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CanChild
Centre for Childhood Disability Research

# *Family-Researcher Collaboration: Bringing the Family's Voice to Research*

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CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

# Contact and Disclosure Information
## AACPDM 69th Annual Meeting | October 21-24, 2015

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- We have the following financial relationships to disclose

  Funding from the Patient Centered Outcomes Research Institute & the Canadian Institutes of Health Research

- We will not discuss off label use and/or investigational use in our presentation

# Our Team

- **Robert Palisano**, PT, ScD, FAPTA, Distinguished Professor, Drexel University, Physical Therapy and Rehabilitation Sciences, Philadelphia, PA & Scientist, *CanChild* Centre, McMaster University, Hamilton, ON, rjp33@drexel.edu

- **Lisa Chiarello**, PT, PhD, PCS, FAPTA, Professor, Drexel University, Physical Therapy & Rehabilitation Sciences, Philadelphia, PA, lc38@drexel.edu

- **Barbara Taylor**, BA, Parent & Executive Director, Grantmakers of Western Pennsylvania, btaylor@gwpa.org

- **Tina Hjorngaard**, BSW, MEd, Parent & Critical Disability Advocate, Toronto, Ontario, thjorngaard@gmail.com

# Our Perspective

Family-Researcher Collaboration has the potential to address:

- Child & family priorities & concerns
- Acceptability & feasibility of interventions
- Translation of findings to practice & daily life

# Our Interest in presenting

- Share our experiences / perspectives
- Learn from your thoughts & experiences
- Advocate for family involvement in research

# Objectives

- Describe the rationale for involving parents & family members on the research team and approaches for stakeholder involvement
- Share parent perspectives on involvement on the research team
- Describe successes, challenges, and solutions to family-researcher collaboration
- Develop and Implement strategies for involving parents and family members in research

# Your experiences?

- Have you involved parents an family members in program development or research?
- What went well?
- What were the challenges?

# Including Stakeholders as Members of the Research Team

- Increases the value, integrity, effectiveness, and efficiency of the research
- Ensures research will be acceptable, feasible, and relevant
  - Brings personal and general perspectives

# Including Stakeholders as Members of the Research Team

- Consistent with democratic principles:
  - Citizenship
  - Accountability
  - Transparency
- Supported by governments and funding agencies

# Terminology from Involve

## National Institute of Health Research, 2012

- **Involvement**: Being actively involved in research projects
- **Participation**: Taking part in a research study (research participant)
- **Engagement**: Receiving and discussing research findings

# Why Stakeholders Decide to Get Involved?

Personal, Professional, Societal:

- Make a change
- Have a voice
- Give back
- Learn

# Families Involved in All Phases of Research

- Identifying research questions and prioritizing
- Commissioning: co-applicants / investigators
- Designing and managing: steering / advisory committee, developing research materials
- Undertaking: collecting data
- Disseminating: developing fact sheets
- Implementing research into health care practice and evaluating impact

# Stakeholder Involvement

- ***Consultation*** (requesting review and taking feedback into consideration)
- ***Collaboration*** (team work involving mutual appreciation of unique knowledge, skills and experience of each member)
- ***User-control*** (controlled and directed by service users and their service user organizations)

# From Consultant to Collaborator: Building Relationships

- Why are we doing this?
- Developing dialogue + shared ownership
  - 2006 referral to *CanChild*
  - Parent perspectives via assessment tools + materials (phone + email)
  - Reciprocal feedback + commitment to continue

# Consultant to Collaborator: Key Ingredients

1. Transparency of Research
2. Expectations of Consultants
3. Ongoing Reflective Process
4. Structure of Consultants' Involvement
5. Power Relationship

# Value for
# Parents & Families

- Doing something positive -> less ‘victim’ perspective
- More informed and engaged families -> better medical consumers, better decisions by entire therapy team
- By being involved in research affecting our children, we are helping to create the world we want our children to live in.

