



Moving from Parent 'Consultant' to Parent 'Collaborator': One Pediatric Research Team's Experience

Doreen Bartlett (PT), Lisa Chiarello (PT), Tina Hjorngaard (Parent), Barbara Sieck Taylor (Parent), and Robert Palisano (PT)



PURPOSE

We share our experiences of working with parents in pediatric physical therapy research, describe how our working relationship has transitioned from 'consultation' to 'collaboration', and propose further enhancements to realize our shared vision

BACKGROUND

- Encouraging researchers to include parents in practicing 'family-centred research' is a relatively new phenomenon¹
- We have worked with parents since 2006, first in the 'Move & PLAY' study and more recently in the 'On Track' study
- Most of our communication in these multisite studies occurs through audio conferences – these are essential, but sufficient?
- As we transitioned between studies, we realized that something was missing; we aimed for a more authentic collaboration
- After a face-to-face retreat with the first four authors, we transitioned from solely an 'on-line' consultant relationship to a collaborative partnership embodying greater trust, mutual respect and shared social responsibility

INITIAL RELATIONSHIP: Role of Consultant

In our Move & PLAY study, parents

- Reviewed the grant applications, provided feedback prior to revision and resubmission
- Reviewed all training materials and data collection forms with a view to being sensitive to potential issues with respect to reception by children and families
- Participated in interviewer training sessions
- Facilitated 'short titles' for 'Move & PLAY' and 'On Track'
- Reviewed and refined recruitment brochures and posters
- Reviewed and refined feedback forms and newsletters for families
- Provided feedback on initial descriptive analyses
- Reviewed and refined all knowledge translation summaries for the Move & PLAY study
- Provided permission to acknowledge contributions to study implementation

When we began the On Track study, we identified a document from the UK² to be useful in distinguishing 'consultation' (requesting review intermittently and taking feedback into consideration) and 'collaboration' (requiring ongoing teamwork, involving mutual appreciation of unique knowledge, skills and experience of each member)

EVOLVING RELATIONSHIP: Role of Collaborator

Using the INVOLVE framework,² elaborated upon by the Australian government,³ we describe our evolving collaborative relationship and identify where further enhancements can be made to realize our shared vision.

The seven parents participating in the On Track study shared that they value researchers who are welcoming and who encourage them to express thoughts and share ideas. It is important to parents that their input is valued. Although they are committed to participating in research, finding time is often a challenge in their busy lives.

Identifying and Prioritizing Research

"People who are affected by research have a right to have a say in what and how publicly funded research is undertaken"², page 8

In both Move & PLAY and On Track, our research questions were generated by our PT team members, based on gaps in PT knowledge to guide collaborative practice.

Examples of parents collaborating in establishing research agendas,⁴ especially relating to effectiveness of complementary and alternative interventions⁵ have been published.

Evaluating Impact

INVOLVE recommends monitoring and evaluating the short- and long-term impacts of consumer involvement in research²

At this time we have initiated informal discussions, sharing perspectives on what and how we are learning about the parent – researcher partnership and impacts on our current research, in part through monthly meetings. Evaluation of impacts was part of a recent focus group discussion and will be ongoing.

Commissioning

Many funding organizations now involve health care consumers in commissioning research.²

Although not directly a part of the research team, funding from PCORI (the Patient-Centered Outcomes Research Institute) considers the public perspective and requires consumer involvement.

Designing and Managing

Involving health care consumers in research design and implementation helps to ensure that the research is relevant, acceptable to research participants and feasible to conduct.²

Parent team members primarily functioned as consultants in the design of our studies. The collaborative role is emerging as parents provide complementary advice to deal with ongoing recruitment and data collection issues.

Disseminating

Involvement of health care consumers enhances widespread dissemination of study results in clear, user-friendly language.²

Parent team members have collaborated in developing knowledge translation summaries from the Move & PLAY study, written commentaries in peer-reviewed journals, and participated in development of conference presentations. In future, they will also participate in key peer-reviewed manuscripts and research presentations. They are proactively planning knowledge translation materials from the On Track study, including submissions to parent magazines and preparation of video materials on how to sensitively communicate prognostic information.

Undertaking

Health care consumers can develop information, conduct interviews, develop research tools, and assist in analyzing and interpreting results.²

Parent team members have assisted in writing newsletters for study participants, prepared short web-based communications 'by parents for parents', guided us in how to provide ongoing study feedback to families, prepared an exit survey to understand participants' experiences in the On Track study (what else should we have asked about your child, what are you most interested in knowing about your child, how do you prefer to receive assessment results) and will collaborate in interpretation of the results.



SUMMARY

- We advocate for true collaboration among all team members at all stages of research:
 - Deciding what to research
 - Deciding how to do it
 - Securing funding and ethical approval
 - Implementing the research plan
 - Communicating the results to a range of stakeholders using multiple formats
 - Facilitating uptake in rehabilitation practice
 - Evaluating outcomes of the partnership
- We encourage others to use the resources referenced below to facilitate truly collaborative research teams

IMPORTANCE TO MEMBERS

- Our shared vision is 'knowledge exchange' of research-based information to impact child- and family-centred rehabilitation practice to enhance outcomes and lives of children with cerebral palsy and their families
- This goal is best achieved through strong collaborations with consumers at all stages of research

REFERENCES

1. Rosenbaum P. Family-centred research: What does it mean and can we do it? Editorial. *Developmental Medicine and Child Neurology*. 2011; 53:99-100.
2. INVOLVE. Briefing notes for researchers: Involving the public in NHS, public health and social care research. INVOLVE, Eastleigh, UK: 2012.
3. National Health and Medical Research Council: Commonwealth of Australia. A Model Framework for Consumer and Community Participation in Health and Medical Research, December 2004.
4. McIntyre S, Novak I, Cusick A. Consensus priorities for cerebral palsy: A Delphi survey of consumers, researchers, and clinicians. *Developmental Medicine and Child Neurology*. 2010;52:270-5.
5. Morris C, Shilling V, McHugh C, Wyatt K. Why it is crucial to involve families in all stages of childhood disability research. Letter to the editor. *Developmental Medicine and Child Neurology*. 2011; 53:769-71

ACKNOWLEDGEMENTS

Additional Academic Investigators:

Sarah Westcott McCoy, Lynn Jeffries, Alyssa LaForme Fiss, Jan Willem Gorter, Steven Hanna, Cheryl Kerfeld, and Kristie Bjornson

Additional Parent Collaborators:

Lisa Diller, Paula Drew, Nancy Ford, Marquitha Gilbert, and Kimberly Rayfield

Coordinators:

Barb Galuppi, Monica Smersh, Erin English Wentz, Gabriell Fraser, Jennifer Miller, Amanda Porter, Tracy Stoner, and Allison Yocum

Students:

Deepa Jeevanantham, Kimberly Ward, Linda Montas and Mohammed Alghamdi

