979-845-8800. You may call him with any questions about being in the study.

The research study has been reviewed and approved by the Institutional Review Board – Human Subjects in Research, at Texas A&M University. If you have questions about your rights as a participant or if you feel that you have been harmed, or for research related problems or questions regarding subjects rights, the Texas A & M Institutional Review Board may be contacted through Angelia Raines, Director of Compliance and Administration, Office of the Vice President for Research at (979) 458-4067 or by email at araines@vprmail.tamu.edu.

G. Confidentiality Statement

What you tell us is confidential unless you indicate to research staff you want to waive confidentiality. If you waive confidentiality your responses may be directly and publicly attributable to you. If maintaining confidentiality is desired, no one except the study staff at the Public Policy Research Institute, Texas A&M University, will have access to your comments, except as otherwise required by law. Furthermore, if confidentiality is desired, any comments made by you will not be attributed to you as an individual but to the collective group of individuals we interview as a whole.

H. Right to Refuse or Withdraw

Doing this interview is VOLUNTARY. You have the right to refuse to answer any questions. You can end the interview at any time you want.

I. Agreement

Do you have any questions?

INITIAL E-MAIL TO EXPERTS

Dear (Insert name of Expert),

I am working on a project called Children and the International Landscape of Disabilities (Project CHILD). This study is a research project to learn more about various cultural and national policies and responses to families of children with disabilities. I got your contact information from (insert information) and believe that you could provide valuable information to Project CHILD on the status of children with disabilities in the (insert name of country).

Project CHILD is sponsored by the Doha International Institute for Family Studies and Development and being implemented by the Public Policy Research Institute at Texas A&M University. We want to request your participation in a telephone or e-mail interview. In this session I will ask questions to elicit responses and discussion concerning families of children with disabilities and their identification, treatment and opportunities for assistance, types of assistance needed and available, educational provisions, and situational impacts of varying policies on families of children with disabilities. We are trying to identify views of children with disabilities around the world as well as report on best practices and Programs of Promise.

The information you give us will be used to help generate an international policy perspective on families of children with disabilities. We also ask that you do the interview because your answers are important, and could help other scholars, policy makers, and families of children with disabilities. Questions will be about your expert knowledge and experience in the field of disabilities. Participation in the interview will take no more than two hours.

If you are interested in participating, I will send you the list of questions we ask so you can look them over prior to the interview. Then, just let me know a time that is most convenient for you and a phone number to reach you at. I hope that you will consider participating as I believe your insight will be valuable to Project CHILD. I look forward to hearing from you.

If you have questions about Project CHILD, please call (insert name of Research Associate), Research Associate, at (insert phone number) or email (insert e-mail address)

Thank you for all the work that you do for people with disabilities and their families.

Sincerely,

FOLLOW-UP E-MAIL TO EXPERTS

Dear (Insert name of expert),

I just wanted to follow up from the e-mail I sent last week about participating in an interview for Project CHILD. I have attached the questions and consent form if you would like to look them over. If you are able to participate, just let me know some days/times that you are available and a phone number to use and I'll call then. I've copied my original e-mail to you below for your reference.

Best Regards,

EXPERT INTERVIEW PARTICIPANTS

Albania

- Confidential

Angola

- Confidential

Antigua and Barbuda

- Jackie Butler, Adele School for Children with Special Needs

Argentina

- Beatriz Zoppi, Regional Office for Latin America - Perkins International - Perkins School for the Blind
- Delia Góngora, 505 Special School - Moreno - Buenos Aires
- Graciela Ferioli, Perkins School for the Blind
- Paula Rubiolo, Special Educator

Armenia

- Susanna Tadyvosyan, Bridge of Hope

Australia

- Confidential
- Glenda Alexander, Vision Australia
- Margaret Verick, National Disability Services
- Maryanne Diamond, World Blind Union and Vision Australia
- Ron McCallum, University of Sydney, Vision Australia and UN Convention on the Rights of Persons with Disabilities Monitoring Committee (2010 Committee Chair)
- Stephanie Gotlib, Australian Association for Families of Children with a Disability

Bangladesh

- Afroza Sultana, Bangladesh Protibondhi
- Ferdausi Moula, Bangladesh Protibondhi
- Romela Murshed, Bangladesh Protibondhi

