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Moving from parent "consultant" to parent "collaborator": one pediatric research team's experience.

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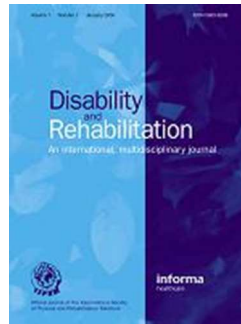


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**Moving from Parent 'Consultant' to Parent
'Collaborator': One Pediatric Research Team's Experience**

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Implications for Rehabilitation

- Involving **service users** in rehabilitation research is important, but not without challenges
- Attaining authentic collaboration requires face-to-face meetings, time, effort, and ongoing open communication
- Research processes are superior and outcomes may be improved with **service user** involvement
- Impact of research on rehabilitation practice is anticipated to be more meaningful with **service user** involvement

Abstract

We share our experiences as academic physical therapists and parents of young people with cerebral palsy working together as a research team, describe and critically review how our working relationship has evolved, and propose further enhancements to realize our shared vision. This manuscript is informed by a call for 'family-centred research', transcripts of face-to-face meetings held over a period of 1 ½ days, the INVOLVE document, and our experiences over almost a decade, as well as other related literature.

Authentic collaborative research partnerships between academic researchers and parents embodying trust, mutual respect, and shared social responsibility take time and effort to develop and sustain. Rehabilitation research is more meaningful and may be more impactful when strong collaborative partnerships between researchers and health **service users** are in place.

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3 Pediatric rehabilitation practitioners have been encouraged to incorporate a family-centred
4 approach to clinical decision-making and service provision for the last two decades [1]. This approach
5 views families as experts about their children; service providers are encouraged to work in partnerships
6 with them to attain the goals that families have for their children. **In family-centred care, meeting families
7 'where they are', providing choices, and supporting their participation are critical. Chiarello [2] has
8 described family members' roles in clinical practice as changing over time and varying along a
9 continuum, though not a hierarchy, including from minimal involvement, information seeking,
10 partnership, service coordination, and advocacy. It is important for practitioners to be flexible and
11 responsive to family choices. Ongoing communication between families and practitioners and
12 revisiting family needs and participation are integral to family-centred services.**
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27 More recently, the notion of 'family-centred research' has been promoted [3], although family
28 involvement in the research process has been advocated for at least two decades [4]. Whereas research
29 initiatives have traditionally been investigator generated, Rosenbaum questioned whether families'
30 expertise should be incorporated in all stages of research, right from the point of identifying research
31 questions, through thoughtful partnerships. In his experience, families have questioned terminology from a
32 deficit-based perspective, emphasized acceptability, relevance, and transparency of all proposed
33 procedures, and advised on respondent burden and appropriate methods of recruitment. Morris and his
34 colleagues [5] responded that families with children with disabilities must be meaningfully involved at all
35 stages of research based on: 1) a philosophical orientation positing that families are uniquely positioned to
36 ascertain research that is most likely to impact their children and their lives, 2) a pragmatic stance
37 proposing that families will be more likely to consent to participate in research that fills their needs and is
38 acceptable to them, and 3) mandatory involvement of **service users** in health research proposals in order
39 to receive public funding in the UK [6]. **Similar to family-centred practice, we align ourselves with
40 family-centred research with the idea that involvement in research can vary across a continuum of**
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3 **roles.**
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6 Although there are many reasons to involve families in research, barriers to effective collaboration
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8 have also been identified. Rosenbaum [3] described researchers' need to 'identify and address some of
9
10 the issues of power, knowledge, and privilege' (pg 99). Morris et al. [5] identified many challenges,
11
12 including: recruiting family members (including youth) willing to participate in research; facilitating, valuing,
13
14 and supporting family members' roles in research; gaining and maintaining a trusting working relationship;
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16 fostering meaningful and respectful partnerships; reconciling priorities for generic versus condition-specific
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18 topics; recognizing research opportunities as distinct from formal complaints or advocacy for better
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20 services; and desiring immediate change versus recognizing the lengthy time for obtaining funding and
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22 ethics approval, study implementation, recruitment, data collection, data cleaning, data analyses,
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24 knowledge translation and exchange, and finally, uptake.
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30 Recognizing that involvement of **service users** in research is advocated by our funders (i.e. the
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32 Canadian Institutes of Health Research; the US Department of Education, National Institute for Disability
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34 and Rehabilitation Research; and the Patient-centered Outcomes Research Institute), and acknowledging
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36 that true, authentic partnerships take time and effort to develop, the purposes of this perspective are to
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38 share our experiences of working together as a research team of academic physical therapists and parents
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40 of young people with cerebral palsy (CP), to describe and critically review how our working relationship has
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42 evolved, and to propose further enhancements to realize our shared vision. **We use the term 'service**
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44 **user' to include the child, youth, parent, or other family members who are making arrangements to**
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46 **receive services, or are receiving (or have received), participating in, or being partners in planning**
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48 **rehabilitation services.** We acknowledge that our work (in both planning and implementation phases) is
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50 also informed with the input of front-line clinicians; however the focus of this manuscript is on work with
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52 parents. With all of our partnerships, our ultimate goal is exchange of research-based and experience-
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54 informed knowledge to impact child- and family-centred, collaborative rehabilitation practice to enhance
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3 outcomes and lives of children with CP (or other developmental disabilities) and their families. By
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5 communicating our experiences, we hope that other research teams will consider what is required to attain
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7 authentic and effective collaborations with families. In addition, we hope that future **service user**
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9 collaborators consider their valued contributions and impact and feel empowered to participate fully (or as
10
11 much as they wish to) in the research process. We believe that the longer-term impact of such
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13 collaboration means that research outcomes will be more accessible and meaningful to a wider group of
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15 health **service users** and health care practitioners.
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19 **Our Experience in the ‘Move & PLAY’ Study: Consultation**

