

Documenting the Lives of Families of Children with Neurodevelopmental Conditions:

FROM UNDERSTANDING TO IMPACT

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DIFFERENT TYPES OF NEURODEVELOPMENTAL DISORDERS



Documenting Whose Life?

- ▶ Neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations.
- ▶ A specific diagnosis may not be identified.
- ▶ Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity.
- ▶ **The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour**

Morris et al., 2013



Type of
impairment is a
stronger predictor
of family and child
outcomes than
the diagnosis itself
(Miller et al., 2016)





Documenting The Lives of Children with Neurodisabilities ***and*** Their Caregivers

Documenting How Many There Are...

National Longitudinal Survey of Children and Youth in Canada: 9.15% (1:11)

- ▶ Checklist of conditions: cerebral palsy, epilepsy, mental handicap and learning disability
- ▶ Health Utilities Index: speech, dexterity, ambulation, cognition (Arim et al., 2015)

PopDataBC: 8.3% (1:12)

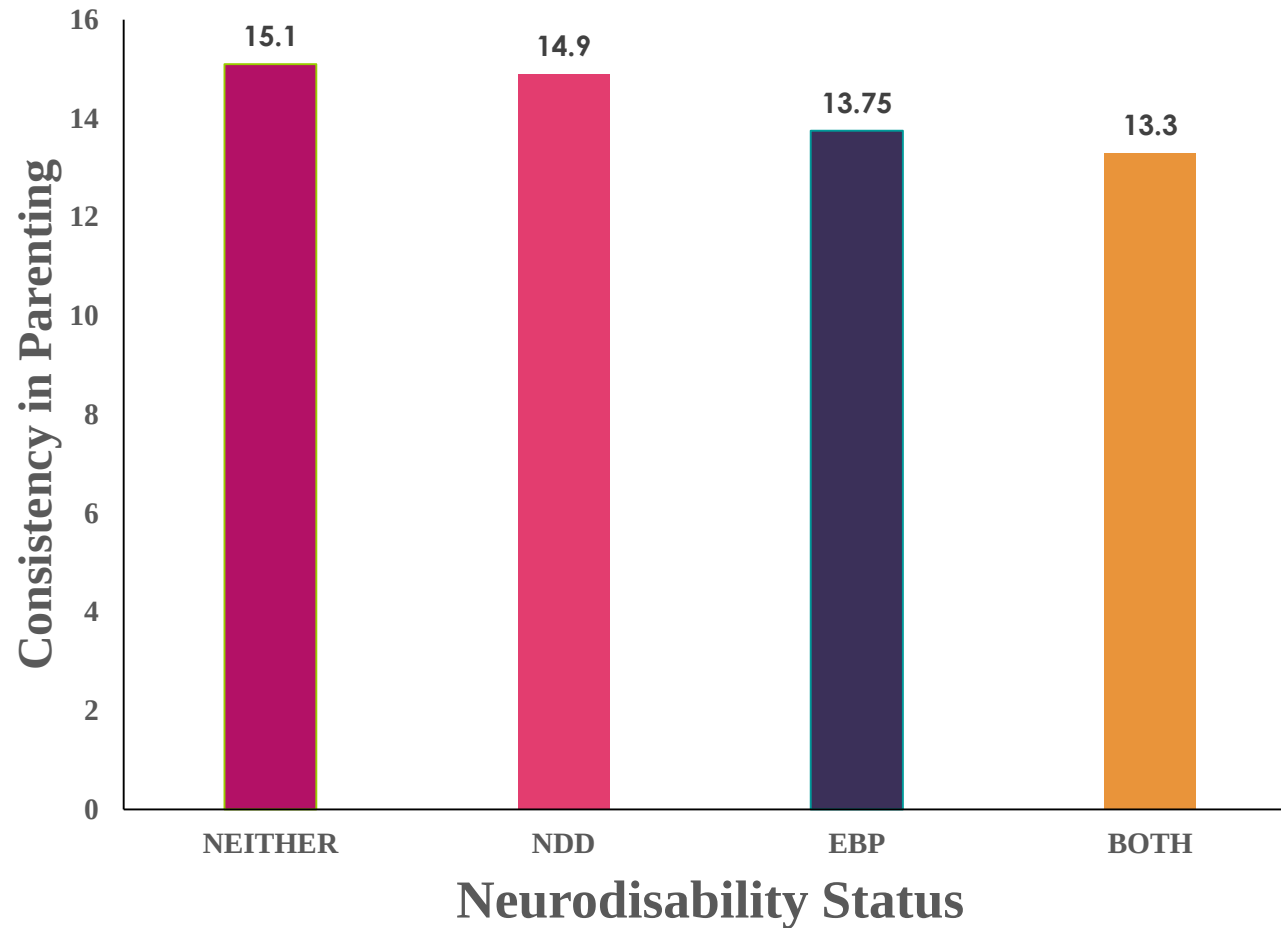
- ▶ Health administrative data
- ▶ Doctor's visits, medication use, hospitalizations (Arim et al., 2017)

