



RECOMMENDATIONS FOR HOPEFUL CLINICAL PRACTICE

Sacha Bailey, MSW, PhD(c)

WHY FOCUS ON HOPE?

In interactions with parents who have children with neurodevelopmental diagnoses, hope is often made reference to. Parents speak of having hope, looking for hope, needing more hope “in the system”, wanting information about their child to be communicated in a way that allows for hope. Parents and clinicians alike wrestle with tensions such as promoting hope on one side and encouraging realism on the other. Questions arise such as: what constitutes “realistic” hope? How to have a balance between hope and realism? How to be hopeful as a parent to a child with unanticipated challenges? These questions and experiences led to a desire to gain a deeper understanding of what it looks like to hope as a parent of a child with a neurodevelopmental diagnosis.

WHY IS THIS RESEARCH NEEDED?

A great deal of research has demonstrated that parents of children with neurodevelopmental diagnoses report having poorer physical and psychological health than parents of typical children. Some of the emerging research on hope has found that hope can act as a resilience factor - meaning that if you have more of it you will adapt better to stressful situations. For example, parents who report more hope also report less depression, anxiety, stress and better coping than those who report having less hope. Despite these favorable findings, we do not yet understand the underlying mechanisms behind these relationships and we still lack an understanding of what it *means* to be hopeful as a parent to a child with a neurodevelopmental condition.

Without having a better sense of what the experience of hope is like for parents, those healthcare providers who work with families are left to make assumptions. Some parents recount having been given the message that if they come across as being *too hopeful*, that they have not fully integrated the news of their child’s condition or that they are in denial. This suggests that parents and healthcare providers can have diverse perceptions and insights about hope. And so it becomes very important to attempt to get a meaningful understanding of the experiences of hope and why it matters to parents.

Through a study of the experience of hope among parents of children with neurodevelopmental diagnoses, a model of how hope is experienced over time was expounded. One aspect of this model explained that parental

hopes for their child shift over time and are largely grounded in the realm of what is possible (for example, hoping for establishing a new normal or hoping for the achievement of milestones). These findings demonstrate the importance of hope to families and the integration of hope into clinical care.

GENERATING RECOMMENDATIONS FOR HOPEFUL CLINICAL PRACTICE

A group of researchers and students from the Parenting Matters! team presented selected findings from our work at a symposium of the Canadian Network of Children and Youth Rehabilitation (CN-CYR) and the Canadian Family Advisory Network (CFAN) at the 2014 annual meeting of the Canadian Association of Paediatric Health Centres (CAPHC). The participants at this symposium included health care providers, parents, policy makers, managers/administrators, and researchers.

HOW WAS DATA COLLECTED?

Participants were introduced to four “myths” related to parenting children with neurodevelopmental diagnoses, followed by evidence from our work that counters the myth, and finally a discussion question was posed relating to how these findings might be integrated into clinical care. One of the myths presented was: **parents who are hopeful are in denial**. The question posed to the group was: **how should hope be integrated into clinical care?**

In small groups of five or six, participants were asked to develop three priorities related to the discussion question; they were given ten minutes to do so. Each participant was then invited to select one of the three priorities that resonated for her and write it down on a small cue card. Participants were then given thirty seconds to walk around the room and switch cards with each participant they saw. When the facilitator told them to stop, participants were to read the recommendation on the card in their hand to the person in front of them.

Together, the two participants were to rate each statement on each card on a scale of 1 (low priority) to 7 (high priority) and to write the number on the back of each card. The card exchange was repeated twice more so that at the end of the activity, each recommendation had three rankings on it, for a maximum score of 21. The cards were collected at the end of the activity and reviewed by the research team to identify the highest ranked recommendations and then analyzed thematically to determine the themes that appeared most frequently among the recommendations.

A total of 88 recommendations were collected for this activity from the participants at the workshop. From those who indicated their role, 5 were administrators or managers, 9 were parents or family members, 31 were service providers, and 2 indicated that they belonged to more than one of those groups. Five recommendations received perfect scores of 21. These top five recommendations are listed in the box below. When the recommendations were analyzed thematically, three themes emerged as the most endorsed by participants.