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21 Our international multi-site work together began from a pragmatic perspective, with Bartlett (located
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23 in London, Ontario) and Chiarello (located in Philadelphia, Pennsylvania) – both of whom are strong
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25 advocates of family-centred services - wanting to involve parents’ perspectives in our Move & PLAY study
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27 (Movement and Participation in Life Activities of Young Children, funded from 2006 to 2009;
28
29 <http://www.canchild.ca/en/ourresearch/moveplay.asp>). The purpose of this study was to follow a large
30
31 number of children at three time-points over a period of one year to gain an understanding of factors
32
33 associated with motor function, self-care, participation and play of young children with CP. We recruited
34
35 429 children in selected sites in both Canada and the United States and collected data on numerous child,
36
37 family, and service factors that were potentially associated with the four outcomes of interest. The results
38
39 of our study provide useful information to improve the effectiveness and efficiency of rehabilitation services
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41 for preschool children with CP. During grant preparation, Hjorngaard (Toronto, Ontario) and Sieck Taylor
42
43 (Pittsburgh, Pennsylvania) were recommended to the research team by a clinical researcher at a large
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45 children’s rehabilitation centre in Toronto and a leader in a parent-support agency in the greater Pittsburgh
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47 area as parents ‘who had something to say’ about participating in research. Our initial work was conducted
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49 solely through distance methods of communication, primarily through teleconferences and email
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51 correspondence. Table 1 summarizes the roles that both researchers and parents undertook in the Move &
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3 PLAY study. As is readily apparent, researchers prepared a variety of materials for review by parents.
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5 Importantly, all of the feedback received was very useful. Examples included revising our conceptual
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7 model prior to grant submission to acknowledge all 'aspects of the child' as one unit, rather than four
8
9 separate constructs, providing numerous tips in our training materials to enhance acceptability of research
10
11 involvement of both children and families, and ensuring that our dissemination materials were meaningful to
12
13 families. The review and refinement of various documents by parents was intended primarily to ensure that
14
15 study plans, implementation, and outputs would be acceptable to children and families. In addition,
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17 throughout the study, we routinely engaged in conversation, with both parents and assessing therapists, to
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19 establish solutions to issues that arose during data collection.
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24 [insert table 1 here]
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27 **Our Transition from Consultation to Collaboration**