Brazil

- Maria Aparecida Cormedi, Associacao para Deficienties da Audio Visao

Burundi

- Bakary Sogoba, UNICEF

Cambodia

- Confidential

Cameroon

- Ondoua Abah Gabriel

Canada

- Debra Mayer, SpeciaLink - the National Centre for Child Care Inclusion
- Confidential

China

- Dr. Helen McCabe, The Five Project, Inc. (USA/China)
- Zhaoyang Chi, Graduate Student - Syracuse University
- Confidential
- Confidential
- Confidential
- Confidential

Costa Rica

- Confidential

Denmark

- Stig Langvad, Disabled Peoples Organization Denmark

Egypt

- Confidential

El Salvador

- Confidential

Equatorial Guinea

- Confidential

Ethiopia

- Mesfin Taye

Finland

- Aimo Stromberg, Finnish Cerebral Palsy Association, International Cerebral Palsy Society

Georgia

- Jaba Nachkebia, Children of Georgia
- Keti Melikadze, First Step Georgia
- Natia Partskhaladze, UNICEF
- Tako Tavartkiladze, Save the Children Georgia

Ghana

- Jude Domosie, CURE Clubfoot Ghana

Greece

- Yannis Vardakastanis, President of the National Confederation of Disabled People (NCDP) - Greece and also President of the European Disability Forum (EDF)

Haiti

- Reninca Hill, House of Blessings

India

- Dr. Chip Kingery, Joni and Friends International Disability Center in Southern California in sync with the ministry of proVISION ASIA in Bangalore, India
- Confidential

Indonesia

- Confidential

Iraq

- Dr. Awring M. Kadir, Teaching Children Rehabilitation Center Sulaymania (TCRC)

Ireland

- James McClean, People with Disabilities in Ireland

Italy

- Luisa Bosisio, Consiglio Nazionale sulla Disabilità

Jordan

- Mohammed Tarawneh, UN Convention on the Rights of Persons with Disabilities Monotoring Committee (Former Chair)

Kenya

- Agnes Kisila, Kenyan Society for Deaf Children
- Confidential
- Confidential
- Joseph Ayieko, Kenya Ear Foundation
- Samuel Kabue, Ecumenical Disability Advocates Network

Kuwait

- Rana F. Nasser, Psychologist - The Kuwaiti Society for Guardians of the Disabled

Lebanon

- Dr. Moussa Charafeddine, Friends for Disabled
- Nada Khawaja, author and Special Education teacher

Macedonia

- Confidential
- Fulvia V. Tomatis, Social Inclusion Program, EducAid, Italy
- Slobodanka Zdravkovska Lazova, Ministry of Labor and Social Policy
- Dr. Vasilka Dimoska, Republic Centre for Support of Persons with Intellectual Disability
- Vesna Samojlovska, Institute for Social Activities

Mexico

- Bree Lair, Push International
- Camille M. O'Reilly, Child Family Health International
- Jamie Rau, Divertigranja
- Confidential

Moldova

- Confidential

Nepal

- Birendra Raj Pokharel, National Federation of the Disabled-Nepal

Netherlands

- Johannes Verheijden, BOSK, Association of Physically Disabled Persons and their Parents

Nigeria

- Paul Caswell, CBM

Palestine

- Mohammed Al Araeir, Right to Live Society

Paraguay

- Cyle Nielsen, Pastoral del Nino
- Confidential
- Confidential

Peru

- Maria Graciela Laynes Valdivia, Hellen Keller Peru Association

Philippines

- Confidential

Qatar

- Sameera ALQassimi, Shafallah center for children with special needs

Romania

- Confidential

Russia

- Sarah Hagnauer, Camphill Svetlana
- Confidential
- Confidential

Saudi Arabia

- Maha Al-Juffali, Help Center for children with Intellectual Disabilities, Jeddah, Saudi Arabia

Slovakia

- Slovak Disability Council:
    - Iveta Mišová, Miroslava Petrovičová, The Association for Help to People with Mental Handicap in the SR (ZPMP in SR), in collaboration with Mária Šustrová, Eva Števková, Ľubica Vyberalová and Terézia Semaňáková;
    - Mária Benková, Slovak Association of the Deaf (Aneps);
    - Mgr. Iris Domancová, PhD, National Institute for Education; and
    - Zuzana Gecziova, Special Educator
- Mgr. Mária Duračinská, Organization of Muscular Dystrophy in the Slovak Republic

