

Raising Resilient Families: Empowering Parents with Cognitive Challenges

Supporting Strength and Growth in Diverse Family Dynamics





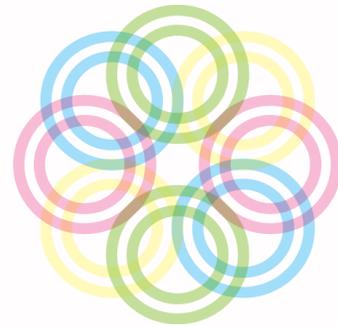
RESEARCH TEAM

Principal Investigators: Amanda Cappon and Kay Corbier

Founder and Executive Director of Starfish Parent Support Program: Vicky Caruana

Research Associate: Deanna Cooper

Parent with Lived Experience: Maryann Cabral



The Durham College Social Impact Hub seeks to identify creative solutions to complex social problems through community-engaged applied research projects and service-learning initiatives.





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PRESENTATION OBJECTIVES

- 1. Increase Awareness:** We will share about the unique experiences and barriers faced by parents with cognitive challenges (CC), highlighting the importance of tailored support and resources.
- 2. Promote Best Practices:** We will share evidence-based strategies and interventions that can effectively support parents with CC, including collaborative care and strength-based approaches.
- 3. Enhance Understanding of Co-Production Practices:** We will highlight the impact that co-production has had on the community and families supported.

DID YOU KNOW...?



- Parents with intellectual/developmental disabilities (IDD) are subjected to stigma and discrimination, including a pervasive **presumption of parental incompetence** (Franklin et al., 2021; McConnell et al., 2020; Tahir & Cobigo, 2025).
- 430 births per year to mothers with ID in the province of Ontario (Brown et al., 2016).
- Parents with intellectual disabilities (ID) **represent over 15% of child welfare cases** (Tahir & Cobigo, 2025).
- **5.6% of newborns to mothers with ID are removed at birth** by child welfare services, compared to less than 1% for mothers without ID (Grant et al., 2024).

BACKGROUND AND CONTEXT

OUR “WHY”

Context of Starfish Parent Support Program (PSP):

- A family who had child apprehended at hospital 18 years ago
- Won the trial decision.
- CAS then started to make referrals; Short-term contracts led to long term support.
- Became a not-for-profit organization in 2017 with 12 families.
- To date, Starfish PSP has helped 32 children be reintegrated into their parents' custody.
- Goal to help families regain and maintain custody, but babies are still being apprehended at the hospital (see Grant et al., 2024).

*For more information about **Starfish PSP**, please visit:*

<https://www.starfishparentsupportprogram.com/>



Our Research Question

How can we develop a model of support that is rooted in existing best practices and that proactively addresses the social issues (including trauma, institutionalization, and violation of human rights) that impact parents with cognitive challenges? How will we ensure we have input from parents with lived experience as well as other key partners?

Stigmatizing Perspectives

“Parents with cognitive challenges are often seen as risks rather than as people with potential.”

“Family preservation isn’t realistic when a parent has a disability.”

“Parents with cognitive challenges are not capable of change and therefore cannot parent a child/children.”

Empowering Perspectives

“Every parent has the capacity to learn and change.”

“Cognitive challenges should never be a barrier to parenting.”

“Too many parents lose their children because systems fail to support them early enough.”

How deep
is it?



It comes up
to my neck.



Other people's reality
isn't yours





COMMUNICATION ALLY

- The parents with lived experience on our steering committee expressed reservations at times about contributing to conversations in meetings due to past trauma and ongoing stigma.
- The communication ally role is a trusted support person who acts as an advocate/intermediary to persons with lived experience.
- This was a best practice integral to fostering the psychological safety needed to elicit the voices of those impacted by the important work of the project.

PHASES OF THE RESEARCH

Phase 1 – Semi-Structured Interviews

- 10 parents with cognitive challenges
- 19 service providers

Phase 2 Part 1 – Building Community Capacity

- 20 service providers received certification in the evidence-based Step-by-Step Parenting Program

Phase 2 Part 2 – Early Intervention

- Supported 3 expectant parents using the Step-by-Parenting Program.