Documenting Parenting

Practice Assumption #1

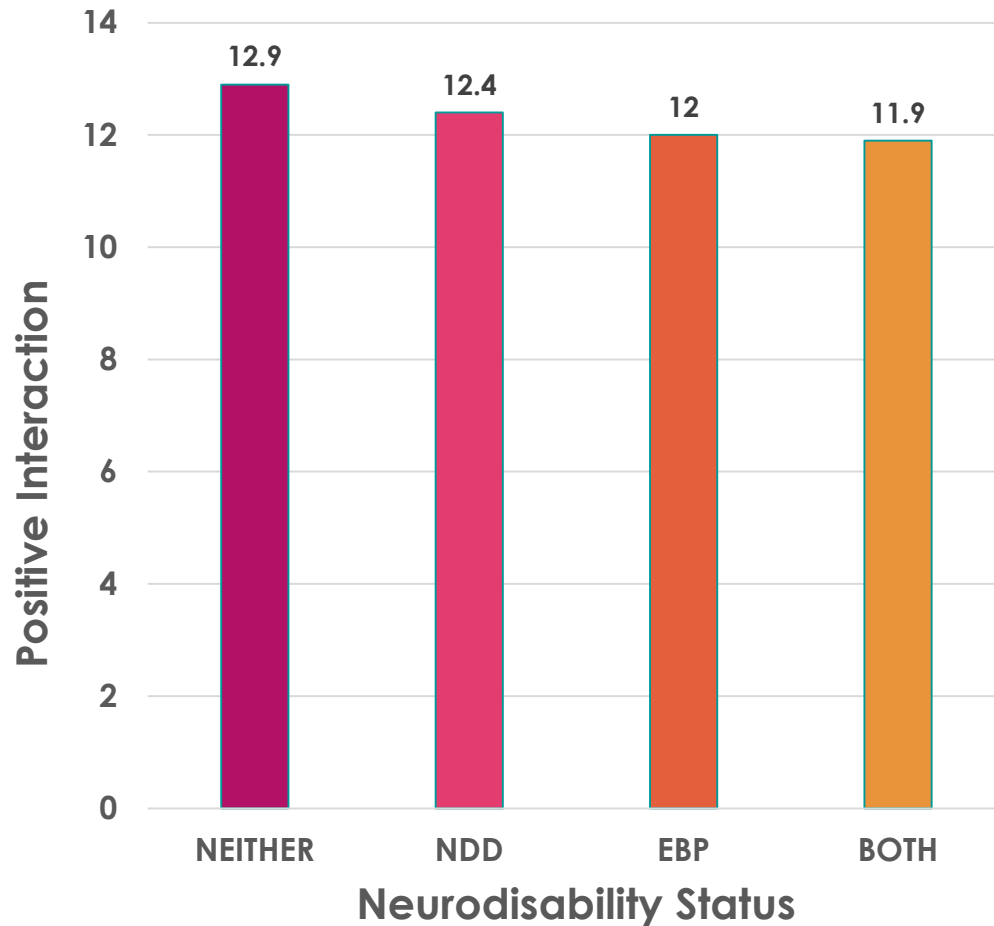
Parenting a child with a neurodisability is just 'parenting +'.

