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“IF I KNEW THEN WHAT I KNOW NOW”: **PARENTS’ REFLECTIONS ON RAISING A CHILD WITH CEREBRAL PALSY**

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Cerebral Palsy (CP) is a movement and posture disorder that occurs due to damage in the brain before or during birth (Rosenbaum, Paneth, Leviton, Goldstein & Bax, 2007). It occurs in 2 in 1000 births, resulting in a considerable number of parents and families who are raising a child with CP (Odding, Roebroek, & Stam, 2006).

Up until this point, research about the experience of raising a child with CP has mainly focussed on parents’ perceptions of the health care system. In general, this research shows that parents are unsatisfied with the level of information and care they are provided with over the lifespan of their children. In 2007, information collected from parents during interviews as part of the Adolescent Study of Quality of Life, Mobility and

Exercise conducted through *CanChild* Centre for Childhood Disability Research showed a general theme of “If I knew then what I know now, I would have done things differently.” New research has examined this theme more closely, and has provided valuable insight into the experience of raising a child with CP from a parents’ perspective. This information can in turn be used to assist health care workers, as well as new parents of children with CP.

During the interviews conducted as part of this new research, parents reflected mostly on their experiences surrounding attitudes, relationships, social factors, and support systems that affected them and their children, while very little focus was put on issues related to body structure and function (i.e. their child’s impairments). As a result, the majority of the information drawn from this study centers around these areas, and is

briefly summarized below:

- Raising a child with CP was seen to affect the whole family – parents felt a need for support and a need to take the time to foster other relationships and their own well-being. Parents reported that they found this type of support from extended family, community members, and professionals.
- Parents expressed that it was important for both the parent and their child with CP to educate themselves and act as advocates in all areas of life.
- Parents said that it was appreciated when health care professionals remained consistent throughout a child’s life and when they built a close working relationship with the child, family, and others important to the family.
- In the community, parents found formal education for their children

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worked best when: educators had positive outlooks, class sizes were smaller, educators stayed consistent, and the school system fostered inclusion and tolerance.

- Parents found that participation in specialized community programs with other families raising children with CP was seen as positive for both the child and the parent. While some parents found integrated programs were positive, others expressed that their child had difficulty fitting in.
- In general, parents expressed that more education is needed for the general public about children with CP.

As this study shows, parents of children with CP are a valuable source of information and advice for other parents of children with CP as well as for service providers. Their prior experiences allow us to learn about what we can do, regardless of how we are involved, to improve the experience of raising a child with CP.

Through a published 'tip sheet' for parents (found at http://motorgrowth.canchild.ca/en/Research/resources/ASQMEmajor_advicesfinaltipsheetjan112010final.pdf), as well as the publication of these findings as a journal article for health care providers (Reid et. al., 2011), this process is already well under way.

Interestingly, although previous research has indicated a gap between what health care professionals provide and what families need, these findings reflect positively on this relationship between professionals and families and support a family-centred approach to care. However it is important to remember that an individualized approach is necessary when caring for a child with CP; one which respects the parents' and child's wants and values, with consideration given to both integrated as well as specialized programs. In the future, research from the child's point of view will only serve to strengthen our understanding of their unique experience.

The above information was posted at the *CanChild* website as an "In Brief" and can be found at http://www.canchild.ca/en/canchildresources/parents_reflections_raising_child_knew_then.asp.

References

- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., & Bax, M. (2007). A report: The definition and classification of cerebral palsy. *Developmental Medicine and Child Neurology*, 49(109s), 8-14.
- Odding, E., Roebroek, M., & Stam, H. (2006). The epidemiology of cerebral palsy: Incidence, impairments and risk factors. *Disability & Rehabilitation*, 28(4), 183-191.
- Reid, A., Imrie, H., Brouwer, E., Clutton, S., Evans, J., Russell, D., & Bartlett, D (2011). "If I knew then what I know now": parents' reflections on raising a child with cerebral palsy. *Physical & Occupational Therapy in Pediatrics*, 31(2), 169-183.

PARENTS' AND ADOLESCENTS' PERSPECTIVES ON THE QUALITY OF LIFE OF THEIR ADOLESCENTS WITH CEREBRAL PALSY: "IT ALL COMES DOWN TO BEING HAPPY"

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Having a child with a disability changes the parents' perspectives on parenting. It doesn't just change parents' expectations and plans; it changes parents themselves. As the child develops, so do parents, and by adolescence, both parents and children have developed an understanding on what are the important things in their lives - those things that contribute to a good "quality of life". That is, as children grow older, both they and their parents increasingly appreciate what they need to focus on to achieve a fulfilled and happy life.