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29 As we transitioned to our next study together, we (the academic physical therapists) questioned
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31 whether what we had experienced was really more of a 'token' involvement, rather than a deep
32
33 commitment to collaborate with families to improve research processes and outcomes for children and
34
35 families. We asked ourselves: *have we done enough?* Concurrently, we became aware of Rosenbaum's
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37 editorial [3] and Morris and colleagues' response [5], and several very useful documents [6,7].
38
39 Interestingly, in the James Lind Alliance Guidebook [7], degrees of involvement are described in terms of
40
41 Arnstein's (1969) 'ladder of citizen involvement' [8], with 'informing', 'consultation' and 'placation' being
42
43 referred to as 'tokenism' (precisely our fear!). We realized that we had stalled at the level of consultation
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45 (even formally referring to Hjørngaard and Sieck Taylor as 'parent consultants') and that we had 'room to
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47 grow' in terms of a more collaborative research partnership. We realized that time constraints associated
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49 with 'in the moment' multiple demands of planning and implementing research had impeded us in
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51 authentically engaging with each other.
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57 Then, despite having worked together for seven years, Bartlett and Hjørngaard first met face-to-
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3 face in early 2013, with a sabbatical leave offering Bartlett time to make the trip to Toronto for a lunch
4 meeting. Buoyed by the increased trust and mutual respect generated by the meeting, a follow-up
5 teleconference was held among the four of us, in which Hjørngaard stated: “our work together would be so
6 much more meaningful if we could all meet in person”. We conducted a map search and discovered that
7 we all lived within a day’s drive of each other. Subsequently, we agreed to meet in Pittsburgh in early July
8 2013. Prior to the meeting, we collaboratively planned our agenda, which primarily aimed to clarify our
9 personal interests in learning more about how to enhance authentic, collaborative, family-centred
10 approaches in research, especially about how to deal with inherent power differentials in this endeavor and
11 how to support validation of the contributions of parents’ life experiences and perspectives in the context of
12 research. Our agenda also contained the following items: a review of recommendations from many
13 national health funding agencies’ guidelines about how researchers should involve health **service users** in
14 research, a review of relevant peer-reviewed literature (noting that not a lot had been published at that
15 time), a review of what we had done together to date (essentially Table 1), description of the peer-review
16 process, and selection of a target journal. Sieck Taylor identified a hotel for overnight accommodation,
17 which afforded three of us who drove a comfortable relaxing space, setting the stage for a creative
18 atmosphere for good conversation. As indicated by our agenda, we had previously decided that a longer
19 term goal was documentation of our experiences through a peer-reviewed manuscript, but first we needed
20 to get to know each other better, as ‘people first’, starting with an informal dinner at a lovely local
21 restaurant. In addition to making arrangements for dinner (and providing a breath-taking tour of Pittsburgh
22 that evening), Sieck Taylor also secured meeting space at what was then the United Cerebral Palsy of
23 greater Pittsburgh (now Community Living and Support Services). This facility was conducive to very good
24 discussions over the period of a day-and-a-half; we were all inspired by many quotes of Al Condeluci [9]
25 posted around the place. The first day comprised exchanging photos of Hjørngaard’s and Sieck Taylor’s
26 children (now aged 17 and 24 years, respectively) and information about our respective families,
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3 'interviewing each other', enabling us to get to know each other's perspectives more deeply, and then
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5 working through our previously set agenda. The first day ended with Sieck Taylor and her husband hosting
6
7 a dinner in their home with additional friends, also parents of children with CP, to continue our discussions,
8
9 which were richer given the increased diversity of perspectives, although everyone came from a position of
10
11 advocating for enhanced outcomes for children and youth with CP and their families, in part through
12
13 participation in meaningful research. We audiotaped our discussions, which were transcribed and
14
15 summarized for the content of the next two paragraphs. **Transcriptions of our first face-to-face**
16
17 **discussions enabled us to reflect more deeply on our shared assumptions, values, and motivations.**
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21 We started with an exploration of who we are (box 1) and what we value, with the assumption that
22
23 just as rehabilitation practice is relationship-based, so too is rehabilitation research. Despite our unique
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25 individual contributions, we learned that we have many shared values, which we believe set us up well to
26
27 further develop a strong, collaborative research partnership. Our shared values are listed in box 2.
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29 Themes of respect, generosity, and inclusivity transcend our values. In terms of the methods used to
30
31 generate new knowledge, our work is primarily quantitative, however we also highly value the qualitative
32
33 information we receive from parents' comments made in the data collection booklets and ongoing
34
35 assessing therapist input. We realized that setting aside several days to get to know each other better and
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37 to explore our working relationship was critical in helping us to evolve to a more authentic collaborative
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39 partnership embodying greater trust, mutual respect, and shared social responsibility. Similar to the
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41 concept of dynamic systems theory in which multiple subsystems contribute to how an individual child
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43 develops [10], so too do individual participants, with variation in personal attributes, experiences, and
44
45 formal clinical and research training, contribute uniquely and meaningfully to a research team's functioning,
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47 with the outcome being greater than a sum of the parts. This sense of 'being more together' embodies a
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49 movement beyond token involvement.
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Our Experience in the 'On Track Study': Collaboration

Since our face-to-face meeting, our research partnership has grown as we continue to implement the On Track Study (Understanding developmental trajectories of impairments, health conditions and participation of young children with CP, with funding from CIHR 2012-2017 and PCORI 2013-2016; https://www.canchild.ca/en/ourresearch/on_track_study.asp). Importantly, we have transitioned from a researcher/parent working relationship (as described in Table 1) to a more collaborative partnership. Our aims in the On Track Study are to describe the changes in balance, range of motion limitations, strength, and endurance, number and impact of health conditions, and participation in self-care, recreation, and leisure activities in young children with CP aged 18 months through 11 years. We will develop longitudinal growth and reference percentile curves, which will assist therapists to understand how an individual child is developing over time. Combined with the results of the Move & PLAY study, therapists will have foundational knowledge to assist with collaborative decision-making with families to assist their children in attaining their selected goals. As we implement the On Track Study, we have been mindful that our funding sources are now even more explicit about the importance of including patients or clients in all stages of research [11,12]. Nonetheless, we are not simply engaging with each other because of funding requirements; we fully recognize that explicating our shared values was a critical step in ensuring an authentic collaborative partnership. With PCORI funding, we have added five parent collaborators to the research team, providing richer perspectives associated with a greater range of children's functional ability levels and ages (from elementary school age to young adulthood), and families' ethnic backgrounds and demographic and functioning characteristics, as well as geographic regions of residence.