(Feldman, M. A., & The Surrey Place Parenting Enhancement Program, 2024)

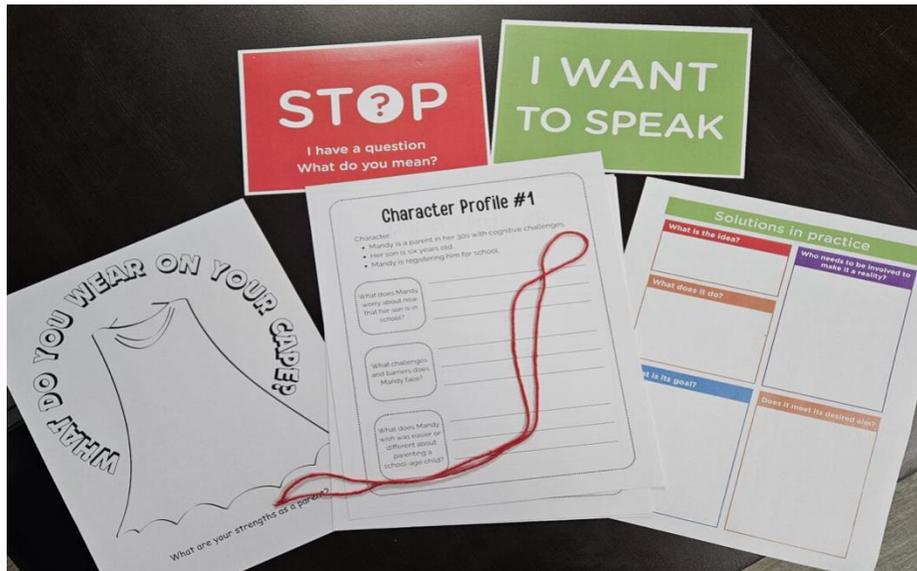


To learn more about the Step-by-Step Parenting Program, please visit:
<https://brocku.ca/social-sciences/applied-disability-studies/step-by-step-parenting-program/>

PHASE 3

Co-Production Sessions

- Held five sessions including both parents with lived experience and service providers who support them.

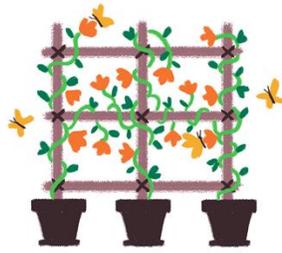


(IRISS, 2017)

Community-Driven Solutions

- Co-designed five innovations to support parents with cognitive challenges.





RAISING RESILIENT FAMILIES: EMPOWERING PARENTS WITH COGNITIVE CHALLENGES A COLLEGE AND COMMUNITY SOCIAL INNOVATION FUND (CCSIF) PROJECT



NEEDS & INNOVATIONS

WE ARE HERE TO CREATE A MODEL OF SUPPORT TO OVERCOME GAPS & BARRIERS!

"We need something to bridge aging out of high school into skills learning."
- Parent Participant

"We need to change the world for future kids. Disability and non-disability."
- Parent Participant

"[Service providers are] too judgmental and quick to make decisions."
- Parent Participant

"They give you ODSP, but they don't tell you about other resources or funding."
- Parent Participant

"We are held to a higher standard than people without disabilities."
- Parent Participant

"When you are labelled as having a disability, that is that!"
- Parent Participant

1. CREATE A RESOURCE FOR POST-BIRTH PLANNING

"IS IT OKAY TO ASK FOR HELP?"

- SUPPORT AT HOME → DURATION? → NURSES → CONTACTS
- FOOD SUPPORT
- HELP W/ DOCUMENTATION
- A PARENT HELPLINE
- A DIGITAL REFERENCE → EASY TO ACCESS, STEP BY STEP, ONLINE FAQ

- FOLLOW-UP W/ MEDICAL APPOINTMENTS
 - SAFE TRANSPORTATION → CAR SEATS!
 - DIAPERS & OTHER MATERIAL NEEDS
- HOW & WHERE TO ACCESS

JUNE 6, 2024



How can we best support parents with cognitive challenges?