Adolescence is a unique stage within a child's development that presents

with important challenges. In a recent study involving 12 adolescents between 12 and 16 years of age who had cerebral palsy (CP), they were asked to talk about what they think is important for their quality of life. Most adolescents referred to participating in activities of their own choosing, being with friends, and having access to valued places and activities as the most relevant factors for them to experience a good life quality. They also reported that the reassurance of having their parents' support at all times contributed to their sense of well-being. This article can be accessed on the Childhood Disability LINK website: <http://www.childhooddisability.ca/cd/en/hcp.php?id=127&diagnosis=cerebral%20palsy>.

In a second part of this study, parents of adolescents with CP were interviewed and asked to elaborate on

the same topic; "what are the factors that contribute to your child's happiness and satisfaction with life?" Their answers demonstrated that they believed that their parenting experiences and efforts translate into concrete actions and into subjective beliefs that together have a great influence on the way their child experiences life. Parents also reported that the family environment and family dynamics, and family relationships between both parents in two-parent families, and between the siblings are also crucial for promoting a good quality of life. According to parents, the possibility of making choices about aspects such as how to spend family vacations, with whom to leave their child while parents do other activities, and what to do in leisure time are all very important for themselves and for their children. However, parents noted that there is a

lack of community resources, health services and supports for adolescents. For example, the financial burden associated with adapting their homes, providing adapted leisure activities, and having special respite care represents a major barrier to achieving successful engagement in different activities and, ultimately, to a good quality of life for their child with CP.

Because CP has an early onset, it is interesting to note that parents described an evolutionary process from their child's early childhood to adolescence. Parents developed a series of adaptive strategies: they learned how to advocate for their child and how best to navigate the health care system (although services are often limited with increasing age of their child), and how to adapt their expectations and plans. We found that parents had different "hopes" for their

adolescents, adjusted to their child's level of ability and ambitions. Parents of children with mild disabilities had greater preoccupations with their child's future and worried about their child's ability to achieve autonomy and independence in adult life. Parents of children with more severe cognitive and physical impairments reported that they had worried about autonomy in the past, but with time, they mainly wanted their child to have a happy life, and therefore were making plans for supported housing and care for their child as they become adults.

Intimacy was also a recurring theme, especially for parents of older adolescents. It is natural that adolescents may want to engage in sexual experiences and have their privacy respected, but these endeavours are often limited by their physical or intellectual limitations. For

instance, parents reported challenges in letting someone else care for an adolescent who needs assistance with toileting, in respecting their child's wish to spend time alone when they are physically dependent for most tasks, and in ensuring that their child can have sexual experiences in a safe context. Parents also talked about the lack of opportunity for their adolescent to engage in spontaneous activities that would be "typical" for adolescents, such as going to a friend's house or staying home alone, as these activities require planning to access adapted transportation or to identify a qualified person to be with their child. Parents felt that this lack of spontaneity in engaging in meaningful activities of their child's choosing inevitably had an impact on their quality of life.

Key Take-home Messages

- When interviewed, adolescents and parents had different perspectives on what is important for a good quality of life, both of which should be considered when developing programs and services for this age group.
- Parents placed more emphasis on disability characteristics and functioning as being influential for their child's quality of life, whereas adolescents were concerned with their current involvement in meaningful everyday activities.
- Parents and adolescents both emphasized that they wanted to live happy lives and be able to make choices about what they do. Therefore, programs and policies should facilitate this "choice-making" process.
- Parents of children with CP develop adaptive strategies over time. By adolescence, these strategies contribute positively to their child's quality of life. Therefore, targeted intervention plans should be aimed at enhancing positive adaptations and coping strategies in parents.

Many aspects of life that are important in promoting a good quality of life for adolescents are potentially modifiable and could be integrated into intervention strategies. A few examples of program and policy changes that could be addressed are:

- o Environmental barriers: Enhance accessibility (physical, financial) to community programs and adapted transportation services.
- o Supports: Provide a list of the community resources available for families in their region; train professional staff in the provision of respite care, both at home and for leisure activities in the community.
- o Access to health care: Adolescents should be integrated more effectively within rehabilitation and general health care services in order to have their needs assessed and strategies implemented to promote participation and family adjustment.
- o Information and resources for transition: Transition programs should be developed to provide support to parents and adolescents/young adults on subjects such as intimacy, alternatives for independent living, and work and leisure opportunities.