As part of the process in becoming a stronger collaborative partnership, we have found a document developed through the National Institute for Health Research in the UK to be particularly useful. First available in 2004 and updated in 2012, the INVOLVE document advocates for greater involvement of the public (referring to everyone who does not have a professional role in health and social care service) in

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3 health and social care research, based on the fundamental democratic principle that “people who are
4 affected by research have a right to have a say in what and how publicly funded research is undertaken” [6,
5 page 8]. This statement resonated strongly with us, particularly as it applies to more vulnerable populations
6 such as children and youth with CP, as well as their parents (both mothers and fathers). The INVOLVE
7 document provides specific recommendations for approaches involving consultation (requesting review and
8 taking feedback into consideration), collaboration (noting that meaningful collaboration requires close team
9 work, involving mutual appreciation of unique knowledge, skills and experience of each member), and user-
10 control (e.g. participatory action research), recognizing overlap among roles. They provide succinct points
11 on how members of the public can participate in identifying research questions and prioritizing,
12 commissioning, designing and managing, undertaking, disseminating, implementing research into health
13 care practice, and evaluating the impact. We have found their framework to be useful in critically
14 examining how we are doing in our quest to develop a stronger research partnership, which is described
15 next.

Identifying and Prioritizing Research

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17 In both the Move & PLAY and On Track studies, our research questions were generated by our
18 physical therapy team members, based on gaps in physical therapy knowledge, to guide collaborative
19 practice. Parents reviewed the research grants prior to submission, assuming a consultant role. Upon
20 reflection, if our focus and methodological orientation was from a participatory action perspective, the
21 parents on the team would have been engaged at a stage prior to simply reviewing the research objectives.
22 Examples of parents collaborating in establishing research agendas in childhood rehabilitation contexts
23 [13], especially relating to the effectiveness of complementary and alternative interventions [5] have been
24 published. The James Lind Alliance Guidebook [7] is an excellent resource for establishing priority setting
25 partnerships.

Commissioning

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3 Many funding organizations now involve **service users** in commissioning research [6]. Although
4 not directly a part of our research team, funding from PCORI [12] considers the public perspective and
5 requires **service user** involvement. In future, it is possible that parent collaborators involved in the On
6 Track study will feel empowered to advocate for specific research agendas with selected funding agencies.
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10 11 12 Designing and Managing

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15 Involving health **service users** in research design and implementation helps to ensure that the
16 research is relevant, acceptable to research participants, and feasible to conduct [6]. Parent team members
17 primarily functioned as consultants in the design of our studies. Based on discussion we have had as a
18 group, parental involvement in the design of a study might result in a higher probability of the best research
19 design in response to their concerns being qualitative, with the perception that results from qualitative
20 studies are perhaps more meaningful to children and families. The collaborative role is emerging in our
21 research partnership as parents provide complementary advice to deal with recruitment (completed) and
22 ongoing data collection issues. We have asked ourselves: *Should we have a parent and provider*
23 *regularly involved in our monthly team meetings?* Involving parents in ongoing implementation meetings is
24 planned in the PCORI-funded part of On Track, but does not occur at the same frequency as investigator
25 meetings. These meetings are typically scheduled during regular working hours when parents are not
26 always available. Those of us who are academic researchers recognize that these meetings are lengthy
27 and very detailed; we fully recognize that parents have limited time that they can give. Therefore, minutes
28 of these meetings are shared and parents are welcome to attend any meeting (or part of meeting) that fits
29 their schedules. Several parents have attended an occasional implementation meeting and have found it
30 useful to understand the administrative responsibilities and rigour required to ensure validity of the data and
31 findings. Nonetheless, given the time demands on parents of children with special needs, it might be
32 prudent to consider if specific meetings or parts of meetings would benefit from parent input. Conversely,
33 parents meet monthly with at least one investigator, typically in the evening. Investigators are welcome to
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3 attend; again, minutes are shared. The focus of these meetings includes updating parents on information
4 shared at the implementation meetings, asking questions for parent input on aspects of study
5 implementation (including obtaining advice on related sub-studies), conducting focus groups to learn
6 parents' perspectives on topics relating to the research, and planning parent-generated products to support
7 study management and dissemination. In their recent comprehensive scoping review on engaging
8 stakeholders in rehabilitation research, Camden et al. [14] described the frequency and duration of either
9 face-to-face meetings or teleconferences as being variable across studies, but keeping people motivated
10 and engaged was perceived to be uniformly important. Considerations for enhancing engagement included
11 convenience of meeting times, involving stakeholders in setting agendas and running meetings, and
12 outlining a sustainability plan from the outset. Based on our experience, we recommend that all team
13 members be respectful of availability of all participants, which usually changes over time, based on both
14 individual life responsibilities and interest and capability in participating in various stages of the research.