Parenting a child with a neurodisability is just like parenting any other child but with more responsibilities and obligations (extra meetings and appointments, managing extra expenses, additional care, equipment)



Are they as
consistent in their
parenting
behaviour?

Both is different
from NDD and
Neither group

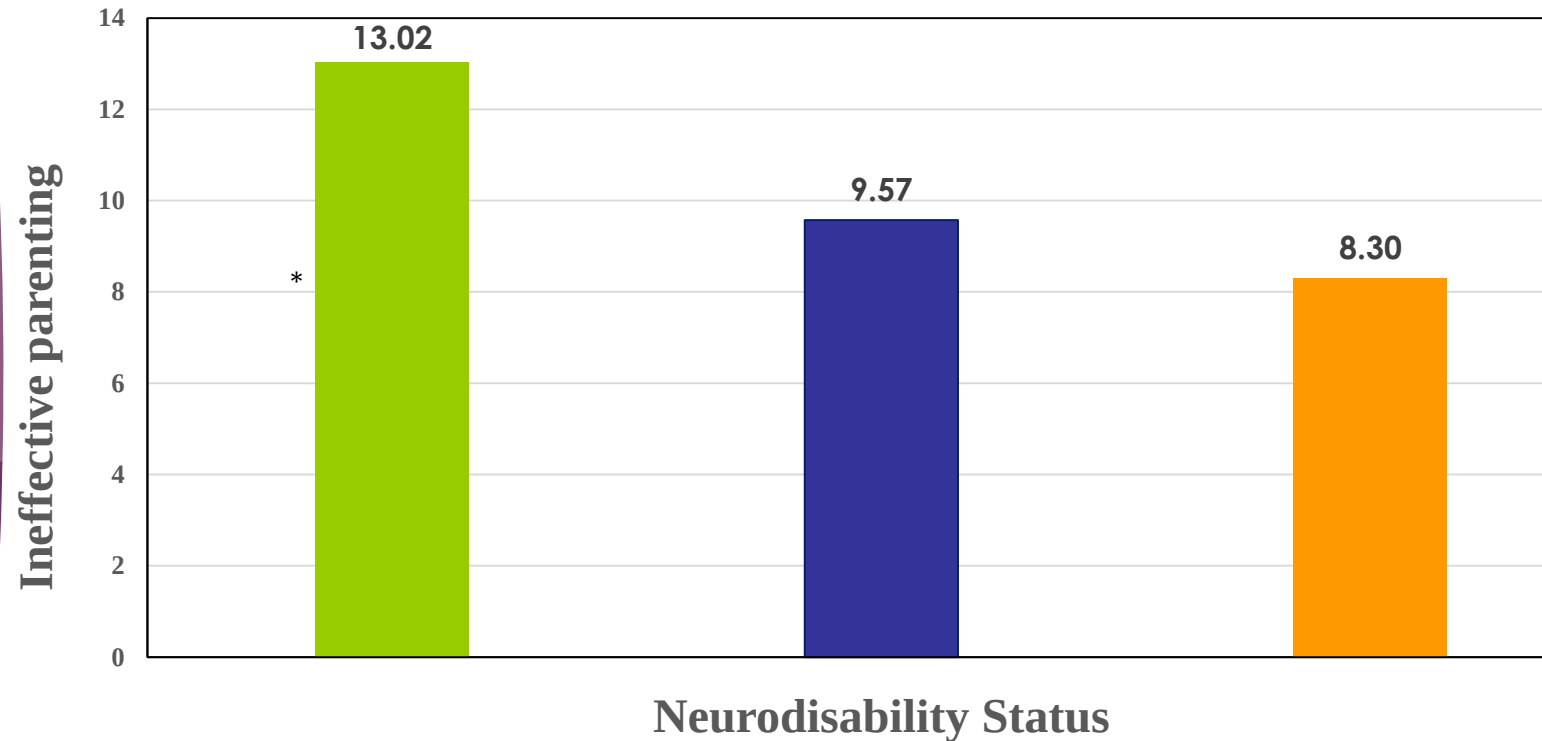


Are their interactions
equally positive?

