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

อารมณ์ที่เหมาะสมกับคุณค่าทางการเมือง:

- 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

 giorno 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.

 giorno 429 children (mean 3.2 years) and families

giorno 2 assessments (1 year apart) & phone interview (6 months)
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
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!


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 additional 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/14xu7z 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

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.

Kimberley 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 stride 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
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 bleachers 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 kids” program.
- The three of us even went to McDonald’s for lunch to work on Jymere’s swallowing.
- I used my membership at the Peace 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 is a research and advocacy centre located at McMaster University, Hamilton, Ontario, Canada. CanChild’s research is focused on improving outcomes for children and youth with disabilities.
- Founded in 1989, CanChild is leader in the field of childhood disability. CanChild’s cutting-edge research and strategies make CanChild the national resource for childhood disability information.
- The public, web-based resource CanChild website is accessible to 3000 people per month from 14 countries. The website provides access to CanChild documents and databases, and offers past and current research, articles, discussion boards, and educational information.
- The website gives a customized experience for parents, service and researchers.

Parent to Parent: Learning to Transition

By Marquita Gilbert

Since the birth of my twins, at 23 weeks gestation, I have had to learn to transition into parenthood, transition into losing a child, transition to caring for a child with special needs...and it keeps going.

Transitions 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.

Transitions 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.

Transitions 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.

Transitions 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.

Transitions from early intervention into preschool: The comfort I had with knowing my child was home was now shattered with a new routine based on 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. Lesson: Be patient; 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. Lesson: Ask for ways to duplicate what you do at home, ask for ways to help observe the development, and be able to share your perspective on improvements or lack of.

Transitions 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"
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
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
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
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