South Africa

- Confidential
- Confidential

St. Lucia

- Lancia Isidore, National Council of & for Persons with Disabilities (NCPD)

Thailand

- Wilaiporn (Kae) Kotbungkair, Graduate Student - Michigan State University

Timor Leste

- Confidential

Tunisia

- Dr. Mongi Ben Hammouda, The Tunisian Union for Intellectual Disability UTAM - Elmay Branch

United Kingdom

- Peter Farrell, Manchester University

United States of America

- Confidential
- Elizabeth W. Bauer, Member, Michigan State Board of Education
- Miriam Roman, Early Childhood Intervention
- Duncan Wyeth, Department of Energy, Labor and Economic Growth, Michigan Commission on Disability Concerns

Uzbekistan

- Confidential

Zambia

- James Mung'omba, Inclusion International

RAIT CONFIRMATION SURVEY INVITATION E-MAIL

Dear [Participant Name]

I would like to thank you again for participating in an interview for Project CHILD. To date, we have interviewed approximately 90 people in 50 different countries around the world and have learned so much. Through these interviews, we have been able to identify several common themes related to children with disabilities and have created a survey to measure the importance of these themes. Please take a few moments to respond to the electronic survey and rate the items according to how strongly you agree or disagree with each statement. The survey will allow us to hone on the most common themes in childhood disability around the world and the quantitative data collected through the survey will enhance the already rich qualitative data provided by the interviews.

All responses to the survey will be treated with confidentiality and anonymity. Only key staff members will have access to individual responses and they are pledged to protect individual identities.

The survey process has been greatly streamlined from prior years. Simply click with your mouse on http://projectchild.tamu.edu. The survey takes about 15-20 minutes, and your participation is greatly appreciated. This is a great opportunity to voice your opinion.

Your ACCESS CODE to the Project CHILD website is [Code]

The purpose of the LOGIN is to insure that only invited participants have access to the website. The LOGIN only notes whether you have taken the survey, so that we may send reminders to those who need them, and not bother people who have already taken the survey.

Thank you for your participation. Click on http://projectchild.tamu.edu and begin.

Sincerely,

Project CHILD Research Staff

RAIT PARTICIPANT DESCRIPTIVES

Total Invited 96

Total Respondents 54

Regions Responding		**Percent**	**Disability Served**		**Percent**	**Gender**		**Percent**
North America	5	9%	All	29	54%	Female	37	69%
Europe	10	19%	All/Children	13	24%	Male	17	31%
Middle East/North Africa	11	20%	Autism	1	2%			
Central America	3	6%	Children/Blind	1	2%			
South America	5	9%	Cerebral Palsy	1	2%			
Asia	13	24%	Club Foot	3	6%			
Oceania	1	2%	Hearing	2	4%			
Africa	6	11%	Intellectual	3	6%			
			Vision	1	2%			
Totals:	54	100%		54	100%		54	100%

Expert Type		**Percent**	**Type of Agency**		**Percent**
Advocate	18	33%	Government	9	17%
Advocate/Practitioner	29	54%	NGO	32	59%
Researcher	1	2%	NGO/Faith-Based	4	7%
Advocate/Practitioner/Researcher	2	2%	NGO/Gov't/UN	1	2%
Advocate/Policy	1	2%	NGO/Private	1	2%
Practitioner	1	2%	Private	2	4%
Advocate/Researcher	2	4%	University	4	7%
			N/A	1	2%
Totals:	54	100%		54	100%