Both and NDD
different from
Neither group

Do they differ in
how effective they
think they are as
parents? *

NDD and Both
reported feeling
more “ineffective”
than Neither



Source: National Longitudinal Survey of Children and Youth, Cycle 1.

Garner et al. *Child: Care, Health and Development*, 2013; 39: 412–421

Documenting The Context of Parenting

Parenting in Context

- ▶ **Worse physical health**

- ▶ Parents of children with neurodisabilities are 1.5x more likely to report a chronic health condition (i.e. back problems, high blood pressure, heart disease, etc.); 1.7x more likely to report having an activity limitation, and are less likely to report their health as excellent/very good (when compared to parents of children without ND). Those whose children also have behavior problems, are at increased risk (2.1x and 2.4x (Lach et al., 2009)

- ▶ **Compromised quality of life**

- ▶ Parents of children with CP report the following: disrupted sleep, difficulty maintaining social relationships, pressure on relationship with spouse/partner, difficulty taking family holiday, limited freedom and time, difficulty maintaining employment...(Davis et al., 2009)

Parenting in Context...

- ▶ **Higher levels of mental health concerns (i.e. depression, anxiety)**
- ▶ Parents of children with ND, have higher levels of depressive symptoms. If child also has behavior problems, odds for having somewhat or very elevated depressive symptoms are 3.7x higher (Lach et al., 2009)
- ▶ Mental health of female caregivers of children with CP was significantly worse than general mental health of general population (Byrne et al., 2010)
- ▶ **Higher levels of stress**
- ▶ 26% of caregivers reported high levels of parenting stress (Parkes et al., 2011)
- ▶ Caregivers had higher levels of salivary cortisol (Bella et al., 2010)

Parenting in Context: An Emerging Alternative Narrative

- ▶ **What's the good news?**
- ▶ 85% of caregivers of children with ND had no to minimal levels of depressive symptoms (68% if child also had a behavior problem) (Lach et al., 2009)
- ▶ **Empowerment**
- ▶ A strong network of social support and family-centred services are critical to a sense of empowerment (Nachshen & Minnes, 2005)
- ▶ **Hope**
- ▶ In a systematic review published in 2015, there were 11 papers on hope (McCool, 2015). If you have hope, you are likely happier, feel positive, less stressed, depressed and anxious, and your family is more likely to be able to adapt to challenges.
- ▶ Turns out, parents have lots of it, layers and layers, and the kind of conversations we have with them as practitioners, are instrumental in shaping it (Bailey, 2018)
- ▶ **Resilience**
- ▶ Doing relatively well given the challenges that a caregiver is facing (i.e. experiencing personal growth, self-efficacy, life satisfaction (for review see Paz & Wallander, 2017)

What makes a difference to parent well-being?

▶ Things that are difficult/impossible to change:

- ▶ Caregiving Demands
- ▶ Income/Education
- ▶ Marital status
- ▶ Challenges in function related to communication and intellectual impairments
- ▶ Pain

Things that could be changed (not always that easily):

Child behavior

Stress management activities (diet, exercise)

Family function (including parenting)

Hope

Social Support

Positive Attitude

What makes a difference to how parents parent?

