

Research Summary

Quality of Life for Children with Long-Term Disabilities



Instrument Development and Validation

March 15, 2001 to December 31, 2004

December, 2004

Research Summary of the Children's Quality of Life Project

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Background and Purpose the Project

Quality of life is a major concern for children (3 to 12 years old) with developmental disabilities and delays, and for their families. Therefore, it is important to understand what makes for a good quality life for this group of children. Once we understand what makes life good (or not so good) for this group, an assessment can be done to see what is good and not so good for an individual child and how his/her quality of life can be improved and/or supported, as needed.

Except for information related to children's physical and cognitive abilities and disabilities, there is not much information about quality of life for this group of children available from research studies. However, parents and some professionals have expressed the need to know more about quality of life issues that are related to everyday living and how to assess these in a family-centred and meaningful way. Some examples of everyday living issues for this group of children are: involvement in community activities and the availability of community based-programs and resources as well as having opportunities to play regularly with peers with and without disabilities and to make friends with other children.

Goals of the Project

Since the purpose of this project was to address the expressed need to know more about quality of life for this group of children, the major goals of the project were to:

1. Develop a new conceptual framework of quality of life for children aged 3 to 12 years, who have developmental disabilities and delays, based on the perspectives of their parents. This framework would provide a way of understanding what makes life good and not so good for this group of children.
2. Develop a new instrument to assess quality of life for this group of children, from the perspective of their parents, based on this new conceptual model. This instrument could be useful to parents, professionals, community-based organizations providing developmental services, researchers, and policy makers.
3. Test this new instrument in order to evaluate its soundness and usefulness for parents, professionals, and others.

Participants and Their Children

Parents who participated in all phases of this research came to know about this study through the research team's contacts with more than 50 community based organizations providing services and/or education related to developmental disabilities. Most lived in and around the Greater Toronto area (GTA), however, some lived in areas further outside of the GTA. Participants included birth, foster, and adoptive parents, as well as kinship carers (e.g., grandparents), of children aged 3 to 12 years. Parents came from a wide range of backgrounds that were diverse in terms of culture, race, income and financial resources, education, employment, geographical place of residence (i.e., from cities and rural areas). Thirty parents participated in in-depth face-to-face interviews in the first phase the research which led to the development of the conceptual framework and the new Instrument. In addition, 186 parents took part in the study that tested the new instrument by completing telephone interviews.

The children of the parents who participated experienced a range of developmental delays and disabilities. Some of the children presented with multiple disability issues (i.e., developmental, physical, sensory, mental health, other). The variety and number of diagnoses reported suggest that many of the children would appear to have very complex presentations and multiple challenges. A single diagnosis of developmental disability was rare. Examples of the many diagnoses for the children included: Autism, Pervasive Developmental Disorder, Down syndrome, Fetal Alcohol syndrome, Fragile X, Asperger's syndrome, Cerebral Palsy, brain injury, and neurological disorders.

All participating parents were informed about the details of the study and signed a consent form before they took part. All the materials, procedures, and forms used in the project received ethical approval from the University of Toronto and also from individual participating community organizations that had their own ethics review panels.

The Research Team

The research team was based at the University of Toronto and included parents of children with developmental disabilities as well as researchers and professionals from various backgrounds (e.g., education, special education, neuro-developmental medicine, occupational therapy, psychology, and social work). The names of the team members are listed near the end of this research summary. Since parents were active members of the team from the beginning to the end of the project, they were at the forefront of the research at all stages of the research.

The New Conceptual Framework

Fundamental Principles

Analysis of the interview data provided by the 30 parents participating in the first phase of the research, revealed a number of basic principles that form the foundation of the new conceptual framework (or model). Various aspects of quality of life for children in 3 different age sub-groups (3 to 5, 6 to 8, and 9 to 12 years) were essentially the same. However, based on information from participating parents, different aspects of quality of life seem to have greater or lesser emphasis at different times in children's lives. For example, sharing good relationships with peers is more important for a 12-year-old than for a 3-year-old. Also, the child's identification as a child with a disability quite often assumes greater importance as the child enters the school system.