# Value for
# Parents & Families

- While family involvement creates a more complex and slower process, diverse voices -> better results
- Intellectual interest
- Knowing parents are helping therapeutic professionals focus on knowledge that is most relevant
- A way for children and families to feel they are helping others: it's empowering

# Collaborator Retention

1. Value consultant as collaborator
2. Project meetings
3. Explicit collaboration
4. Reciprocity

# Move & Play
# On Track Studies

# *Understanding Determinants of Motor Abilities, Self Care, and Play of Young Children with Cerebral Palsy*

- Validate a multivariate model of determinants of change in basic motor ability and engagement in self-care and play of young children with cerebral palsy.
- 429 children (mean 3.2 years) and families
- 2 assessments (1 year apart) & phone interview (6 months)

Move & Play

# *Developmental Trajectories of Impairments, Associated Health Conditions and Participation of Children with Cerebral Palsy*

**Create developmental trajectories (18 months - 12 years) for:**

- Primary impairments & secondary impairments
- Health conditions
- Self-care
- Participation in recreational activities
- 771 child & families, 2-5 assessments 6 or 12 months apart

# Multisite Studies

- *Move & Play* funded by Canadian Institutes of Health Research (CIHR) & National Institutes on Disability and Rehabilitation Research
- *On Track* funded by CIHR and Patient Centered Outcomes Research Institute
- 4 geographical regions in US and 6 provinces in Canada
- PI & Co-I: Doreen Bartlett, Sally McCoy, Lynn Jeffries, Alyssa Fiss, Piotr Wilk, Steve Hanna , Peter Rosenbaum, Jan Willem Gorter

# Procedure

- Therapists administered standardized measures of body functions & structures, activity, and participation

- Parents completed measures to describe their family, children’s development, amount and focus of therapy, and extent service needs were met

# Team Meetings

***Move & Play Study***

- Monthly teleconferences
- Meetings at conferences

***On Track Study***

- Monthly  teleconference (primarily investigators)
- Monthly teleconference by parent members and 2-4 academic investigators
- 1-2 times per year – entire team meets

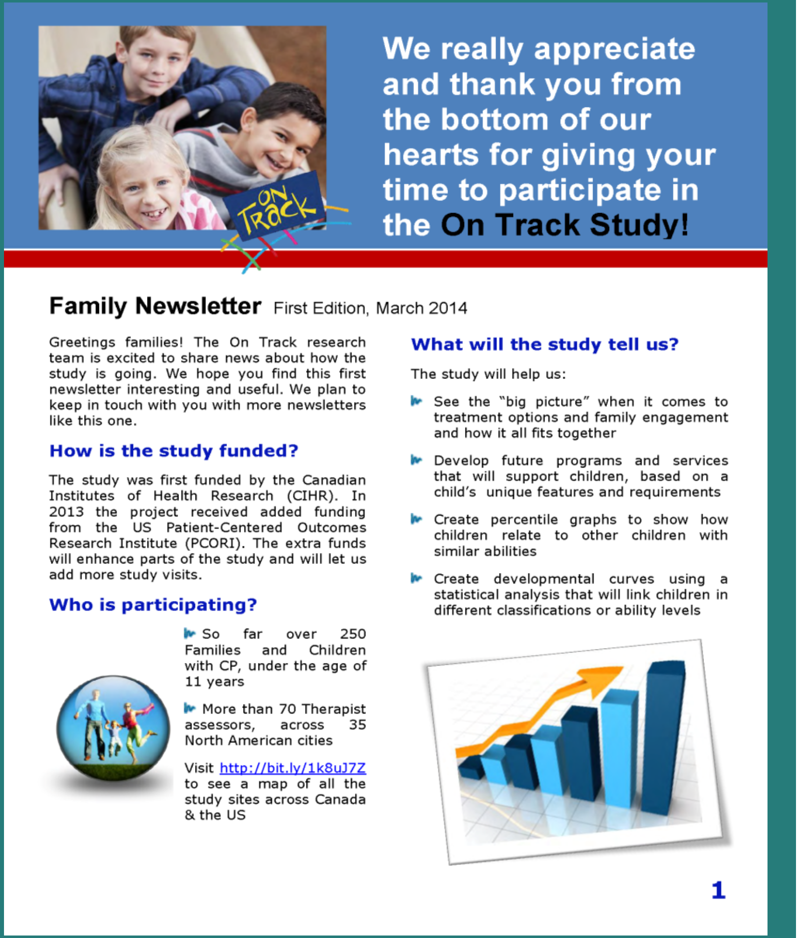
# PCORI grant

- Mission:

  Help people make informed health care decisions by producing and promoting high integrity, evidence-based information – that comes from research guided by patients, caregivers and the broader health care community

- Funds  for 7 parent members – representing geographical regions where study conducted

# Activities and Family Contributions



**We really appreciate and thank you from the bottom of our hearts for giving your time to participate in the On Track Study!**

## Family Newsletter First Edition, March 2014

Greetings families! The On Track research team is excited to share news about how the study is going. We hope you find this first newsletter interesting and useful. We plan to keep in touch with you with more newsletters like this one.

