

This report gives a summary of the results from the Adolescent Study of Quality of Life, Mobility and Exercise (the ASQME Study, pronounced “ASK ME”). The ASQME Study was done by *CanChild* Centre for Childhood Disability Research at McMaster University in Hamilton, Ontario. We appreciate the time and effort of everyone who was part of this project. We know that this work would not have been possible without your help! We have learned a great deal from all of you and we would like to share that information with you now. You can also view this report, as well as other *CanChild* project reports, online at www.canchild.ca

WHY DID WE DO THE ASQME STUDY?

Our earlier study, called the Ontario Motor Growth study (from 1995-2002), helped us to create gross motor curves. The curves show us how children with cerebral palsy (CP) under 12 years of age develop their ability to move. The second step in our research was the ASQME Study, to learn about life with CP during the teenage years. Understanding what happens with quality of life, mobility, and exercise during adolescence is important for supporting youth as they become adults. We were especially interested in learning from the youth themselves. We believe that the ASQME Study findings will be of interest to youth, families, health care providers, and community agencies. What we have learned can help to identify resources, supports, and services. All of these things play a part in assisting adolescents and young adults with CP as they are getting ready for post-secondary education, work, and becoming part of their community.

HOW WAS ASQME INFORMATION GATHERED?

The ASQME Study began in 2002 and collected information about movement and function in young people with CP aged 11 years and older. The participants were 230 young people and their families. Study assessments were completed each year over a four year period. The last assessments were completed in 2007. Detailed interviews were also done with 10 young adults (aged 17-20 years) telling us about their own experiences in their own words. When we put it all together, through the Ontario Motor Growth Study and the ASQME Study, we now have information from as many as 657 people over a time period up to 10 years. The information describes development of children and young people with CP between 2 and 21 years of age.

CREATION OF A 12-18 YEAR AGE BAND FOR THE GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM

The Gross Motor Function Classification System (GMFCS) was created by our research group. The GMFCS is online at www.canchild.ca/en/measures/gmfcs.asp# The GMFCS was important to allow us to group together people with similar abilities as we charted the development of children with CP over time in the Ontario Motor Growth Study. The GMFCS has 5 levels of gross motor function. The differences between levels are meaningful in daily life. The GMFCS was originally used for children 12 years of age and younger because not very much was known about gross motor function of adolescents at the time the GMFCS was created (1994-1996). The GMFCS is now used throughout the world as the standard way to classify gross

motor abilities of children and youth with CP.

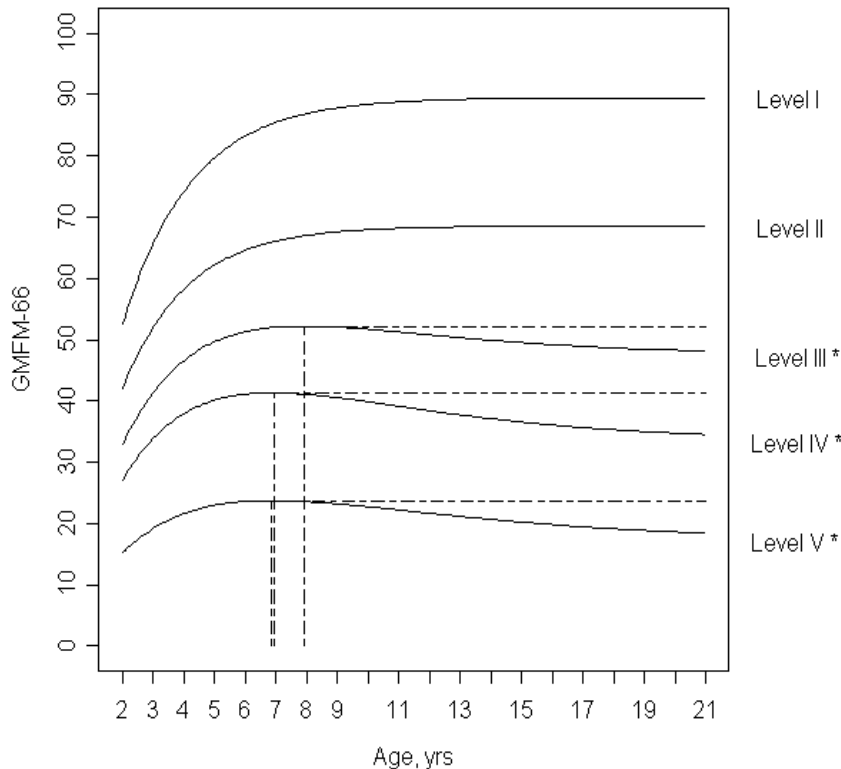
adolescence means that they will need more help for transfers and mobility.