"Nothing for us without us."

2. CREATE PRESENTATIONS TO EDUCATE THE COMMUNITY

- INTERACTIVE
- INVOLVE PEOPLE IN EDUCATION. MEDICAL & SOCIAL SUPPORT WORKERS
- PARENTS WORKING TOGETHER W/ SERVICE PROVIDERS
- LOCATIONS: LIBRARIES, DURHAM COLLEGE, THINK OF ACCESSIBILITY!
- EDUCATION NEEDS TO ADDRESS STIGMA & DISCRIMINATION
- "A PICNIC OR BARBECUE"
- STRESS-FREE INFORMAL ORGANIC DIALOGUE
- A CHANCE TO TELL OUR STORIES



What are your strengths as a parent?

- "MIND READER"
- "ROLE MODEL"
- "UNCONDITIONAL LOVE"
- "TRUSTWORTHY & SAFE"
- "GOOD LISTENER"
- "COMFORTING"
- "PROVIDING ADVICE"
- "MULTI-TASKING"
- "SUPER GREAT DAD"

3. CREATE A PARENT SUPPORT GROUP FOR PARENTS WITH COGNITIVE CHALLENGES

WITH A FOCUS ON PEER AND MENTORSHIP FROM OTHER PARENTS

- PEER TO PEER → MIXED W/ PROFESSIONALS
- GUEST SPEAKERS (STARFISH, COMMUNITY LIVING)
- *HAVE NEURODIVERGENT PARENTS PRESENT "SUIT THE LEARNING NEEDS OF PARENTS"
- "ENSURE THAT SUPPORT IS ALWAYS OFFERED - IN A COLLABORATIVE WAY."
- ACCESSIBLE: CAN YOU TRAVEL TO IT? LIBRARY? HOST AT HOME? AGENCY-CONTRIBUTED SPACES?
- PAY PEER MENTORS!
- A HOTLINE FOR SUPPORT OUTSIDE MEETING HOURS
- LEARN SELF-CARE/MENTAL HEALTH SUPPORTS
- ↳ MASSAGE THERAPY
- "BRAVE SPACE / SAFE SPACE"
- ↳ A DROP-IN SPACE

- "PAYMENT vs. NON-PAYMENT"
- "OPEN GROUP OR CLOSED GROUP"
- "FOOD → MAKE IT A POTLUCK!"
- "IN-PERSON & ONLINE"

4. PROVIDE EDUCATION (SBS TRAINING) FOR EXPECTANT PARENTS WITH COGNITIVE CHALLENGES

- EARLY INTERVENTION IS KEY
- DIVERSE NEEDS → DIVERSE SOLUTIONS
- SEVERAL STAKEHOLDERS INVOLVED → INCLUDE E.C.E.
- HOSPITAL/LABOUR & DELIVERY TRAINING
- CPR + CRISIS RESPONSE TRAINING → E.C.E.'S
- "Note that parents with disabilities are asked to do parenting training, while other parents are not"
- "IT'S NOT FAIR ALL THE TIME"
- APPROACH DR. FELDMAN → T4T MODEL
- HAVE SUPPORT NETWORKS PRESENT
- NUTRITION FOCUSED
- MANAGING DOCTOR'S APPOINTMENTS
- 4P PILLARS OF PARENTING
- DEVELOP TRAINING CURRICULUM W/ PUBLIC HEALTH COORDINATING W/ DEVELOPMENT AGENCIES

- HAVE A LIST OF WHAT'S REQUIRED OF PARENTS & HOW TO ACCESS AVAILABLE SUPPORTS!



- MAKE SURE PARENT'S NEEDS ARE MET TOO
- REALISTIC INFANT SIMULATOR FOR PRACTICE
- TEACH PARENTS HOW TO COOK & SOCIALIZE!