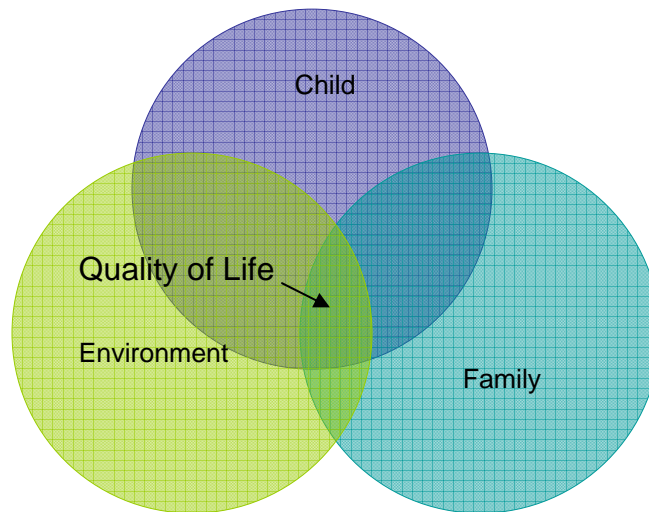
A second underlying principle is that parents see the child's quality of life and her/his family's quality of life as highly interconnected – what is good (or bad) for the child is good (or bad) for the parent and *vice versa*. Finally, to a considerable extent the child's quality of life is dependant upon others in her/his life. This dependence extends beyond parents to include siblings, peers, teachers, professionals, and community members. This connection between quality of life and important others in his/her life are important for all children but it is even more critical for children with disabilities.

Conceptual Framework

Based on the further, in-depth analyses of the face-to-face interviews with these 30 parents, three fundamental elements of quality of life were identified: (a) the **child**, (b) her/his **parental and family environment**, and (c) the **broader environment** (e.g., neighbourhood, community, school, service providers, and other institutions such as governments whose policies may affect the lives of these children and their families). Both the family environment and the broader environment have physical aspects (e.g., the family home, the child's school, and the playground) and social aspects (e.g., the family's relationship with the child, attitudes about disability held by people in the child's community).

These three elements operate together in an ongoing relationship that may change, and usually does change, over time. Each element brings (or does not bring) its own contributions to this relationship. The child's quality of life is determined by the "fit", or overlap, between these three elements. The better the fit, the better the child's quality of life will be. Conversely, a poorer fit (i.e., a smaller degree of overlap) among these elements results in a poorer quality of life for the child. The illustration below shows the major elements of this new conceptual framework (model) of quality of life, which emerged from the analyses of parents' interview data.

Figure 1: Conceptual Model of Quality of Life



Three major domains, or aspects, of quality of life were found to emerge from the ongoing relationship among the child, his/her parental and family environment, and the broader environment. These domains were identified as: ***Being*** - who the child is perceived to be; ***Belonging*** - the child's connections to people and places; and ***Becoming*** - the child's nurtured growth and development.

To illustrate some of the ideas articulated by parents relevant to these three aspects of their child's quality of life, sample word-for-word quotes are included in the following discussion. (The notation within a quote indicates missing words. The use of square brackets indicates a word inserted by the authors to make meaning of the quote clearer.)

The ***Being*** domain deals with the child's identity, which is determined by how others perceive her/him. This part of the child's life will be good to the extent that the child is seen and treated by others, in the family and the community, first and foremost as a child rather than simply as "a disability". The way in which it may come into play, with peers for example, was stated by one parent:

They just treat him like one of the kids. And see, this is what makes his life, you know, wonderful is that they accept him for him...He can be with whoever he wants and he's happy when he's himself.