The Disability



Dx,
Complexity,
Behaviour problems

The Family



Parent morale and hope
Co-parenting alliance

Parenting Behaviour



Autonomy/Dependence

The Child

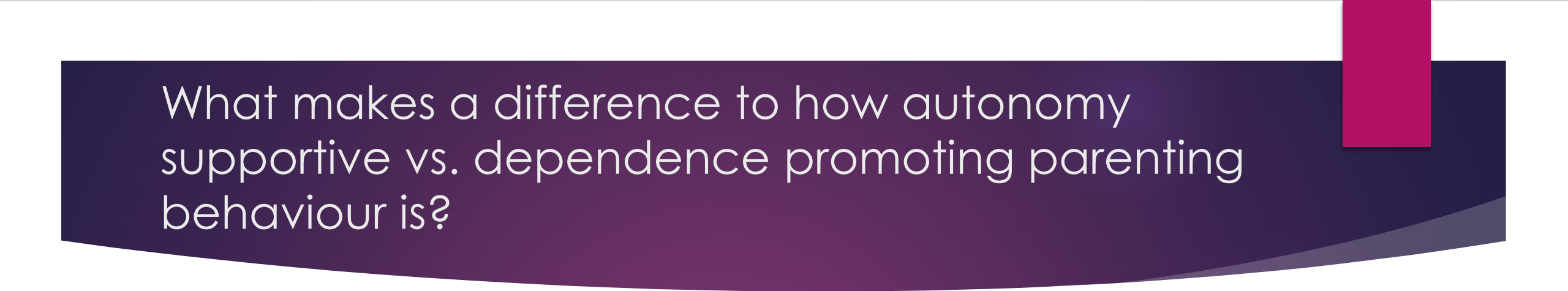


Prosocial behaviour
Mastery

Parent-teacher relationship

Social Environment





What makes a difference to how autonomy supportive vs. dependence promoting parenting behaviour is?

- ▶ Parenting behaviour that promotes child's autonomy over dependence is associated with:
 - ▶ Lower complexity of child's neurodisability
 - ▶ Higher parental hopefulness – thoughts about child's future

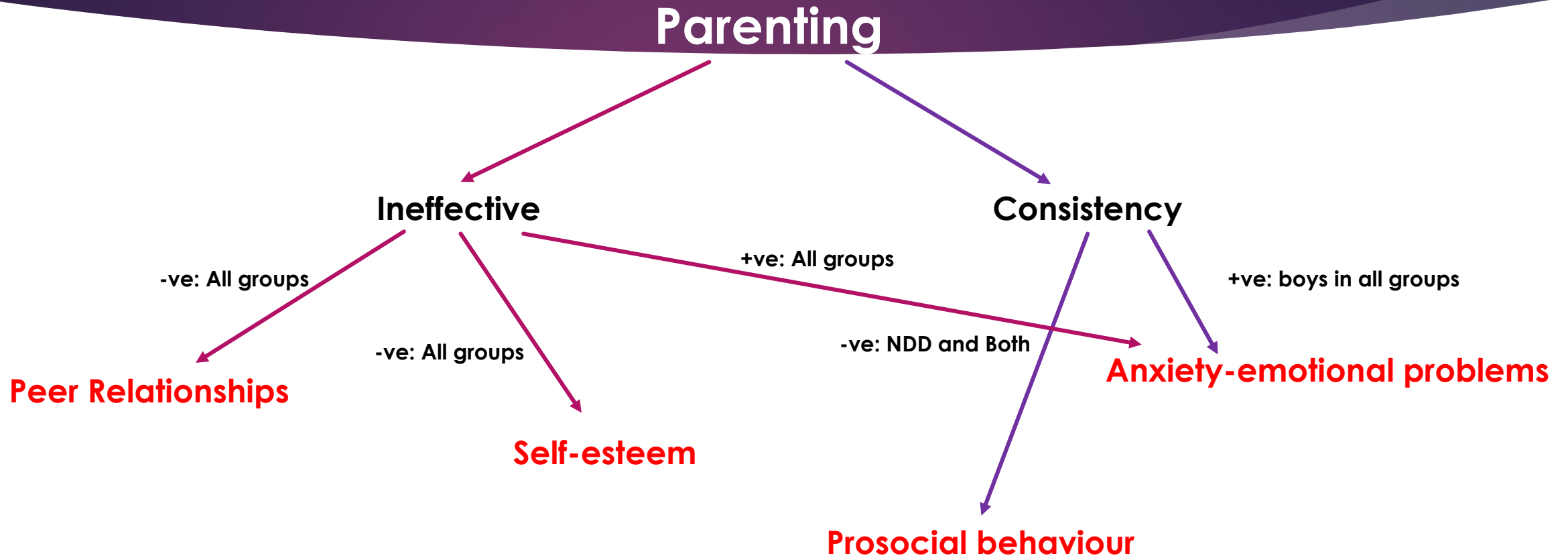
Practice Assumption #2



vs.



What difference does parenting make to these child outcomes?



