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.

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.

REFERENCES