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RAISING RESILIENT FAMILIES:

EMPOWERING PARENTS WITH COGNITIVE CHALLENGES



FINDINGS AND OUTCOMES

SCAN ME

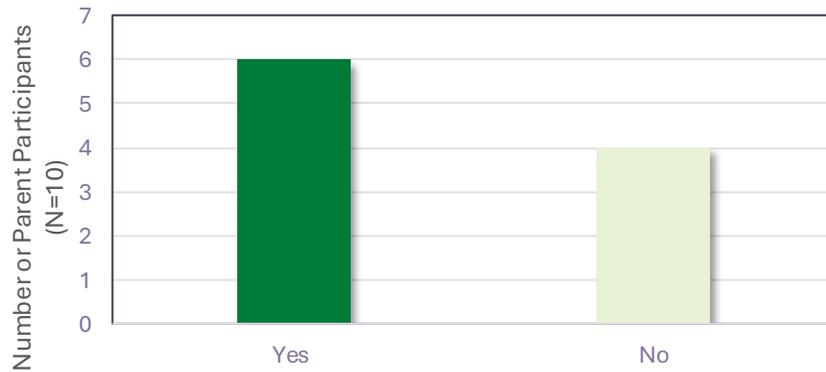


(Cappon et al., 2025)

SUMMARY OF FINDINGS – PHASE 1

Parent Participants (N = 10)

Are you confident in your own abilities to make decisions?



Did you feel as though your decisions were being questioned by others in your life about your parenting?



Barriers

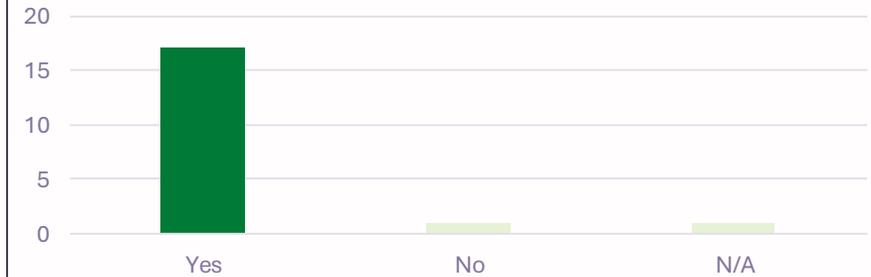
- x Stereotypes
- x Negative bias
- x Discrimination
- x System navigation
- x Trauma

Best Practices

- ✓ Early intervention
- ✓ Ongoing support through stages of child development

Service Provider Participants (N = 19)

Do you believe parents with ID/DD/CC are constantly judged on their abilities as a parent within the human service/social service sector?

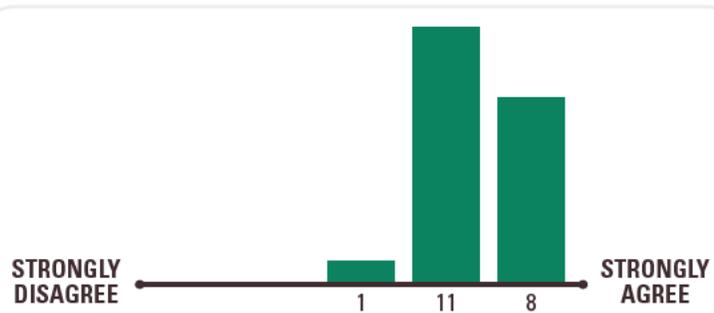


Do you believe there is bias within your workplace/company towards parents with ID/DD/CC?



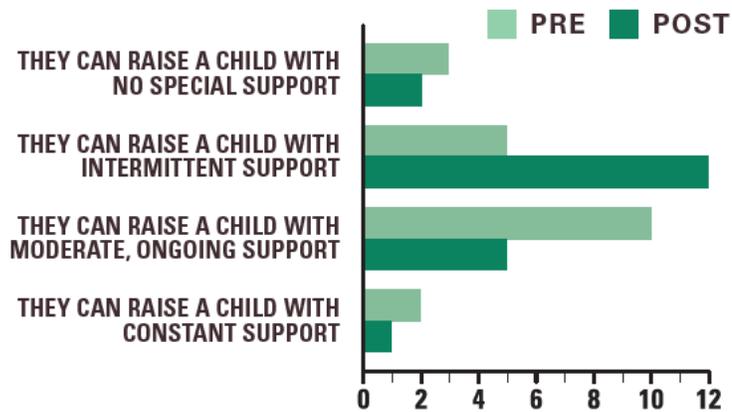
SUMMARY OF FINDINGS – PHASE 2

“I am confident that I developed the skills and competencies to support parents/expectant parents with cognitive challenges.”