As part of the ASQME study, the GMFCS was expanded and reworked to include information about 12-18 year olds. The new version is available on the *CanChild* website (www.canchild.ca). We found that especially in this older age group, it is not just ability but also environmental factors and personal choices that play an important role in how people with CP move at home, school, outdoors, and in the community. We found that for youth in GMFCS Levels IV and V, the growing that their bodies do in late childhood and

WHAT DID WE LEARN ABOUT GROSS MOTOR FUNCTION?

We used the Gross Motor Function Measure (GMFM) to measure gross motor “capacity” or what youth “can do” when asked to perform specific activities. The GMFM was also used earlier in the Ontario Motor Growth Study. Once the ASQME Study was completed we had enough information to extend the gross motor curves for children up to age 21 years (see Figure 1)

Figure 1. Predicted Average Development by Gross Motor Function Classification System (GMFCS) Levels.



In the figure the numbers up the side are the scores on the GMFM, ranging from 0-100, and the numbers across the bottom are the ages of children. Each GMFCS level has its own distinct ‘motor growth curve’. Each curve describes the average pattern of GMFM scores for people with CP in that GMFCS level – and the changes in scores over time. The dotted lines for GMFCS levels III, IV and V show what we originally thought the GMFM scores were. The solid lines for levels III, IV and V should what we actually saw over time. The original motor growth curves from the Ontario Motor Growth study can be viewed at <http://jama.ama-assn.org/cgi/content/full/288/11/1357> (see figure 2 and 3).

Here we can see that there are some changes in the average abilities of some people in GMFCS Levels III, IV and V. On average, young people in these GMFCS Levels reached their highest GMFM score at about 7 or 8 years old. On average, their performance on the GMFM measure went down between 4-8 points in the following years. This change seems to start before the teen years. We do not yet have a clear understanding of what leads to these changes. This will be the focus of future research by *CanChild* and probably by other researchers as well. It is important to note that we did not see performance going down on the GMFM measure for youth who walk without an assistive device (GMFCS Levels I and II).

WHAT DID WE LEARN BY ASKING YOUTH ABOUT THEIR MOBILITY & PHYSICAL ACTIVITIES?

Wherever possible we asked youth to complete the *Activity Scale for Kids* (ASK) to tell us what they usually do in everyday life at home, at school and in the playground. Young people who move around most easily (GMFCS Level I) told us that they did almost all physical activities by themselves. People with some problems walking (GMFCS Levels II and III) said they had some assistance for physical activities throughout the day. People with the greatest challenges in gross motor function (GMFCS Levels IV and V) reported needing help for most activities.

It was good news to see that just over half of the youth in GMFCS Levels IV and V reported “got around by myself” at home or in the community. This tells us that they are using powered mobility (electric powered chairs). These patterns did not change over one year, suggesting that youth kept these abilities over time. Factors such as energy level, physical barriers, and time constraints may play a

part in whether and how often young people do physical activities on their own.