After taking into account neurodisability status and demographic factors...4%-11% variance;
Betas 0.06 and 0.11

What about quality of life?

- ▶ Parents who rate their child's quality of life as higher also:
 - ▶ Being: **Higher parental morale and hopefulness**
 - ▶ Becoming: lower complexity, **higher parent morale, higher hopefulness, lower parenting behaviour reflective of dependence**, better parent-teacher relationship
 - ▶ Belonging: higher income, **higher parent morale, higher hopefulness, higher co-parenting alliance**, better parent-teacher relationship

Practice Assumption #3

Parents want and need a support group



What do parents say they need?

Top 10 needs across the developmental trajectory

1. Accurate and up-to-date information
2. Care coordinator/navigator
3. Mutual parent support
4. Assistance with framing needs and expectations of themselves and of their child
5. Continuity of care across services and transitions
6. Child leisure/recreation programs
7. Family programs
8. Parent self-care
8. Financial Support
9. Public awareness and education

What do parents say they need?

Top 5 at the time of diagnosis:

- Hope
- Parent-to-parent support
- Centralized, Accessible and Accurate Information
- Timely Access to Services and Supports
- Assistance with guidance and planning

Top 5 at the time of school entry:

- Finding the right school
- Getting the right services in place - Ensuring a smooth transition between service providers
- Support to navigate difficult child behaviours
- Support to navigate social situations in caregiver's life
- Parent-to-parent support

Practice Assumption #4

Problematic behaviour among children with neurodisabilities can be managed through better parenting.

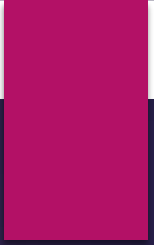
Parents genuinely feel that they want to parent in a manner that supports their child's happiness and well-being.

HOWEVER

Making parents RESPONSIBLE for changing their child's behaviour is problematic as there are many many factors that conspire to inform a child's comportement.

What Do We Know So Far?

- ▶ Children diagnosed with neurodisabilities have higher rates of emotional and behavioural problems than children who do not have neurodisabilities.
- ▶ Parents who are caring for children diagnosed with both a neurodisability and behaviour problems have more compromised physical and mental health, are more likely to be separated/divorced, have lower income, have more challenging family and parenting lives, etc.
- ▶ Finding help is challenging for these families as traditional mental health services do not feel equipped to manage dysregulated behaviour in children with brain-based developmental disorders and traditional health care services (developmental paediatricians, paediatric psychiatrists, neurologists) also do not feel they have the expertise (and sometimes the time) to provide intervene.



Designing, Implementing and Evaluating a Parenting Program

Strongest Families - Neurodevelopmental

- ▶ 1st Wave – COPE (Chuck Cunningham)
- ▶ 2nd Wave – Children with mental health issues (Patrick McGrath and Dalhousie University)
- ▶ 3rd Wave – Children with FASD (Patrick McGrath and James Reynolds)
- ▶ 4th Wave – Children with neurodevelopmental disorders

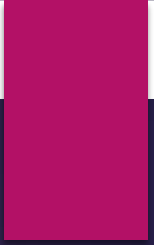
- ▶ Key Primary Outcomes:
 - ▶ Child outcomes: Emotional Regulation
 - ▶ Parent outcomes: Parental Self-Efficacy
- ▶ Key Secondary Outcomes:
 - ▶ Child outcomes: Behaviour problems
 - ▶ Parent outcomes: Quality of parent-child relationship, parent satisfaction with program, parental depression, anxiety and stress; hope

Strongest Families - Neurodevelopmental

- Introduction
- Notice the good
- Spread attention
- Ignore whining and complaining
- Prepare for changes
- Plan ahead
- A reward system
- Outside the home
- Working with daycare
- Calming down
- Problem solving
- Putting it all together