31 Undertaking

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34 Health **service users** can develop information, conduct interviews, develop research tools, and
35 assist in analyzing and interpreting results [6]. Parent team members have assisted in writing newsletters
36 for study participants (see On Track website), prepared short web-based communications 'by parents for
37 parents', guided us in how to provide ongoing study feedback to families, prepared an 'exit survey' to
38 understand participants' experiences in the On Track Study (e.g. what else should we have asked about
39 the children enrolled in the study?, what are you most interested in knowing about your child?, how do you
40 prefer to receive assessment results?) and will collaborate on interpretation of the results.

49 Disseminating

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52 Involvement of health **service users** enhances wide-spread dissemination of study results in clear,
53 user friendly language [6]. Parent team members have collaborated in developing knowledge translation
54 summaries from the Move & PLAY study (<http://www.canchild.ca/en/ourresearch/moveplay.asp>), written
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3 commentaries in peer-reviewed journals [15,16] and participated in conference presentations (for example,
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5 instructional courses “Family-Researcher Collaboration: Bringing the Family’s Voice to Research” were
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7 presented at both the Division for Early Childhood and the American Academy of Cerebral Palsy and
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9 Development Medicine annual meetings in October 2015; and a poster ‘Moving from Parent ‘Consultant’ to
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11 ‘Collaborator’: One Pediatric Research Team’s Experience’ was presented at the Ontario Association of
12
13 Children’s Rehabilitation Services annual conference in November 2015).

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17 In future, parents will also participate in key peer-reviewed manuscripts and research
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19 presentations. They are proactively planning knowledge translation materials from the On Track Study,
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21 including submissions to parent magazines and preparation of video materials on how to sensitively
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23 communicate prognostic information.
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27 We believe that collaboration in dissemination activities is a relative strength in our research
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29 partnership, but we continue to ask questions. *Are we doing all that we can with respect to communicating*
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31 *in ‘jargon free’ terms?* The INVOLVE website (<http://www.involve.org.uk/>) has a section entitled “Jargon
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33 Buster” in their resource section, intended to break down barriers associated with research terminology;
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35 this is something we need to continue to work on. *Should we engage families and therapists together in*
36
37 *developing end-of-study summaries?* To date, we have not engaged both groups together, inclusively and
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39 in a reciprocal manner, which will be a focus of the end-of-study grant activities once data collection for the
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41 On Track Study is completed. *Have we done all that we can to transcend the research – practice gap to*
42
43 *address information needs of service providers, families and policy makers?* To date, we have focused on
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45 peer-reviewed presentations and instructional courses, invited invitations, peer-reviewed manuscripts,
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47 knowledge translation summaries, and power point presentations that primarily target service providers. In
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49 future, we might engage more in blogging, tweeting and developing podcasts, which might be appealing to
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51 both parents and therapists who are younger than most of our current team members. Importantly, these
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53 sorts of methods require an on-going commitment, and it will be important to secure appropriate resources.
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3 We are considering providing examples of what a decision-making process might look like through 'story-
4 telling' of meeting a family and child, understanding their goals, conducting physical examinations and
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7 interviews to collect information from the parent's perspective, interpret the data and then planning
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10 intervention and monitoring outcomes collaboratively. We need to do more to communicate with children
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13 and youth, in addition to families, and with policy makers, discussed in more detail in the next section.

14 15 Implementing Research Results in Practice

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18 Involvement of health **service users** can influence, support, and strengthen the uptake of research
19
20 in practice [6]. To date, the focus groups have been very useful in clarifying how research information
21
22 should be shared with children and families. Basically, parents were very clear that they prefer specific
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24 information that is relevant and meaningful to their own child, rather than having scores interpreted based
25
26 on reference to other children (either with or without CP). Furthermore, they reported that total scores were
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28 not useful; they preferred a breakdown of relative strengths within an assessment. Finally, transmitting
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30 information that their child is 'behind' is not useful as this is typically already known. Instead, information on
31
32 how to move forward, from a very practical perspective, is valued. Recent work conducted by an MSc
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34 student under Bartlett's supervision revealed that parents particularly appreciate mediation of research
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36 information by a service provider who is very familiar with their child and family, rather than either solely
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38 accessing, interpreting, and using research information independently, or with assistance of a 'generic'
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40 knowledge broker affiliated with a children's rehabilitation centre [17].
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46 As we move to planning knowledge translation and exchange activities from our two studies, we
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48 plan to engage in a 'deliberative dialogue' [18,19], or a variation thereof, with a wide range of stakeholders,
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50 including parents of children with CP, youth with CP, physical and occupational therapists, developmental
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52 pediatricians and/or physiatrists, rehabilitation managers, chief executive officers of rehabilitation centres,
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54 and policy makers in a provincial healthcare system. In addition to being part of the group to engage in a
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56 full discussion of how our research can be integrated into practice, parents will also be instrumental in
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3 assisting with preparation of briefing notes, ensuring that a synthesis of our research results is
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5 understandable by the diverse stakeholders before the dialogue takes place.
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8 Evaluating Impact