### How is the study funded?

The study was first funded by the Canadian Institutes of Health Research (CIHR). In 2013 the project received added funding from the US Patient-Centered Outcomes Research Institute (PCORI). The extra funds will enhance parts of the study and will let us add more study visits.

### Who is participating?

- So far over 250 Families and Children with CP, under the age of 11 years
- More than 70 Therapist assessors, across 35 North American cities

Visit http://bit.ly/1k8uJ7Z to see a map of all the study sites across Canada & the US

### What will the study tell us?

The study will help us:

- See the "big picture" when it comes to treatment options and family engagement and how it all fits together
- Develop future programs and services that will support children, based on a child's unique features and requirements
- Create percentile graphs to show how children relate to other children with similar abilities
- Create developmental curves using a statistical analysis that will link children in different classifications or ability levels

you the chance to tell us in your words what you think is most important about your child and his or her progress while in the study. Also, please remember that you are always encouraged to add comments to the study booklets. Feel free to use the opposite blank page or the page at the end of the booklet to include any additional information you would like us to know about your child. If filling out the questionnaires online, feel free to use the "comments" section. Our parent team also plays a big role in putting together newsletters like this one, finding resources, and passing on helpful tips.

Feel free to contact the parent team if you have ideas to share! Their contact information is listed on the study website.

### Parent Investigator Profiles

In each newsletter we will feature two of the parents. In this issue, we would like to introduce you to: Kimberly Rayfield and Barbara Sieck Taylor.

**Kimberly Rayfield** is a single mother of three children in Philadelphia, Pennsylvania. Over the years Kim has been tested with many obstacles but she seems to overcome them with flying colors. In 2001, her youngest son Jymere (age 14) was struck by a vehicle at age two. From that very moment her life changed dramatically. Not only did she become the voice for Jymere, but she became an advocate for people with disabilities of all ages. Kim is also a cancer survivor.

What gives her strength? Kim's inner strength comes from her son Jymere. His smile and strive for life runs her motivation. She has made it her goal in life to make sure that Jymere gets to enjoy life as much as any other child his age. He gets to play in the park and play baseball (catcher or pitcher). He is involved in the local community center where he plays "hide & seek," board games, and does arts and crafts with the other children.

**Barbara Sieck Taylor** lives with her husband Mark and her son William, 22, in Pittsburgh, Pennsylvania. She has over 30 years of experience in the nonprofit sector, working as a professional actress, a nonprofit administrator, a program officer for two foundations, a fund development officer, and most recently as executive director of a professional association for philanthropies. For six years, she served on the board of directors of the ARC of Greater Pittsburgh, including one year as its chair. For two years, she directed ACHIEVA's Disability Health Policy Forum, an advocacy project focused on oral health care for people with disabilities in Pennsylvania.

As a parent volunteer, for eight years she was the co-director of Conductive Education of Pittsburgh (now Steps to Independence); creation of this program brought a special education system designed specifically for children with CP, and widely used in the U.K. and Europe, to the Pittsburgh region for the first time.

Barbara was a parent consultant to the Move & Play study (2006-2009). She co-authored a commentary published in 2010 in Physical & Occupational Therapy in Pediatrics titled Parent Perspectives: The Family-Therapist Relationship.

Her most meaningful accomplishment is that William, who has cerebral palsy and intellectual disabilities, is healthy, happy and enjoys loving support from his family and friends.

# Undertaking

- Trainings: supportive guidance to data collectors
- Recruitment: breadth of avenues to make research accessible

# Designing and Managing

- Refinement of titles, models, and measures: clarity, feasibility, acceptance, relevance
- Communications to keep family participants and therapist assessors informed and engaged: family newsletters, parent to parent column, and contribute to assessor newsletters and teleconferences
- Input when questions and issues arise

On Track Family Newsletter

First Edition, March 2014

## Parent to Parent: Therapy in Natural Environments

My name is Kimberly Rayfield and my son's name is Jymere. As a parent of a child with a disability, I know it's hard trying to get everything done in your day—no matter how hard we try we can't always do it. In trying to balance the needs of all of my children, I learned to incorporate new ideas about therapy. In Pennsylvania, early intervention services are provided in natural environments. Natural environments include not just the home but also places in the community that are part of family routines and where young children learn and play.