Belonging, the second aspect of quality of life, will be good to the extent that the child has a safe and secure environment, is readily understood by others, enjoys positive interactions with important others in her/his life (e.g., family, friends, teachers, etc.), and there is a good fit between the child and her/his environment. For example, the impact of a lack of good connections with other children was addressed by another parent:

...he needs to have social interaction with children his own age apart from school where you have to sit and learn, apart from being at home with a mom. He doesn't have any little friends that he can just say, "I wanna hang out with you" or "do you want to watch T.V. together."

The third domain, **Becoming**, is concerned with the child's nurtured growth and development. This part of the child's life will be good to the extent that the her/his current major needs are both identified and accommodated. As one parent put it:

I think all children need, they need stability, they need love, they need nurturing, they need unconditional love and they need the care. They need someone that's there that provides for them. All children need it. In fact, that's what makes them grow.

Providing for the child's growth and development is the responsibility of all of the important people and systems in the child's life, as summed up by another parent:

...how much he can gain, you know, how much more he can do, I think depends on how much more we can offer him, you know.

The New Instrument

Development

The development of the new instrument involved several rounds of composing and refining the items (questions) and the scales used to rate the items. After the research team had completed each round of composing, the items and rating scales were reviewed by groups of parents of children with developmental delays and disabilities in the community. Their feedback was included in the process of further developing the instrument. These processes continued until there was a high degree of agreement among the parents reviewing the instrument and the research team.

The main themes of the conceptual model were used to create the items in the instrument. Sixty items were constructed to address these themes. The items were organized under the domain headings, **Being** (8 items), **Belonging** (34 items), and **Becoming** (19 items). Each item is rated on 3 scales: **Applies**, **Importance**, and **Satisfaction**, using a 5-point rating scale. Scores for each rating scale can range from 1 (Does not apply / Not at all important / Not at all satisfied), to 5 (Applies very much / Extremely important / Extremely satisfied). Space was provided at the end of the instrument to allow parents the opportunity

to state any other areas that were important to their child's quality of life but were not addressed in the instrument.

Testing (Validation) of the New Instrument

The new instrument was tested (validated) through telephone interviews with 186 parents, recruited through contacts with more than 50 community-based organizations that provide developmental services and/or education.

Following data collection and input, the new 60-item instrument was assessed based on: (a) results of extensive statistical procedures and (b) qualitative feedback gathered during several dissemination meetings with stakeholders (e.g., parents, professionals, researchers, community organization representatives, and policy makers); as well as (c) conceptual considerations. After reviewing this complex information, the research team shortened the measure to 50 items, but kept the 3 original rating scales.

Two new items and 48 original items were included in the final version of the instrument. The new items were composed based on: (a) information provided by the 30 parents completing the face-to-face interviews with the original 60-item instrument concerning what important quality of life issues had not been addressed in the questionnaire and (b) feedback from several community dissemination meetings during which the 60-item instrument was discussed with parents and other stakeholders. This final version of the instrument was evaluated for psychometric soundness in terms of its validity (how well it measures what it is intended to measure) and reliability (how well it is able to measure quality of life with regards to consistency and repeatability). Since two new items were composed for the final version of the instrument (based on feedback), only 48 items could be appropriately evaluated using statistical procedures. These two new items are listed at the very end of the next section which shows sample items.

Sample Items from the New Instrument

BEING

Who my child is perceived to be

- Other people treat my child first and foremost as a child
- Other people see only my child's disability
- My relatives treat my child like any other member of the family
- Other people treat my child like any other member of the community

BELONGING

My child's connections to people and places

- My child has friends
- People who understand how my child's disability affects my child treat my child better than people who do not know about her/his disability
- Other people in the community are able to understand what my child says/communicates
- My child is able to go to her/his neighbourhood school or daycare