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10 INVOLVE [6] recommends monitoring and evaluating the short- and long-term impacts of **service**
11 **user** involvement in research. At this time, we have initiated informal discussions, sharing perspectives on
12 what and how we are learning about the parent-researcher partnership and impacts on our current
13 research, in part through monthly meetings. Evaluation of impacts was part of a recent focus group
14 discussion and will be ongoing. Importantly, at our face-to-face meeting, we found that setting aside time
15 for reflective discussion was a productive method for confirming our accomplishments and identifying other
16 avenues for expanding our relationship. Interestingly, in the recent scoping review [14], only 6 studies
17 collected data to document the impact of stakeholder engagement, but none used standardized measures.
18 The Public Involvement Impact Assessment Framework (<http://piaf.org.uk/>) was recommended as an
19 evaluation strategy.
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34 **A summary of our current and possible future collaborative roles in the research process is**
35 **contained in Table 2.** Although we have made some progress in moving from a purely consultative
36 relationship, analysis of all of the steps in the research cycle indicates that we still have room for growth in
37 moving to a stronger collaborative partnership as we continue to implement and complete the On Track
38 Study and engage in future research together. The INVOLVE document [6] was useful to us as a basis for
39 reflection on what we are doing well and where we can improve.
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48 [insert table 2 about here]

49 **Further Considerations in Strengthening Research Partnerships**

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52 The following questions highlight some additional issues that we've encountered, as well as some
53 recommendations for consideration, both for members of our research team and for others.
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57 *What is an optimal number of parents to be involved?*
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3 In our Move & PLAY study, we engaged only two parents. Hjørngaard has suggested a 'little
4 working group' might have been better, recognizing that she is not the only one 'with something to say'.
5
6 She **has** also expressed concern about the 'pressure' or 'responsibility' of representing all parents of
7
8 children with CP in a whole country. As indicated earlier, we have added five parents, incorporating cultural
9
10 diversity, based on PCORI's specific request (see parent biosketches on the On Track website). To date,
11
12 all parent collaborators have been mothers. A focus for future research partnerships is also including
13
14 fathers to incorporate their perspectives. INVOLVE recommends engaging more than one person
15
16 representing the public's interest. **In a recent newsletter to families (May 2016, available on the On**
17
18 **Track website), parents reflected on their involvement in this research project, eloquently stating**
19
20 **their beliefs that the work, with their input, will benefit other families, 'both here and abroad', that it**
21
22 **is making 'a contribution to a body of knowledge that helps other families', produces 'benefits to**
23
24 **knowledge and practice for kids in the future', and that 'diversifies and deepens the meaning and**
25
26 **application of research'. Importantly, although service user involvement is limited to 7 parents in**
27
28 **our current work, they are all committed to 'speaking for those who are not at the table', feeling a**
29
30 **commitment to improving knowledge and rehabilitation services that are useful to all children with**
31
32 **CP and their families.**

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41 *How should parents be recruited?*