As a young child, Jymere's early intervention services were often provided in the community:

- Sometimes the physical therapist and I would take Jymere to the park while my older son, Darryl, practiced basketball
- When Darryl's games conflicted with Jymere's PT, we took the physical therapist with us to the gym, where we worked on positioning on the bleacher so that Jymere could watch the game and I could learn how to position Jymere
- The physical therapist also went with us to the supermarket to work on positioning in the cart while I shopped
- We scheduled therapy sessions at a local recreation center, where Jymere learned to ride his bike, play ball, and play with other children on the floor mats
- Jymere, his speech therapist, and I would also go to the library for the "reading for tots" program
- The three of us even went to McDonalds for lunch to work on Jymere's swallowing
- I used my membership at the *Please Touch Museum* to bring the occupational therapist and work on Jymere's sensory motor skills and stretching.

I encourage parents to utilize the resources that are in their community (natural environments) and incorporate them in their therapy sessions, which sometimes involves the whole family. When discussing options with your child's therapists speak from your heart on what you want your child to try to do or be able to do!

## Resources

CanChild
Centre for Childhood Disability Research

- *CanChild* Centre for Childhood
  Research is a research and ed
  centre located at McMaster Ur
  Hamilton, Ontario, Canada. *Ca*
  research is focused on improv
  of children and youth with dis
  their families.
- Founded in 1989, *CanChild* is
  leader in the field of childhood
  disability. *CanChild*'s cutting-e
  research and strategies for ma
  findings available to a wide ra
  audiences make *CanChild* the
  for childhood disability inform
- The public, web-based resour
  *CanChild* website are accessed
  3000 people per month from
  countries. The website provid
  access to *CanChild* documents
  past and current research, art
  Keeping Currents, measures,
  interesting websites
- The website gives a customize
  experience for parents, servic
  and researchers

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On Track Family Newsletter

Second Edition, September 2014

Parent to Parent

## Parent to Parent: Learning to Transition.

**By Marquitha Gilbert**

Since the birth of my twins, at 23 weeks gestation, I have had to learn to transition… transition into parenthood, transition into losing a child, transition to caring for a child with special needs…and it keeps going. Transitioning means: leaving what you have come to know as your "norm" and going to a place that is unfamiliar, different, sometimes exciting but most often scary. I accepted that each transition has had a lesson that made moving through the transition just a bit more manageable.

**Transitioning from hospital to home:** Few people like being in the hospital. For a fragile child, however, the hospital had a level of security. People and machines that were ensuring appropriate care. As we left, there was fear of losing the extra eyes that watched my child and assured me all was okay; it was leaving the machines that showed me hourly that my child was breathing and functioning appropriately; it was being a parent - in our case, for the first time - with machines and tubes we now took home and had to monitor ourselves. It was scary. *Lesson*: Ask a lot of questions, be comfortable in what you know and don't be ashamed to ask about what you do not understand.

**Transitioning into in-home nursing care:** My home went from being a sanctuary to having many "strangers" - i.e., nurses for day or night shift with different nurses on different days, therapists for all aspects of care - in and out on a regular basis. Things were no longer in their place, things were missing or broken, and there was no longer peace. I set schedules, parameters and still I felt invaded, yet grateful, since the presence of people abated some of the fear developed from leaving the hospital. *Lesson*: Set ground rules, establish clear expectations on both sides, and make sure that you address any issue early to avoid letting it fester.

**Transitioning into early intervention:** Now, added to the nurses were therapists. Their goal was to teach us ways to integrate little things into our daily routine that would encourage development. *Lesson*: Make sure the therapists understand your family life. Be comfortable saying what is realistic with your routine and that you understand the purpose and intent of the activity.