Appendix I

RESEARCH ANALYSIS INTERVIEW THEME (RAIT) CONFIRMATION

	Strongly Agree	*Agree*	*Undecided*	*Disagree*	*Strongly Disagree*
Early Intervention: In my country...					
1. Disabilities in children are not identified early enough.	21[38.89%]	20[37.04%]	7[12.96%]	6[11.11%]	0[0%]
2. Services for infants and young children are lacking.	21[38.89%]	24[40.74%]	3[5.56%]	8[14.81%]	0[0%]
Education: In my country...					
3. Schools do not include children with disabilities in the regular/general education classroom.	8[14.81%]	24[44.44%]	4[7.41%]	14[25.93%]	4[7.41%]
4. There are not enough specially trained teachers for children with disabilities.	22[40.74%]	24[44.44%]	5[9.26%]	3[5.56%]	0[0%]
5. The quality of education for children with disabilities is not adequate.	22[40.74%]	17[31.48%]	5[9.26%]	10[18.52%]	0[0%]
6. Many children with disabilities do not attend school.	21[38.89%]	16[29.63%]	5[9.26%]	7[12.96%]	5[9.26%]
Accessibility: In my country...					
7. Physical access to buildings is a big problem.	19[35.19%]	25[46.3%]	6[11.11%]	4[7.41%]	0[0%]
8. Public transportation is not accessible to persons with physical/mobility disabilities.	30[55.56%]	17[31.48%]	2[3.7%]	4[7.41%]	1[1.85%]
Transition to adult life: In my country...					
9. Transition services from secondary school to adult life are not adequate.	32[59.26%]	19[35.19%]	0[0%]	3[5.56%]	0[0%]
10. There are few/no vocational training opportunities available for youth with disabilities.	14[25.93%]	26[48.15%]	4[7.41%]	10[18.52%]	0[0%]
11. There are few/no adult services to assist young adults.	16[29.63%]	24[44.44%]	7[12.96%]	7[12.96%]	0[0%]
12. Higher education (University) is not encouraged for most persons with disabilities.	17[31.48%]	20[37.04%]	4[7.41%]	11[20.37%]	2[3.7%]
Health Care/Rehabilitation Services: In my country...					
13. Children with disabilities do not have access to adequate habilitation or rehabilitation services.	11[20.37%]	26[48.15%]	1[1.85%]	12[22.22%]	4[7.41%]

	Strongly Agree	*Agree*	*Undecided*	*Disagree*	*Strongly Disagree*
14. Children with disabilities do not have access to adequate general health/medical services.	4[7.41%]	26[48.15%]	4[7.41%]	13[24.07%]	7[12.96%]
15. Medical doctors do not have current information about disabilities.	11[20.37%]	18[33.33%]	10[18.52%]	12[22.22%]	3[5.56%]
16. There is a great disparity between services in rural versus urban areas, with few services available to children with disabilities in rural areas.	28[51.85%]	22[40.74%]	1[1.85%]	1[1.85%]	2[3.7%]
17. The cost of rehabilitation services is too much for most parents to pay.	17[31.48%]	20[37.04%]	4[7.41%]	10[18.52%]	3[5.56%]
18. Parents are not aware of available services.	11[20.37%]	23[42.59%]	11[20.37%]	9[16.67%]	0[0%]
19. It takes a long time for children with disabilities to get the assistive devices they need.	18[33.33%]	18[33.33%]	7[12.96%]	11[20.37%]	0[0%]
Statistics: In my country...					
20. Reliable and valid statistics on disability prevalence are not available.	20[37.04%]	20[37.04%]	4[7.41%]	7[12.96%]	3[5.56%]
Cultural Views/Attitudes: In my country...					
21. Having a child with a disability is a stigma.	12[22.22%]	25[46.3%]	10[18.52%]	6[11.11%]	1[1.85%]
22. Attitudes toward people with disabilities have become more positive over the last 10 years.	11[20.37%]	35[64.81%]	4[7.41%]	2[3.7%]	2[3.7%]
23. Children with intellectual/cognitive disabilities have fewer opportunities than those with other types of disabilities.	13[24.07%]	24[44.44%]	10[18.52%]	5[9.26%]	2[3.7%]
24. Many people regard having a child with disabilities as a punishment or curse.	4[7.41%]	23[42.59%]	14[25.93%]	7[12.96%]	6[11.11%]
25. Many people believe children with disabilities are helpless and will always be dependent.	15[27.78%]	23[42.59%]	10[18.52%]	3[5.56%]	3[5.56%]
26. Children with disabilities are pitied.	11[20.37%]	31[57.41%]	6[11.11%]	5[9.26%]	1[1.85%]
27. Disability assistance is seen as a charity issue.	14[25.93%]	20[37.04%]	9[16.67%]	9[16.67%]	2[3.7%]

