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# How can we facilitate the use of research evidence to optimize outcomes of individual children with cerebral palsy?

Deliberative Dialogue Summary  
November 18, 2016

# Summary of the Dialogue

On November 18<sup>th</sup> 2016, seventeen stakeholders with diverse perspectives convened at CanChild at McMaster University to engage in a deliberative dialogue about the issue of how to facilitate the use of research evidence to optimize outcomes of children with cerebral palsy (CP) who receive services in Ontario. Stakeholders included 3 Service Providers, 2 Researchers, 3 Service Managers, 1 Service Administrators, 2 Policy Makers, 3 Young Adults with CP and 3 Parents of an individual with CP. Participants were given name tags and colour-coded stickers to signify which perspectives they identified with. The deliberative dialogue opened with an introduction to the Chatham House Rule, reinstating that participants in the meeting should free to use the information received, but the identity/affiliation of the speakers and participants should not be revealed.

In an icebreaker activity, participants were asked to introduce themselves by first name and to declare which perspective they knew most about as well as which perspective they knew least about. Through this ice breaker, it was clear that many participants knew least about the development of policy into change in practice and about the lived experience of people with CP.

The dialogue established that there are many steps involved in getting research evidence into practice: from Research to Policy to Practice to People (youth and families). The discussion reminded us that evidence is only one factor in government decision making and that a politician's consideration of issues heard from constituents is another factor within the process. This is an interesting tension for policy representatives as they must take into consideration both evidence and a range of stakeholder perspectives.

Participants watched a short presentation highlighting the Background Information and Overview of Evidence from the Issue Brief circulated prior to the dialogue. This was followed by a short video called "Checking Up and Checking In: Partnering with Families of Children with Cerebral Palsy" to promote the developmental curves and percentile graphs being created in the On Track study which fit nicely with the goals of regular check-ups and check-ins between children with CP, their families, and health care professionals: Finding the balance between results of standardized assessments and the individual priorities and concerns of families.

Overall, participants were pleased with the multiple perspectives represented in the dialogue discussion, although younger children with CP might have been included as well.

## DELIBERATION ABOUT THE ISSUE: CONSIDERATIONS AND CHALLENGES

### **Respecting and Accommodating Parents/Families:**

- Parents all have different levels of understanding of and sensitization to research. It can be very difficult to find and understand research reports and to navigate the system. This can cause parents to feel disenfranchised and distrusting.
- Paring down research evidence to find how it applies to an individual is important in order for each person to see the relevance.

- In general there is a need for a more positive tone, both for clinical reports and conversations with youth and families with a strengths-based approach that focuses on abilities rather than limitations.
- The classification systems (for gross motor, manual and communication abilities) are positively worded and focus on the abilities more than the limitations. However, classifications may be most useful in early conversations for thinking about goals, and it may not be necessary to refer to them throughout care.
- Parents may feel resistant to evidence comparing children to any type of norms. No parent wants to see evidence that shows their child is not fitting, not measuring up, and may prefer individualized discussions and goals that are unique to the child.
- Some parents expressed preference for models that are clear, clean, and simple (including classifications, standardized assessments and norms).
- Respect the diversity of parent preferences and acknowledge that it isn't "one size fits all" and there isn't just one way to speak to parents.

### **Keeping Service Providers in the Know**

- How do service providers access research and where do they go to help translate it so that they can speak knowledgeably to youth and families?
- Instructors and teaching institutions have the responsibility to educate new service providers about the need to spend time helping families to navigate and understand research findings – to empower themselves.
- Time is a major barrier for clinicians. There is an unwritten expectation to be up-to-date but yet there isn't much conversation or support for how to do that. We need to acknowledge that clinicians require built-in time to find information and to have collaborative discussions with colleagues about implementation strategies. It is unclear whether time is available for clinicians across all children's rehabilitation centres in Ontario.

