



# HOW DO INDIVIDUALS WITH CEREBRAL PALSY (CP) AND THEIR FAMILIES PREFER TO RECEIVE AND USE INFORMATION

## WHY DID WE DO THIS STUDY?

We found that there was a **gap in knowledge** relating to how children with CP and their families prefer to receive and use information related to their development and assessments. The 3 major objectives were therefore to:

1. To **describe the format** in which children with CP and their parents prefer to receive information about individual development
2. To understand how children with CP and their parents **intend to use** this information
3. To gain insight on **how children with CP wish to be represented** in the information both comprehensively and respectfully

## WHO PARTICIPATED IN THIS STUDY?

Ten children with CP, aged seven to 17 years, and their parent(s) and/or legal guardian(s).

## WHAT DID WE DO?

**Semi-structured interviews** were conducted with the children and their families. We asked things like:

- ✓ Have there been times when you wished you had more information about your assessments?
- ✓ What format do you prefer when receiving information?
- ✓ Do you prefer text, graphics, or other visuals?
- ✓ How much information do you want?
- ✓ How do you want to use the information you are given about your/your child's assessments?
- ✓ Do you share assessment information with others? E.g. family, schools, etc.
- ✓ How do you feel about your interactions with your/your child's therapists?

## WHAT DID WE FIND?

### **Theme 1: Child Preferences for Information Format**

- Visual information (pictures, charts)
- Use of colour
- Point-form and straightforward
- Address child directly with appropriate language

### **Theme 2: Parent Preferences for Information Format**

- Combined text and visual information
- Brief, point form when possible
- Format that encourages two-way communication

### **Theme 3: Type of Information Children Want**

- Children DO want information!
- Specific visual information about themselves
- Stories about other children/people with CP

### **Theme 4: Type of Information Parents Want**

- Child's strengths and limitations
- Child's function related to others with similar CP level
- Child's prognosis
- Community resources

### **Theme 5: Other Families as an Information Source**

- Valuing the lived experience of others
- Going beyond medical information

### **Theme 6: Not Receiving Enough Information**

- Dilemma of accessing and appraising information from Internet

### **Theme 7: Being Inclusive and Respectful**

- Address children directly, not just their parents
- Use empowering language

### **Theme 8: Sharing Information with Schools**

- Brief and succinct information – one page
- Clear on what child needs and does not need

## HOW DO THESE RESULTS ASSIST WITH DISSEMINATION OF THE ONTRACK STUDY RESULTS?

The first three bullet points under Theme 4 on the previous page are directly related to the OnTrack Study:

- OnTrack **reference percentiles** provide parents with detailed information on their children's **strengths and limitations** by means of comparing their children's status at one point in time to:
  - ✓ **Other children's status**
  - ✓ Their **own individual progress** over time (roughly one year interval)
- Comparing a child's motor status to the **longitudinal curves** of children of similar age and severity of CP allows families to better understand their children's motor development and **overall prognosis** (Rosenbaum et al., 2002)
- Therapists can use longitudinal curves to tailor anticipatory guidance that further ensures **realistic developmental expectations** (Edwards, 2016)

Themes 1 and 2 of this study provide guidance on how to format the information that the OnTrack study will provide:

- Parents and children are interested in receiving information in a way similar to **school report cards**
- They are familiar with school report cards and their format matches their preferences (themes 1 and 2)

Based on this information, we created mock-ups of Progress Reports for disseminating the information from the OnTrack study to children and their families. The Progress Reports come in **three levels of information** to meet a range of audiences, including one for young children and youth with cognitive limitations.

## REFERENCES

- Edwards, J. D. (2016). Anticipatory guidance on the risks for unfavourable outcomes among children with medical complexity. *The Journal of Pediatrics*, 180, 247-250.
- Rosenbaum, P., Walter, S., Hanna, S., Palisano, R., Russell, D., Raina, P.,... Galuppi, B. (2002). Prognosis for gross motor function in cerebral palsy: Creation of motor development curves. *Journal of the American Medical Association*, 288, 1357-1363.
- Russell, D. J., Sprung, J., McCauley, D., de Camarago, O. K., Buchanan, F., Gulko, R.,... Gorter, J. W. (2016). Knowledge exchange and discovery in the age of social media: The journey from inception to establishment of a parent-led web based research advisory community for childhood disability. *Journal of Medical Internet Research*, 18, e293.

## HOW CAN THERAPISTS ASSIST WHEN PROVIDING INFORMATION TO FAMILIES?

Parents in this study consistently raised two points:

- The most valued source of information is the lived experiences of **other families**
- There is a constant struggle to **find resources** in the family's community

Both interacting with other families and finding resources are made more difficult when families live in rural areas.

Therapists can help by:

- ✓ Supporting **Internet-based interaction**, e.g. through Facebook (Russell et al., 2016)
- ✓ Linking families to **credible sources**

## HOW CAN THERAPISTS IMPROVE COMMUNICATION WITH CHILDREN WITH CP?

When providing information to children, therapists are encouraged to:

- ✓ **Communicate with child directly**, whether he or she is verbal or non-verbal
- ✓ Sit or stand as even with child's height as possible
- ✓ Maintain comfortable **eye contact**
- ✓ Use appropriate tone and language (not condescending)
- ✓ Use **empowering language**
- ✓ Explain the purpose of the interaction
- ✓ Keep your body language in mind

## FOR MORE DETAILED INFORMATION

Please visit <https://ir.lib.uwo.ca/etd/4627/> for more detailed information on the study, results, and mock-ups.