- There was a notable increase in perceived confidence of supporting parents with CC reported by majority of service providers who attended SBS training.

“What is your opinion regarding parents with cognitive challenges?”



- Service providers' perceptions of parents with CC shifted from the pre survey before the training to the post-survey after the training.

Outcomes for parents who participated in SBS training:



- All parents increased, maintained, and generalize the skills they learned with their own babies

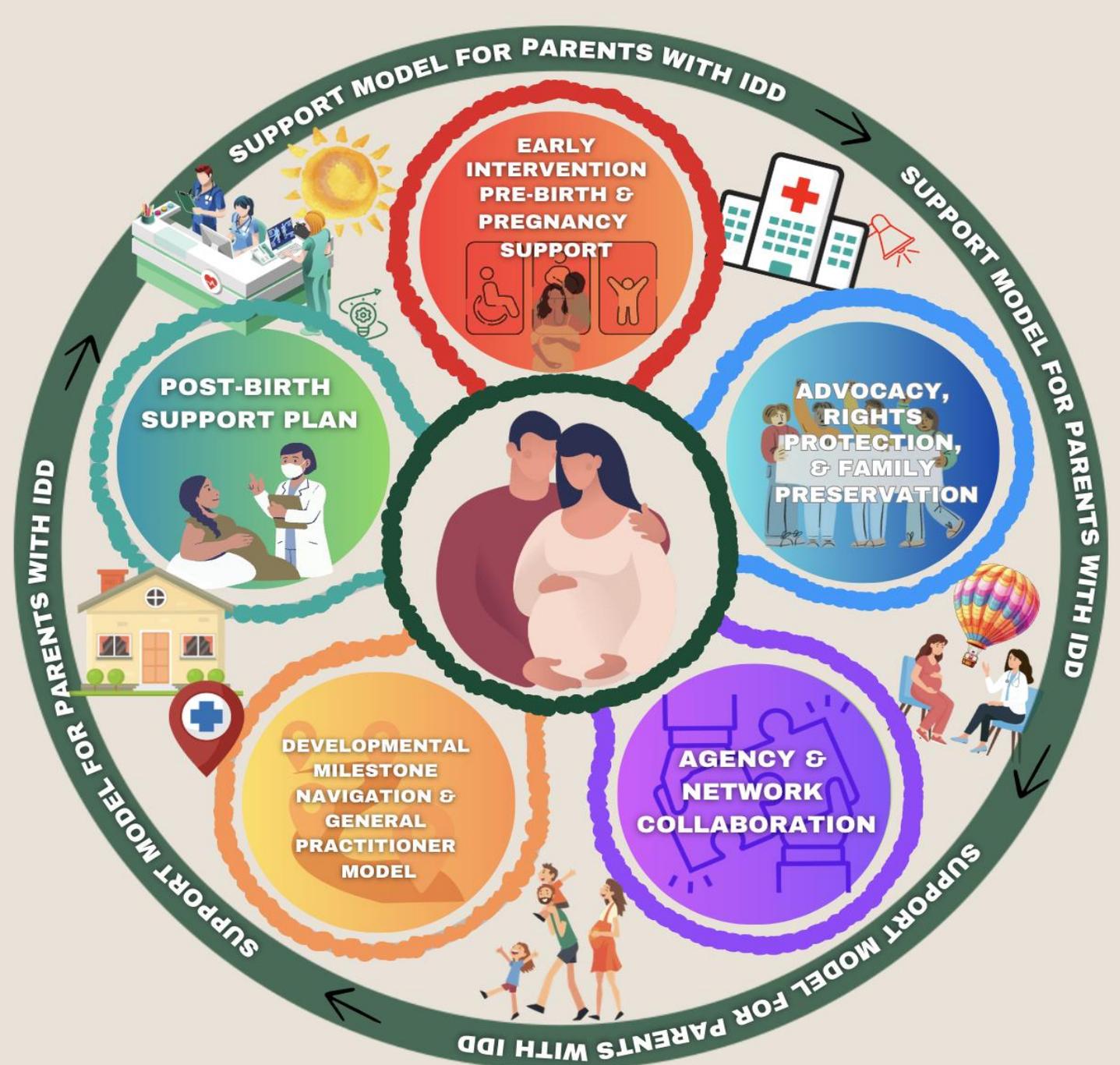


- All parent participants retained custody and generalized skills post-birth to their babies.

MODEL OF SUPPORT – PHASE 3

Model of Support:

- ✓ Post-birth plan
- ✓ Template of parent-support group
- ✓ More staff trained in SBS Parenting Program
- ✓ Increased community collaboration
- ✓ Advocacy: Shift in perception of parenting capacity



(Image courtesy of N. Corbier; personal communication, February 25, 2025)

MY POST-BIRTH PLAN

This plan helps me get ready to go home with my baby. It includes important information, support people, and things I may need.

SECTION 1 (fill out before birth)



About Me

My name is:	
My phone number is:	
My current living situation is:	
I receive financial support from:	
My baby's due date is:	
These are the people who help me (names of family, friends, support workers or agencies):	1.
	2.
	3.
	4.
In case of emergency, please contact:	Name of emergency contact:
	Phone number of emergency contact:

POST-BIRTH PLAN

Who is This Document For?

- This document can be used by parents-to-be who have cognitive challenges and can also be used by supports who are involved in the lives of parents-to-be.

How Can This Document Be Used?

- This document can be printed, or it can be saved electronically and brought on a phone/iPad/Tablet to the hospital.

Section 1:

- ("*About Me,*" "*Before Birth,*" "*Going Home Plan,*" "*After Baby is Born Plan*")

Section 2:

- ("*How I Feel About Going Home,*" "*Baby's Information,*" "*Other Things to Bring Home*")



SPECIAL ISSUE ARTICLE **OPEN ACCESS**

Preliminary Evaluation of the Step-by-Step Parenting Program for Expectant Parents With Intellectual Disabilities