	Strongly Agree	*Agree*	*Undecided*	*Disagree*	*Strongly Disagree*
Social Inclusion: In my country...					
28. Children with disabilities are more visible in the community than in previous years.	5[9.26%]	34[62.96%]	11[20.37%]	4[7.41%]	0[0%]
29. Many children with disabilities are kept hidden at home.	8[14.81%]	21[38.89%]	10[18.52%]	8[14.81%]	7[12.96%]
30. There are very few opportunities for children with disabilities to have fun with other children in the community.	16[29.63%]	25[46.3%]	4[7.41%]	9[16.67%]	0[0%]
Family: In my country...					
31. A strong family is an important variable in positive outcomes for a child with a disability.	36[66.67%]	16[29.63%]	2[3.7%]	0[0%]	0[0%]
32. Having a child with disabilities is a huge strain on the family.	20[37.04%]	27[50%]	3[5.56%]	3[5.56%]	1[1.85%]
33. Parents of children with disabilities need more support than they are getting now.	33[61.11%]	20[37.04%]	1[1.85%]	0[0%]	0[0%]
34. The greatest concern of parents of a child with a disability is "Who will care for my child when I die, or can no longer care for him/her?"	29[53.7%]	19[35.19%]	4[7.41%]	2[3.7%]	0[0%]
35. Families need access to training on learning how to be a successful advocate for their child.	30[55.56%]	21[38.89%]	2[3.7%]	1[1.85%]	0[0%]
36. There is pressure from society for parents to put their child with a disability in an institution.	3[5.56%]	7[12.96%]	16[29.63%]	18[33.33%]	10[18.52%]
37. Parents are very concerned about the education of their child with a disability.	15[27.78%]	28[51.85%]	6[11.11%]	5[9.26%]	0[0%]
38. It is necessary for parents to be strong advocates for their child with a disability.	41[75.93%]	12[22.22%]	1[1.85%]	0[0%]	0[0%]
Funding: In my country...					
39. Government/public funds do not provide sufficient financial support to families of children with disabilities.	23[42.59%]	21[38.89%]	4[7.41%]	3[5.56%]	3[5.56]%]
40. Disability services are not a priority for government or public funding.	19[35.19%]	19[35.19%]	4[7.41%]	7[12.96%]	5[9.26%]

	Strongly Agree	*Agree*	*Undecided*	*Disagree*	*Strongly Disagree*
41. Services for children with disabilities are funded by NGOs, charities or churches (without government assistance).	7[12.96%]	16[29.63%]	9[16.67%]	15[27.78%]	7[12.96%]
42. There is an overall lack of funding for disability programs.	18[33.33%]	20[37.04%]	3[5.56%]	10[18.52%]	3[5.56%]
43. Policies/laws are not put into effect due to a lack of funding or resources.	14[25.93%]	17[31.48%]	8[14.81%]	14[25.93%]	1[1.85%]
International Communication: In my country...					
44. Most families do not have access to the internet.	17[31.48%]	19[35.19%]	4[7.41%]	8[14.81%]	6[11.11%]
45. The internet is a useful tool for families of children with disabilities to get information.	17[31.48%]	24[44.44%]	7[12.96%]	3[5.56%]	3[5.56%]
46. The internet is a useful tool for service providers of children with disabilities to get information.	20[37.04%]	24[44.44%]	7[12.96%]	2[3.7%]	1[1.85%]
47. Providers are not aware of programs used to work with children with disabilities in other countries.	9[16.67%]	24[44.44%]	7[12.96%]	13[24.07%]	1[1.85%]
48. Information about programs from other countries has positively influenced services for children with disabilities.	9[16.67%]	31[57.41%]	9[16.67%]	4[7.41%]	1[1.85%]
United Nations/Major Laws: In my country...					
49. The 2006 United Nations Convention on the Rights of Persons with Disabilities has had significant impact on laws and policies.	6[11.11%]	17[31.48%]	19[35.19%]	7[12.96%]	5[9.26%]
50. Major laws and policies for persons with disabilities were put in effect prior to the 2006 United Nations Convention on the Rights of Persons with Disabilities.	5[9.26%]	19[35.19%]	18[33.33%]	10[18.52%]	2[3.7%]
51. The 1981 International Year of Disabled Persons brought about more awareness of persons with disabilities.	6[11.11%]	23[42.59%]	18[33.33%]	6[11.11%]	1[1.85%]
52. The United Nations has had a significant positive impact on laws and/or policies for people with disabilities.	9[16.67%]	23[42.59%]	15[27.78%]	5[9.26%]	2[3.7%]
53. There are many positive laws/policies, however, they are not always put into practice.	20[37.04%]	22[40.74%]	6[11.11%]	6[11.11%]	0[0%]

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