### **Accessibility of Research**

- When researchers publish results in academic journals, they are not easily accessible especially for parents or members of the general public and they are generally not written in a user-friendly way.
- Research needs to be easy for everyone to digest. Stakeholders have one key question: What is the bottom line? What do the findings mean for parents? For youth? For service providers? For policymakers?

### **Service Inefficiencies and Inconsistencies**

- Lack of consistency exists across Ontario. Different regions and centres have different age cut-offs and varied guidelines for service.
- In general, people with high needs are a priority for service and others who are deemed "less complex" receive less care.
- Do older youth know that they can still receive services from Children's Treatment Centres (CTC)s? Services tend to be more family-centered at younger ages but as children approach school age, services become less so.

- Regular, comprehensive assessments do not appear to happen consistently across all CTCs and time and resources seem to be one of the biggest reasons.
  - What if we mandate these type of regular checkups and a family doesn't want them? That isn't being family centered, telling them what they need instead of letting them decide what they need.
- Ontario Association of Children's Rehabilitation Services (OACRS) centres are receiving an increase in clients who are younger in age but the resources have not increased accordingly.
- Services for children with autism spectrum disorder have received new funding and resources; this is an example where policy change was driven by what families asked for.

### **Complexity of Policy**

- There are multiple layers to policy, including governmental and organizational.
- A lot of people are currently in service in the current system so it's not realistic to think we could stop the clock and start over. Things need to roll out slowly with internal approvals.
- There's a need for better integration of rehabilitation services across the province, through all OACRS centres and across communities.

## **DELIBERATION ABOUT IDEAS TO ADDRESS THE ISSUE AND IMPLEMENTATION CONSIDERATIONS**

### **Annual Assessments**

- Is this happening already to some extent? We need a baseline of what is currently happening in OACRS centres.
- The purpose of annual assessments is to help families and youth find their way as children develop over time, keeping everyone engaged. Whether or not parents want an annual assessment needs to be discussed with them.
- How is an annual “assessment” different from an annual “review”? Calling it “annual family team meeting” puts the focus more on being more collaborative.
- Who would be at these meetings? What is the vision for who runs the assessment?
- Important to maintain choice for everyone involved.
- Potentially bring these assessments to individuals in their homes or close to home. People in the circle of care need to be mindful about the stress on the children and the adults.
- Be aware of services that are hard for families to access, as opposed to families who are hard to serve.

### **Suggested tools for Knowledge Translation (KT)**

- *Archived Webinars*
  - Economical and can watch them on your own time (~1 hour for professionals).
  - Could be open to families and youth with a different and more engaging approach with contact opportunity to follow up and ask questions.
  - Offer through CanChild with materials posted for easy access – one stop shopping.
- *KT Summaries*

- Design separate packages for clinicians and families but allow everyone to have access to all. Focus on the bottom line, succinct key messages.
- Packages for youth should be much shorter – quick and entertaining. Materials that are relevant to families should be written and directed to families; clinicians and policymakers will see and hear the messages.
- We must sufficiently impress and hook people with credible evidence. No need to dumb things down – but maintain credibility in an interesting manner.
- Parents may need education/tips about how to evaluate credibility of evidence.
- Outreach to pediatricians and family doctors to have access to KT summaries.
- *Research Position*
  - Each OACRS centre could hire a part time research person to support families and professionals on finding, understanding, and integrating relevant research evidence.
- *Collaborative Research*
  - Engage clinicians all over the province as participants in research, beyond the usual suspects/usual centres who participate in research. This helps to normalize behaviours, recognize that we are all working together toward the same goal, developing relationships, champions, and a network of people who are engaged.