Strongest Families - Neurodevelopmental

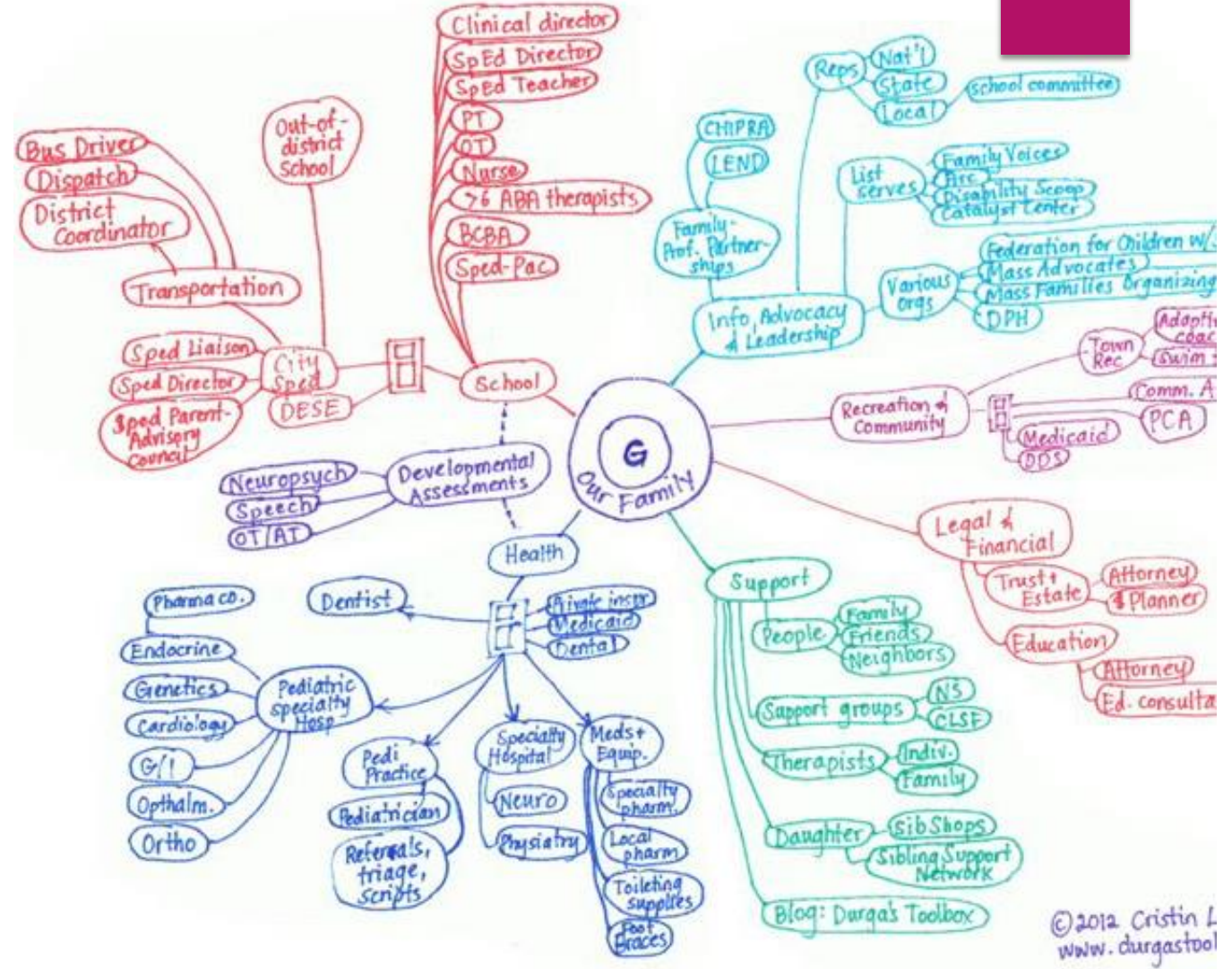
- ▶ Randomization to 3 Arms
- ▶ Arm 1: Access to resource information (Childhood Disability Link www.childhooddisability.ca)
- ▶ Arm 2: Access to resource information + parent-to-parent Facebook group + access to online modules
- ▶ Arm 3: Access to resource information, parent-to-parent Facebook group, access to online modules + group coaching



Changing How Navigation Supports and Services are Delivered

What is the Problem?