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43 Hjørngaard and Sieck Taylor were recruited through professional contacts who purposively
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45 recommended them. Although INVOLVE [6] recommends not being concerned about representativeness
46
47 (instead, they recommend a focus on obtaining input from people with diverse perspectives), PCORI
48
49 explicitly requested inclusion of collaborators from various minority groups. In future work, we might
50
51 consider recruiting parents of younger children and those with more variability in level of education, as well
52
53 as representation of fathers. Social media might be useful to recruit a broad, diverse group of people
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55 willing to serve. Camden et al. [14] describe both targeted and open approaches to recruiting. In targeted
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3 approaches, either individuals or agencies were contacted to nominate individuals for the role. In open
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5 approaches, invitations are widely disseminated to solicit involvement. Criteria for selection were
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7 summarized as 1) stakeholder's characteristics (do they match key features of the group they are intended
8
9 to represent), 2) individual's willingness to speak for the group they represent, rather than solely their
10
11 personal opinions, 3) effectiveness as a communicator, and 4) representing diverse opinions. The
12
13 Peninsula Cerebra Research Unit has a particularly innovative 'faculty of families', all of whom provide
14
15 diverse perspectives to ongoing research in the unit (<http://www.pencru.org>).
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20 *What does involvement mean?*
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22 Based on our experience, 'involvement' has changed over time, from a consultant to a collaborator
23
24 role and the relationship has extended longer than any of us initially expected. Ideally, there should be role
25
26 clarity from the outset of a partnership. It is possible to link roles to stages of the research cycle, as
27
28 described in the INVOLVE document [6], potentially having different people for different stages.
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31 **Consistent with family-centred research**, some parents might prefer to have a review role, others might
32
33 prefer to be more involved at the design stage of a research project, some might be instrumental in
34
35 identifying social media outlets to assist with dissemination, and still others might welcome the role as a full
36
37 co-investigator. Others have suggested roles that involve serving on working, steering, or advisory
38
39 committees or on an expert panel [14] or being a research communicator, co-presenting research findings.
40
41 Camden et al. [14] emphasized the importance of having a clear job description, clarifying and agreeing on
42
43 realistic expectations at the beginning of the process and having ongoing, open communication among all
44
45 team members. We agree with Morris and colleagues [5] that it is essential that parents understand the
46
47 difference between advocating for services to support individual children or being involved in research with
48
49 the expectation that one's own child will benefit versus their role in helping to generate new knowledge to
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51 support system-level change for children in the future. We also believe that it is important to explicitly
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53 recognize the benefits that parents will receive if they participate in research: being a part of something
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3 bigger than one could accomplish alone, for the benefit of others.
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5 *Should parents be expected to volunteer for such work or should a salary be provided?*
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8 The issue of remuneration is important to consider carefully. Should parents be expected to
9
10 volunteer as a social responsibility or through a sense of altruism? If not, how does one put a price on the
11
12 collective wisdom of good collaborators? Our practice in both the Move & PLAY and On Track studies has
13
14 been to offer only very modest annual honoraria that might be considered only a 'token'. Parents on our
15
16 research team describe this stipend as meaningful recognition of contributions, commenting that it is not
17
18 the primary reason for being involved in research. In their scoping review, Camden et al. [14] identified that
19
20 providing a salary was perceived to be a facilitator for stakeholder identification and engagement.
21
22 Additional funding should be planned for travel expenses, training, promotional activities and dissemination
23
24 [14]. Parents on our research team have expressed appreciation in having conference expenses covered
25
26 through a grant; although some have participated using vacation days. In future, we might give
27
28 consideration to 'buy out' time of full- or part-time employment as a recognition of the value of parents' input
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30 and generosity with time in an otherwise busy schedule. Clearly, families with a high degree of financial
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32 stress and limited supports and resources have additional challenges in participating in research.
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38 *What ought we have done to facilitate a more meaningful collaboration earlier on?*
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41 Without question, the biggest 'learning point' in our experience is to plan for a substantive, face-to-
42
43 face meeting early on in the research partnership. Although designing and implementing a research project
44
45 is time-intensive, fostering a respectful and meaningful partnership needs to be a priority. We recommend
46
47 setting aside time to get to know each other as 'people first', in a social setting, over a meal together.
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49 Exploring shared values worked well for us as a basis of developing a stronger working relationship. In our
50
51 experience, face-to-face meetings facilitate a level of trust that is difficult to establish with distance
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56 communications.

57 *How do we manage 'issues of power, knowledge, and privilege'?*
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3 INVOLVE [6] posits that public involvement in research has the potential to empower people who
4 use health and social care services. We believe that this potential is realized only if a trusting relationship is
5 forged, with mutual recognition and respect of unique individual contributions of all team members ‘for the
6 greater good’. In a recent focus group with parent collaborators in the On Track study, we learned that
7 parents value researchers who are welcoming and who encourage them to express thoughts and share
8 ideas. It is important to parents that their input is valued.
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17 Avoidance of jargon was mentioned in the context of dissemination. We have also experienced that
18 it is important, in the context of ongoing team meetings, to strenuously avoid research jargon, or at the very
19 least, to take time to describe what different terms mean (e.g. secondary analysis, impact factor, lay
20 abstract). Using language that communicates with ‘insider researchers’ is not helpful and contributes to
21 power imbalance.
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29 Camden and colleagues [14] use the term ‘power sharing’, which is required for meaningful
30 engagement, teamwork, and collaboration. They recommend that consideration be given to a balance in
31 numbers of researchers and collaborators and having a flexible stance on the role that various stakeholders
32 will have over time.
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39 **Future work**

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41 Our partnership includes **mothers** of children with CP, **albeit in relatively small numbers**. In
42 future, **in addition to adding the perspective of fathers**, we have an interest in adding the voices of
43 children, youth and young adults with CP. In particular, as we move to the knowledge dissemination phase
44 of the On Track study, we are interested in working with children (and their families) to understand how
45 they prefer to receive and use feedback on the range of assessments we have developed. We believe this
46 will be a critical step to contributing to self-management as children mature.
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55 A recent systematic review on involving children and youth with disabilities in the research process
56 [20] recommended enhancing communication techniques, being flexible in adapting to needs and
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3 preferences, and securing sufficient support and funding for involvement. It will be prudent to adhere to
4 these recommendations as we proceed. Importantly, outcomes for youth were positive, and included
5 increased confidence, self-esteem, and independence.
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10 **Conclusion**

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12 We have transitioned from a purely consultative relationship to one incorporating more
13 collaboration, but we have a way to go yet. We do not have any components of the 'user control' stage –
14 this really requires a very different orientation, and much greater flexibility in posing a variety of research
15 questions and matching them with innovative and, likely, qualitative approaches. More evidence is needed
16 to identify effective strategies for meaningful health **service user** engagement that leads to more useful
17 rehabilitation research that positively impacts practice and client outcomes [14]. We hope that our
18 descriptive account and information sources cited contribute to this identified gap in knowledge.
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49
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For Peer Review