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ABSTRACT

Background: This study evaluated the Step-by-Step Parenting Program (SBSPP) to prepare expectant parents with intellectual disabilities to care for their newborns.

Method: Two expectant parents with intellectual disabilities were seen once or twice weekly in their homes for about 2 h over 16 and 20 weeks (21 and 27 sessions), respectively. The key measure was percentage correct scores on parenting skill checklists with an infant simulator (IS) and eventually the newborn. Newborn-care skills trained were sponge bath, dressing, ear and nose care, and treating cradle cap. SBSPP-IS training consisted of instructions, prompting, modelling, and feedback. Multiple baselines across skills and participant designs were used.

Results: Trained skills increased and transferred to the newborns. Both parents have maintained custody of their infants for over 1 year.

Conclusion: This study provides preliminary evidence that prenatal parent training may help expectant parents with intellectual disabilities to properly care for their newborns.

EVIDENCE-BASED OUTCOMES

SCAN ME



(Feldman et al., 2025)

VOICES OF IMPACT

What was it like to be part of the steering committee that helped guide this project?

What is one thing you are proud of from being part of this project?

How has being part of this project helped you or people you know?

KEY TAKE-AWAYS



Centering the voices of those who are marginalized

- Working with parents, especially those with cognitive challenges, to protect children and strengthen family systems is critical.

Supporting Family Preservation

- Tailored interventions, peer support, and accessible resources promote resilience in vulnerable parents.

Trauma-Informed Approaches

- Using trauma-informed and anti-oppressive methods can improve intervention effectiveness and outcomes. Addressing cultural and systemic factors is essential for equitable child protection service delivery.

“It takes a village...”

- Efforts from multiple social service and healthcare organizations in alignment with child protection organizations all with centering the voices of parents with lived experience.