- Children with neurodisabilities (e.g., cerebral palsy, autism spectrum disorder, intellectual disability, fetal alcohol spectrum disorder) and their families come into contact with numerous and multiple systems of care and support



What is the Problem?

- Parents become primary navigators of these systems of support, but are often left to 'fend for themselves'

Sometimes I really don't know what I am supposed to ask for...or how to go about [it], or what he really needs because I don't know what to do to help him sometimes (parent of 8 year old with ID)



What is the Problem?

- Families and service providers are not aware that navigational supports exist and how to access them





What is the problem?

- ▶ Siloes between health, education, and social care sectors and between government and non-government organizations

What is the Problem?

- Knowledge regarding the unique needs of these children and their families within these siloes is low



ORIGINS OF 'NAVIGATION'

Used by Dr. Harold Freeman in 1990 as a strategy to improve adherence to breast cancer care among African American women

Navigator facilitates access to services and accompanied the patient to follow-up appointments while providing emotional support, education and advocacy

- Results: increase in rates of early diagnosis and decrease in rates of late diagnosis in cancer care

Broder-Fingert et al., 2015; Carter et al., 2018

Wave 1 – Case Management

Wave 2 – Family Care Coordination

Wave 3 - Navigation



Definitions of Navigation: Something that Parents Do



“...A process of collaboration between a professional (e.g., nurse, social worker) or lay person (e.g., peer) with a patient and his or her family and/or caregivers to provide navigational support, including education, emotional support and logistical guidance, **as they attempt to navigate** through a complicated maze of services, treatments, clinical interventions and/or programs”

Definitions of Navigation: Something A 'Navigator' Does



- Navigators assist with fragmentation of the health and social health care system through various methods including: communication with multiple agencies, facilitating access to care, navigating the system and services, or assisting individuals with health insurance.

Navigation in 3 Jurisdictions: Yukon, Vancouver BC, Edmonton AB



KBHN ALBERTA NAVIGATION PROJECT VISION

- ▶ Families with children and youth with ND will be able to easily access needed and available services

OBJECTIVES

- ▶ Identify key components of a sustainable model of community-based regional navigation support for central through northern Alberta
- ▶ Identify viable systems improvements to achieve this vision
- ▶ Develop a framework for implementation

Aim and Research Question

- ▶ To learn from service providers and families about service navigation within Alberta and to use this knowledge to make recommendations
- ▶ Research question: What approaches underlie navigation practices of service providers who work with children with ND and their families?

Who has Participated?



- 136 service providers
- 97 parents
- 17 self advocates
(youth with NDD)

Methods

- ▶ Participatory Action Research
 - ▶ Engagement with community leaders in various sectors
 - ▶ Development of interview questions and guiding scripts for engagement
- ▶ Sampling; maximum variation and snowball
 - ▶ Health (1°, 2°, 3°; physical and mental), education, social care (disability, child welfare, child and family), early intervention
 - ▶ Government and NGO
 - ▶ Rural and urban communities
 - ▶ Indigenous communities
- ▶ Focus groups or individual interviews (given choice)
- ▶ Approach: Interpretive Description (Thorne, 2016)
 - ▶ Researchers and interviewers had previous experience with the system
 - ▶ Ongoing process of conceptualizing and interviewing

Approaching Navigation as a Practice

- ▶ **How issues are framed: individual vs. person-in-environment**
- ▶ **Approach to assessment/intervention: Strengths/Asset-Based vs. Deficit-Based; 5F's**
- ▶ **Scope of practice: Services that are Specialized vs. Generalist**



Recommendations

- ▶ Stronger relationships among service providers/agencies across sectors (e.g., disability services, health, education, etc.)
 - ▶ Working together prior to or when delivering services facilitates the search for services for providers who offer navigational support to families
 - ▶ Regional Collaborative Service Delivery



Building an Infrastructure to Support ND Service Delivery



- ▶ Increased training for service providers
- ▶ Increased engagement with families
- ▶ Information-sharing protocols to support service provision
- ▶ Greater program- and system-based evaluation

Partner Acknowledgement



An agency of the Provincial
Health Services Authority



fassy Fetal Alcohol
Syndrome
Society Yukon