TOP FIVE RECOMMENDATIONS FOR INTEGRATING HOPE INTO CLINICAL CARE

1. As a manager, ensure clinicians have the knowledge, skills, and attitudes to engage in conversations about hope.
2. As a clinician, integration into curriculum of healthcare students the importance of hope in care.
3. Clinician: Make the question “what do you hope for today” (ask child directly or ask parent), as a routine part of rounds or daily interactions – just Family-Centered Care!
4. Clinician inviting parent to share his/her immediate hope for their child
5. As a clinician, I can integrate hope by listening to parents without judgment and validate their feelings.

THREE RECOMMENDATION THEMES

1. **Create opportunities for discussion about parent and child hopes where families feel listened to, respected, and supported** (41 recommendations)

The importance of integrating explicit conversations about hope into clinical care was widely endorsed by participants. By inviting parents to share their immediate and long-term goals, wishes, and hopes for their child, and listening with non-judgmental curiosity, clinicians can help parents explore their hopes and can offer examples of hopes and goals when parents are struggling to find them. One example of how to create these opportunities is to make hope questions a routine part of interactions with families. For example, asking the child and/or parent: "What do you hope for today? Tomorrow? The future?" or "What does hope look like for you?" The responses to such questions could form the basis of the formulation of care plans and goals.

2. **Offer hope training to clinicians** (20 recommendations)

In order to integrate conversations about hope into clinical encounters, clinicians may require training to feel confident in their ability to broach the topic of family hope and to explore family members' hope and goals for the future. For example, clinicians may be preoccupied with wanting to support families in finding a balance of hope and realism in their goals for the future for their child. This requires having frank discussions about a child's level of complexity and potential to advance. Some clinicians may benefit from additional training about how to have these kinds of conversations with families. Participants suggested educating

clinicians about the importance of hope, exploring myths related to hope (such as the one presented in the workshop), and training them to engage in hope-inspiring dialogue and conversations about hope with families. Participants noted that training and professional development should begin with integration into allied healthcare curricula and should be ongoing.

3. **Align service provision with family goals, needs, and hopes** (15 recommendations)

Once health care providers are comfortable exploring a family's hopes for the future, they can integrate them into the child's care plan. For example, parental hopes for their child and child hopes can be used as springboard for short and long-term goal setting. In other words, clinical goals should be shaped toward family hopes for the child, rather than toward generic goals or goals that may not be important to the family. In this way, health care providers empower and facilitate the realization of child and family hopes.

WHAT CAN BE DONE WITH THESE RECOMMENDATIONS?

The clinical recommendations generated from this activity can be taken up by healthcare settings at both a systemic and an individual level to enhance the services provided to families of children with neurodevelopmental diagnoses. Our hope is that these ideas might spark discussion on your team about how recommendations such as these might be taken up. Perhaps you might take one or more of the recommendations and consider how they might be helpful to you in your particular context with your particular clientele. We look forward to hearing about how you have incorporated, expanded, and promoted these important practical recommendations.



ABOUT PARENTING MATTERS!

Parenting Matters! is a project which explores the biopsychosocial context of parenting children with neurodevelopmental disorders (NDD) in Canada. The aim of this project is to better understand the extent to which parenting children with NDD differs from parenting in general, what makes a difference to parenting, the difference that parenting makes to child outcomes, and whether there are ways of understanding parenting that is unique to this population. This project consists of four multi-method studies:

1. A systematic review of quantitative and qualitative research to understand parenting behavior, cognition, and style as well as social, family, and child correlates of parenting;
2. Secondary data analysis of the Canadian population-based National Longitudinal Survey of Children and Youth (NLSCY) to quantitatively compare parenting children with NDD to parenting typically developing children;
3. A clinical study to examine predictors and experiences of parenting children with NDD;
4. A review of the legislation and a survey of existing policies and programs to document those services available to Canadian parents of children with NDD in the areas of income support, respite/alternative care, and case management.

The Research Team is comprised of Peter Rosenbaum (nominated principal investigator); L. Lach and D. Kohen (co-principal investigators); R. Birnbaum, J. Brehaut, R. Garner, M. McKenzie, T. McNeill, A. Niccols, D. Nicholas & M. Saini (co-investigators); S. Bailey, A. Bogossian, G. Glidden, & A. Ritzema (doctoral research assistants), as well as additional graduate research assistants.

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