Helping out at home helps young people to become more capable, self-reliant and independent. Many youth reported that they helped out at home, but only a small percentage of youth in GMFCS Levels IV and V reported that they did jobs or chores at home. This finding most likely reflects the challenge in coming up with ways for youth with more problems in motor function to participate in home activities. A recommendation is to get youth involved in conversations about how they can contribute to the family. Service providers can help by consulting with youth and families on task accommodations and assistive technology to make participation possible.

The 10 young adults who completed the detailed interviews with us talked about mobility as being important for *self-sufficiency*. *Safe and efficient mobility* to allow for participation in daily activities was a priority. These young adults told us that getting from place to place without assistance “spells freedom”, and that they choose the methods of mobility that work best for them in each situation. Participants spoke of constantly *adapting to situations* where they lack control, and they expressed *dissatisfaction with public transportation* and always needing to *plan ahead* to go places. Physical and social aspects of the environment such as availability of transportation, design and layout of buildings and places at school and in the community, and availability of someone else’s help posed fewer challenges for youth in GMFCS Level I.

In the ASQME study parents also completed the *Pediatric Evaluation of Disability Inventory* (PEDI) questionnaires. We were interested in learning about mobility and self-care activities in the daily

lives of people with CP through their adolescent years. We looked at *performance or what adolescents actually do in every day life* - instead of what they **can** do. We measured performance in mobility and self-care with questionnaires that were filled out both by the adolescents (ASK) and parents (PEDI). We found 1) that adolescents' and parents' views on mobility and self-care activities showed similar patterns, and 2) that in general there was a slight improvement over time in adolescents' performance of these activities. The good news from the ASQME study is that most adolescents continued to show improvement in their level of self care and mobility functioning through their teenage years.

WHAT DID WE LEARN ABOUT ENVIRONMENTAL BARRIERS?

Parents completed the *Craig Hospital Inventory of Environmental Factors* (CHIEF) which measures how often and how much of a problem environmental challenges can be. Environmental barriers include 'attitude and support barriers', 'services and assistance barriers', 'physical and structural barriers', and 'work and school barriers'. Families in the ASQME Study reported very few barriers overall. The average score reported by parents was 1.5 on a scale of 0-8, where scores closer to 0 indicate no barriers. 'Physical and structural barriers' were reported most by parents. 'Attitude and support barriers' were reported least by parents. Parents of youth in GMFCS Level I reported the fewest environmental barriers. The findings suggest that overall, school support services and health services and supports are addressing needs of youth with CP aged 11 years and older. The findings about environmental barriers are important if we are going to improve disability awareness in the community.

WHAT DID WE LEARN ABOUT EXERCISE AND PHYSICAL ACTIVITY?

Youth with more independent mobility participated in more physical activities than those with less mobility. There were no differences in exercise participation between males and females. Walking, swimming, basketball and dancing were the most frequently reported activities. Few young people were participating in cardiovascular exercises (activities which increase their heart rate) or strengthening exercises. Those who were less mobile tended to engage more in stretching exercises. Participation in any exercise decreased quite a lot over the four years of the study. The findings support the need to teach youth about the importance of regular physical activity and to identify opportunities for participation in community recreation and sports programs. This will be the focus of future research by *CanChild*.

Youth who have more trouble getting around were more limited in their ability to move their joints and spine. Youth with greater mobility had more flexibility and range of motion in their joints. People in the study had less joint flexibility as they got older. This finding supports the importance of regular physical activity and interventions to maintain range of motion during periods of rapid physical growth.

WHAT DID WE LEARN ABOUT PAIN?

Pain is common among young people with CP, with approximately half of the participants reporting pain in the previous month. Pain does not appear to be associated with level of gross motor function. The area where pain was reported did differ by GMFCS level: pain was most frequent in the neck and lower back for more of the youth who walk, while the upper back was most painful for those

who were less mobile. Across all levels of the GMFCS, young people reported pain in their ankles, arms and shoulders. Those who reported pain indicated that it had a significant impact on their daily activities. In future, both clinicians and researchers should focus on efforts to identify and manage pain early in the lives of those people with CP.