RESOURCES FOR YOUR USE

Name of Resource	Webpage link
Starfish Parent Support Program	Starfish Parent Support Program
Provincial Council for Maternal and Child Health	Disability and pregnancy resources for healthcare providers and administrators
Durham College Social Impact Hub	Social Impact Hub
Videos about this project, including video of those with lived experiences	Raising Resilient Families Project Video Voices of Parents with CC Video
Step-by-Step Parenting Program	Step-by-Step Training Resources
Lake Ridge Community Support Services	Lake Ridge Community Support Services

Q&A AND FINAL THOUGHTS



What are your key takeaways?

This session encouraged questions and reflections from you to foster engagement and deeper understanding of the experience of persons with CC who are also parents. What are your take aways?



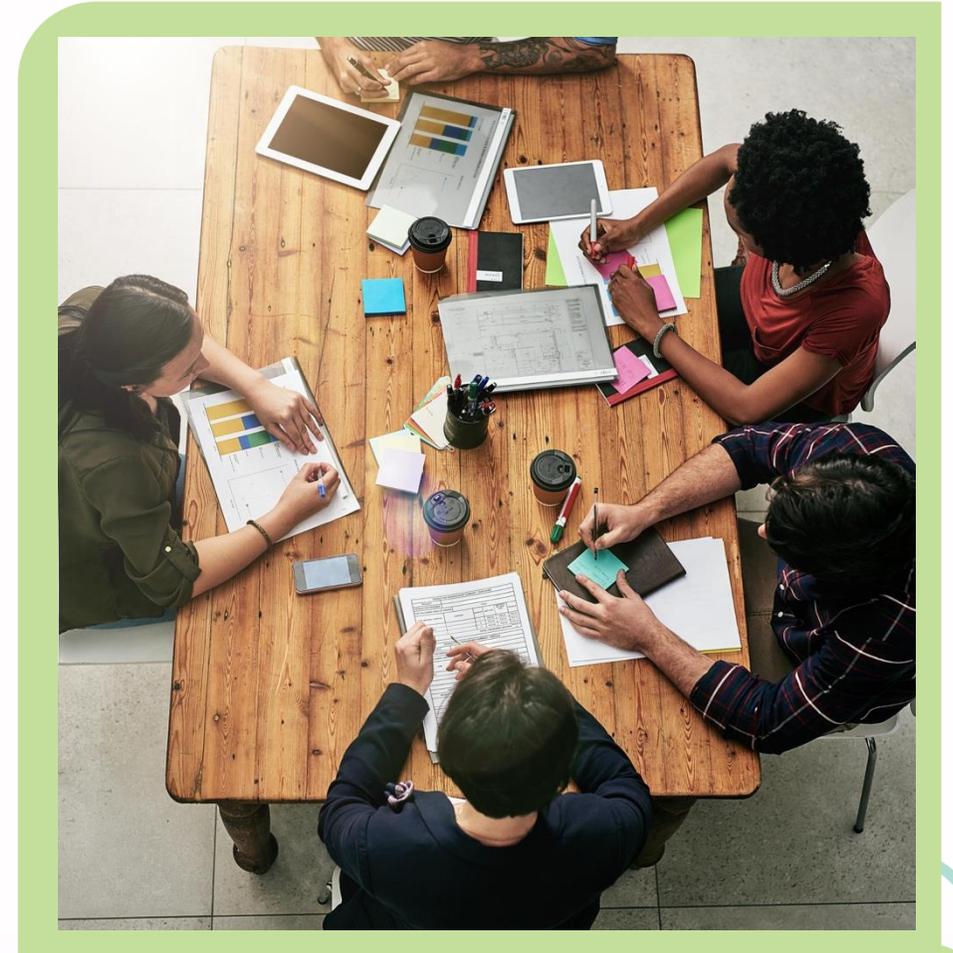
Collaborative Solutions

This research project highlighted the potential for collaborative approaches to create sustainable solutions, but we are not there yet. Do you have ideas for collaborative approaches to create sustainable solutions?



Future Engagement

Who in the community will share this important work with?



ACKNOWLEDGMENTS

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DURHAM COLLEGE SOCIAL IMPACT HUB

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