**Transitioning from early intervention into preschool:** The comfort I had with knowing my child was home was now shattered with a new routine based in a school setting. The separation was both normal and terrifying. I now had to learn a new "system" in the school and learn how to let go of what I had just learned how to manage. Therapies were now done in school and were no longer integrated into the family routine. I was less involved in many ways and was feeling left out. *Lesson*: Use the team meetings with the teachers and therapists to fully understand their goals and be sure to share what you see and do at home, ask for ways to duplicate what they do to help observe the development, and be able to share your perspective on improvements or lack of. Keep communication open!

**Transitioning from preschool to elementary school:** When my child attended preschool, the teachers and therapists regularly shared a great deal of information on how she was doing. The preschool staff seemed to have an implicit

# Informing

- What families want to know about the development of their children with cerebral palsy
- How should assessment information be shared with families?
- Development of family exit survey

# Disseminating

- Videos that feature families and children and integrate their stories and key messages / findings from the research
- Knowledge translation fact sheets: Implications for families and therapists
- Presentations on involving families in research: Division for Early Childhood Conference
- Article in preparation: "Moving from Parent Consultant to Parent Collaborator: One Research Team's Experience"

## What does this mean?

### Thoughts for families

- Therapists need to know about the whole child, and all aspects of how the body functions; a problem with moving around is not the whole picture of your child's health
- Knowledge about your child's health issues, and about how these health conditions affect daily life, is important for everyone involved in their care
- Parents need to share information with their children's therapists about health conditions, hospitalizations, and surgeries, so that together, they can plan the best care
- Therapists are health care professionals, and a source of information regarding your child's health

### Thoughts for service providers

- There is a lot of variation in children's health
- Service providers working with young children with CP need to regularly ask about health conditions, and consider their impact when planning care
- Children with CP are affected by more health conditions than children without CP, and the average impact of these conditions is also greater among all children with CP, regardless of motor ability
- The high occurrence of a variety of health conditions, and the extent to which they affect the children's daily activities, suggests that more attention be paid to this important aspect, particularly for children with lower motor abilities
- It is important for therapists to discuss with families how the children's health conditions impact the children's daily lives. Service providers have a role in health promotion and prevention. They can include strategies in care plans to reduce the impact of health conditions on daily life of children and families
- There is a need for coordinated care, including monitoring children's health, and providing information to families. Service providers should make referrals to other appropriate health professionals as indicated

# Parent Members
# "On Track" Research Team

- Lisa Diller, Seattle, Washington
- Nancy Ford, Atlanta, Georgia
- Paula Drew, Edmonds, Oklahoma
- Marquitha Gilbert, Philadelphia, Pennsylvania
- Kim Rayfield, Philadelphia, Pennsylvania

# Parents' Themes

- *My child has unique abilities*
- *What might I expect? From my child, myself, our therapist*
- *What can we do to help my child?*
- *How is my child making progress in functional abilities?*
- *Comparisons to other children are not useful*
- *Use clear language when sharing results*
- *Life goals: Working together is the key*

# William

# Mika

# Parent Team Process

Start:

- Formal
- Professional + Academic
- Exclusive
- Limited Overview

# Parent Team Process

Middle:

- Insight + Validation
- Investment in Project
- Ownership

# Parent Team Process

Current:

- Integrity of Group
- Evidence of Sustainability
- Retention of Parent Team Collaborators

# Parent Collaborators:
# What we have learned

- Our knowledge & experiences matter
- Representative inclusion is beneficial
- Parents bring creativity to research
- Critical perspective to medical model

# Academic Researchers: What we have learned

- Many stakeholders: families, children, youth, adults with a disability, practitioners
- Start early: wish that we had families involved in generation of research question and proposal
- Reflect, discuss, plan
- Get to know each other as people: in person and online

# Academic Researchers: What we have learned

- Communicate: clarify roles, responsibilities, time commitments, payment; inform group of actions and decisions
- Productive meetings through group discussion and teleconferences
- Give adequate time for review of materials
- Offer and provide support / resources

# Academic Researchers: What we have learned

- Provide parents the opportunity to share their thoughts and perspectives
- Make sure everyone on team is heard
- Families are engaged: hopeful stance, committed, confident, solution-focused
- Families value learning about the academic world

# Academic Researchers: What we have learned

- Family contributions are invaluable
- Document process
- Takes time and interest: Our value for the process keeps us grounded

# Thoughts & Suggestions

- Optimizing family involvement & collaboration in research
- Envisioning the possibilities

# Take Home Messages