WHAT DID WE LEARN ABOUT QUALITY OF LIFE?

“Quality of life” (QoL) is best defined as a person’s judgments about their own life circumstances. We used the *Quality of Life Profile* (QOLP) which asks about feelings of “being” (who I am as a person), “belonging” (how good is the fit between me and my environment), and “becoming” (what I do to reach my goals, aspirations, and hopes). We assessed QoL and also “health-related Quality of Life” (HRQoL) using the Health Utilities Index (HUI). HRQoL gives a description of people’s functional abilities rather than how they personally judge and value life with those abilities.

Overall we found that GMFCS level **was not** associated with self-reported QoL. In other words personal judgments about quality of life are not determined completely by functional abilities. This means that QoL and HRQoL are somewhat related, but they do measure different parts of life and must be considered separately when looking at the lives of youth with functional limitations. Some aspects of QoL varied greatly depending on whether reported by the young person or by their parent, with youth generally reporting a higher level of QoL.

The important message in these findings is that people should be cautious in assuming that someone with a disability automatically has a poor ‘quality of life’ – because, as we

have shown, that does not appear to be true!

WHAT DOES ALL THIS MEAN FOR YOUNG PEOPLE & THEIR FAMILIES?

The findings from the ASQME Study suggest that there are important differences in what youth “can do” in the best circumstances (capability), what a person usually “does do” (performance) as part of daily activities and routines, and also what they “want to do”. On average, youth in GMFCS Levels I and II continued to walk without assistance during the four years of the study. Although walking was important for youths, they sometimes chose other forms of mobility, making a decision based on the safest and most efficient method for a particular situation. For youth who walked and also used wheeled mobility, the preferred method often varied for home, school, and outdoor settings.

We can not emphasize enough the importance for youth with CP to develop and maintain regular physical activity habits. The findings about some youth in GMFCS Levels III-V showing a change in their scores on the GMFM, along with the findings for joint flexibility and range of motion, pain, and the low levels of self-reported exercise, all point to the importance of maintaining physical activity, although this is an area that needs further research.

The finding that quality of life was not strongly related to physical abilities reminds us of the importance of “looking past” physical abilities (and disabilities!) and giving youth opportunities for decision making and “real world experiences”. These will help them to develop knowledge, skills and support systems including friends and mentors. One role of health care professionals is to consult with

youth and families to create supportive environments and help them achieve best possible function through task accommodations and assistive technology.

WHERE WILL WE (AS RESEARCHERS) GO FROM HERE?

We now know that in some cases, mobility-related activities learned during early childhood may drop off as youths get older. This might mean that youth with CP may be more likely to develop secondary health problems such as obesity and cardiovascular disorders later in life. To tackle this problem, *CanChild* is planning the “Stay-Fit” study. This study will look at the effects of a program to promote, coach, and educate to encourage an active lifestyle in adolescents with CP. Results from the ASQME study should help us to

put together programs for older children and adolescents with CP, aimed at improving their overall health, self-management and quality of life.

In addition, we hope to contact you in a few years to continue to expand on the Ontario Motor Growth Study and ASQME Study and find out about experiences as you are entering into your twenties. This added knowledge will be of interest to individuals with CP and their families throughout Ontario, Canada, and the world! As we indicated earlier in this report, following the same participants from childhood to adulthood is a unique opportunity and an extremely powerful way to study development. We look forward to inviting you again in the future to join us in the next adventure!

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ASQME Study Group: Peter Rosenbaum, Robert Palisano, Doreen Bartlett, Stephen Walter, Dianne Russell, Steven Hanna, Maureen O’Donnell, Debra Stewart, John Lawless, Lorie Shimmell, Lisa Avery, Barb Galuppi, Kamal Mangat.

For more information, please contact: Peter Rosenbaum, (905) 525-9140 **ext:** 27834
Fax: (905) 524-0069 **Email:** rosenbau@mcmaster.ca