## **Strength-Based Strategies**

- *Social Media and Marketing*
  - Clinically relevant Short Videos for youth depicting relatable people, images, and content (e.g. Draw my life/whiteboard videos) on YouTube or Facebook or in waiting areas with TV monitors. Videos of topic of week/month with invitation to visit an event or a website. CTCs could share these videos on their own websites. CTCs could also be encouraged to connect to social media such as Facebook and Twitter.
  - Facebook groups designed to disseminate information to parents who join the group or who join a list through short videos.
- *Culture Shift and Services*
  - Search for those (families or service providers) who have the desire and opportunity to learn. Change in perspective regarding productivity – more emphasis on doing the best, not the most.
  - More opportunities to attend conferences and time allotted to share what was learned with colleagues.
  - Revisit accreditation at OACRS – do the standards include the developmental monitoring measures we are considering? Establishing standards in performance plans so that they can be measured in some way may increase the likelihood of follow through. If we don't *need* to do something, we may not get to it.
  - Educational Outreach: train the trainer type visits – the downside of this is that typically there is peaked interest at first but then interest diminishes over time.
  - CanChild is meant to be an honest broker and they hold a unique position to offer KT services. Clinicians at OACRS centres should know that CanChild is a good place to start when they have a clinical question.
  - Researchers should remember to send executive research summaries both to the Board of Directors Chair, as well as the Chief Executive Officers of the OACRS centres. Also remember to direct new evidence to the CEO of OACRS; her role is to disseminate through many networks/pathways to get information out to all centres.

- *Engage Families and Youth*
  - Encourage children and family to create demand. Through educational guidelines regarding what to expect, regardless of geographic location, families will know what to expect from their CTCs with respect to annual assessments. Although heterogeneous, we can find some commonalities that should be occurring during rehabilitation annual assessments. We can empower families to speak up about their rights.
  - Engage family advisory councils and have a separate youth advisory committee to take part in dissemination and educational strategies.
  - Ensure that groups always include individuals with CP/families of individuals with CP to continue and expand the validation of the knowledge and the value parents and youth bring to the relationship. That it not be an event, give effort, and respectful attention to this so it unfolds organically until we always work together in a unified way.
  - Engage youth and families in day-to-day interactions consistently.

## **RECOMMENDATIONS FOR KEY STRATEGIES TO MOVE EVIDENCE INTO PRACTICE**

- *Creating educational materials to encourage KT*
  - Combined with one-on-one sessions for clinicians and families to understand the specific application of “how this applies to me”.
- *Focus on CanChild efforts*
  - Ensure that clinicians at CTCs know how to navigate CanChild website.
  - Email blast from CanChild/OACRS to highlight key items and key pieces of evidence and their potential impacts with different versions for families and clinicians.
  - Hold parent information sessions.
  - Advertise CanChild use and website in waiting rooms more.
- *Knowledge Brokering*
  - Combined with other educational and advocacy efforts (mentioned above).
  - Having research information formatted in lay terms would be helpful and more efficient to understand.
  - Research knowledge must be validated by family and youth experiences.
- *Communication efforts targeted towards young people*
  - Draw my life, whiteboard style presentations (30-60 seconds).
- *Efforts Geared to Clinicians*
  - Make time for service providers to keep up with research evidence and share information with one another. Build in time for scheduled learning blocks for clinicians for webinars.
  - Reminder to direct families to existing KT materials/CanChild
  - All regular output shared with parents should also be shared with clinicians – constant update about what is going on.
- *Explore Relationship Between Program Supervisors, Communities, and Ministries.*
- *Value the Knowledge of Children, Youth, Parents, and Families.*
- *Continue to grow and expand the relationship between OACRS and CanChild.*

## **NEXT STEPS**

The meeting wrapped up with a description of the next steps in this process, including preparation of this summary, post-deliberative dialogue interviews with each participant, participants' reviews of their transcribed interviews, and finally, a qualitative analysis of all of the planning and documentation of the deliberative dialogue using grounded theory methods to describe the findings of this collaborative work. The results will inform the KT plan of the On Track Study (and other studies) conducted through CanChild.

The Deliberative Dialogue process addresses an issue through collective problem solving. Through this process we are able to harness information, convene stakeholders, and facilitate change by empowering participants to meet pressing health issues creatively, setting agendas, taking well-considered actions, and effectively communicating rationale.

### **Acknowledgements**

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### **Citation**

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