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Table Captions

Table 1. Differentiating roles of the researchers and parents in the Move & PLAY study

Table 2. Summary of current and possible future collaborative roles of service users in the research process

Box Captions

Box 1. Description of who we are

Box 2. Our shared values

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Differentiating roles of the researchers and parents in the Move & PLAY Study.

| Role of Researchers | Role of Parent Consultants |
|--|--|
| Prepared the grant submissions to the Canadian Institutes of Health Research and the National Institutes of Disability and Rehabilitation Research | Reviewed grants, provided feedback, prior to revision and submission |
| Prepared data collection booklets and training materials for therapist assessors and interviewers | Reviewed all training materials (binders, power point presentations) and data collection forms with a view to being sensitive to potential issues with respect to children and families Participated in interviewer training sessions |
| Proposed 'short titles' for research projects | Reviewed 'short titles' for research projects and responded on behalf of families about the potential interpretations |
| Drafted recruitment brochures and posters | Reviewed and refined recruitment brochures and posters |
| Drafted feedback forms and newsletters for families | Reviewed and refined feedback forms and newsletters for families |
| Drafted knowledge translation summaries | Reviewed and refined knowledge translation summaries |
| Drafted peer review manuscripts | Provided permission to acknowledge contributions to study implementation |

Box 1. Description of 'who we are'

| Name | Description |
|--------|---|
| Doreen | pediatric physical therapist for 37 years, university professor, wife, sister, aunt, great-aunt, cook, hiker, Taoist tai chi instructor |
| Lisa | Pediatric physical therapist for 32 years, university professor, wife, mother, friend; enjoys simple pleasures of reading, being outdoors, spending time with family and friends |
| Tina | Mamma Bear, social worker, mental health counsellor, service user -collaboration advocate, accidental activist |
| Barb | Proud parent of William, age 24; married to Mark since 1980; and has worked in nonprofits and philanthropy for her entire career. Additional roles she enjoys are sister, sister-in-law and aunt to a wonderful group of nieces and nephews |

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3 Box 2. Our shared values
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5 We value:
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- 7
- 8 • A commitment to fostering family-centred, evidence-informed services for children and families
- 9
- 10 • Experiential and tacit knowledge of health **service users** (e.g. children, youth, families) and
- 11 service providers
- 12
- 13 • Empowerment of children and families in the research context, including affirming ongoing consent
- 14 and respecting decisions about when to participate and what not to participate in
- 15
- 16 • Respectful interactions between research team members and study participants that do not treat
- 17 the person as 'an object'
- 18
- 19 • The generosity of research participants sharing their information for the benefit of others
- 20
- 21 • Inclusion of multiple perspectives, including those not represented on the research team
- 22
- 23 • Diverse membership with individuals with multiple identities on research teams to facilitate shared
- 24 power in knowledge generation
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- 26 • Generation of knowledge that is meaningful to individual children and families
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- 28 • Knowledge generated from both quantitative and qualitative methods
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Table 2. Summary of current and possible future collaborative roles of service users in the research process

| Issue | Our current situation | Possible Future Directions |
|---------------------------------------|--|--|
| Identifying and Prioritizing Research | Generated by academic physical therapists in context of gap in knowledge | Involve service users in setting research objectives |
| Commissioning | Funders have a role in encouraging user involvement | Service users empowered to commission research or advocate for research agendas |
| Designing and Managing | Collaborating to ensure that research is relevant, acceptable, and feasible to conduct Minimal meetings with both academic and parent researchers | More meaningful qualitative research might result with different research objectives Greater, ongoing mutual involvement in implementation |
| Undertaking | Parent collaborators have prepared newsletters for study participants, short web-based communications ('by parents, for parents'), feedback for participants, and an exit survey Assisting with interpretation of data | Service users can further participate by conducting interviews and / or collecting additional study-related data |
| Disseminating | Collaborated in preparing knowledge translation summaries, written commentaries in peer-reviewed journals, conference presentations about the collaborative process In process of developing a video on rehabilitation 'check ups' and tips on sensitively communicating prognostic information | Service users can and will participate in key peer-reviewed manuscripts and research presentations of substantive findings Service users and service providers can both collaborate with academic team members to prepare knowledge translation summaries Use of blogs, tweets, podcasts |
| Implementing Research in Practice | Focus groups with service users to understand how children and families prefer to receive research-based information about their individual children, from a service provider who is familiar with their child | Deliberative dialogue with key stakeholders of regional pediatric rehabilitation centres to understand optimal uptake at the systems level Further in-depth qualitative research on how children and families prefer to receive individualized research- |

| | | |
|-------------------|--|---|
| | | based information |
| Evaluating Impact | Informal discussions and focus groups on short-term impacts of collaboration | Formal, long-term evaluation of impact, possibly using The Public Involvement Impact Assessment Framework |

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