BECOMING

My child's nurtured growth and development

- Important people in my child's life recognize her/his specific needs related to the disability (e.g., people from the government, communities, professionals, school, family, etc.)
- Important people in my child's life recognize her/his needs related to being a child (e.g., love and affection, attention, play, etc.)
- Professional therapists are available for my child when s/he needs them (e.g., speech, OT, PT, behaviour, psychological, medical, etc.)
- My family receives enough support to enable us to support my child's growth and development
- What I do for my child's growth and development now is guided by my concern for her/his future **(new item)**
- The resources and supports my child has are because of my own efforts **(new item)**

Importance and Significance of This Project

The project accomplished several important goals and resulted in significant outcomes. It addressed a much needed area of research. Specifically, a new conceptual model (or framework) of quality of life for children who are aged 3 to 12 years old and have developmental disabilities and delays was developed, based on in-depth interviews with 30 parents. A new instrument based in this model was also created and extensively tested with 186 parents. The results of this testing show that the instrument is: (a) useful because it measures quality of life as it was intended to do and (b) relevant to this group of children and their families.

This project captured families' voices and perspectives throughout the research process. Parents' voices are reflected in the conceptual framework and the new instrument. Participating parents, as broadly defined (i.e., birth, adoptive, and foster parents as well as kinship carers) came from many different backgrounds (e.g., in terms of culture, ethnicity, financial status) and situations. Their children experienced a range of developmental delays and disabilities and

some had multiple disability issues (i.e., physical, sensory, mental health, other). The parents who participated were recruited through contacts with a wide variety of community-based organizations providing developmental services and education. This research was distinctive in that most other studies concerning children with disabilities have relied, solely or heavily, on samples of parents obtained through hospitals, clinics, and treatment facilities.

This project was participatory in nature. Several members of the research team are parents of children with developmental delays and disabilities. In addition, the model of quality of life developed was emergent, that is, it was resulted from analysis of detailed, word-for-word information from parents. Further, careful checking was done to ensure that parents agreed with the major themes and ideas that emerged from the analysis of the information they had provided. The new instrument was based on this model and used some of the actual language parents had used in their interviews. In addition, feedback on the research results was actively sought and received from participating parents and agencies at several stages of the research. Thus, it is not surprising that the new conceptual framework and instrument have been enthusiastically received by parents and by organizations, as well as by practitioners and researchers from different parts of the world who value participatory methods.

Potential Uses of the Research and Future Research Directions

The major outcomes of this project -- the conceptual model and the standardized instrument -- have a great deal of potential for future applications. They can be very useful to researchers and practitioners and to families, as well as to policy makers and analysts for the following reasons: (a) the careful and systematic approach used in their development and testing; (b) the strength of the support for their soundness and usefulness as indicated by quantitative and qualitative evidence; and (c), not least of all, their acceptability by and relevance evident from feedback from parents, professionals, policymakers, and researchers.

Both the new conceptual framework and the new instrument focus on everyday lived experiences and issues relevant to child's life as a whole. Thus, the instrument will allow parents and service providers to pinpoint issues that require additional attention, support, and intervention. So, it has the potential to provide a way to evaluate programs with the goal of improving those services for children with developmental disabilities and delays. Both the conceptual framework and the instrument can provide valuable information to service providers and can be useful to public policy-makers who are involved in health and social policy development and evaluation for this group of children and their families. The conceptual framework and instrument will also be useful to researchers in the area of childhood disability, rehabilitation, health and social services, education, and public policy.

The research team will try to increase the likelihood of these positive outcomes through circulation of this report and other forms of dissemination (e.g., conference presentations and publications) directed to parents, researchers, service providers in health, social services, and education, community organizations, and policy developers. It is hoped that this process will lead to acceptance and use of the conceptual framework and the instrument by some of these stakeholders and their colleagues.

In Conclusion

We leave you with the words of one parent who participated in the first phase of the research. Her comment captures both the holistic nature of quality of life and the importance of acknowledging, understanding, and supporting quality of life for children with developmental disabilities and delays:

...quality of life means to me giving them the best that you can give them, whether that's financially, mentally, emotionally, physically, spiritually -- in any form of life -- just giving to them, the maximum that you can give them.

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