

RAISING RESILIENT FAMILIES: EMPOWERING PARENTS WITH COGNITIVE CHALLENGES



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INTRODUCTION

THE ROLE OF PARENTS IS CRITICAL AS THEY HAVE THE ABILITY TO QUITE LITERALLY SHAPE FUTURE GENERATIONS, ESPECIALLY DURING THE EARLY YEARS BEFORE THEIR CHILDREN'S PEERS BECOME A MORE PROMINENT FACTOR. AS INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (ID/DD) EMBARK ON THEIR JOURNEY OF BECOMING PARENTS, THEY MAY REQUIRE INDIVIDUALIZED SUPPORT (LEARNING HOW TO DIAPER, FEED, BATHE, BEDTIME ROUTINES, ECT.) TO FOSTER A SAFE AND HEALTHY ENVIRONMENT FOR THEIR CHILD(REN).

BACKGROUND & STATISTICS

According to Proctor and Azar (2013), most parents with ID/DD have a mild diagnosis, and are able to hold jobs and live independently with minimal support. However, they are **30-60 times more likely to be involved in child welfare proceedings** (Bachrach, 2022), and the average global rate of **custody removal for those that become parents is between 40-60%** (Theodore et al., 2018). This represents a rate of child removal of approximately 1 in 2, which is significantly **higher than any other group of children** (McConnell & Llewellyn, 2002).

Importantly, the removal of a child from their biological parent(s) and placement in the Child Welfare System at any point in the child's life can have a **traumatic impact on both parent and child** (Blakely et al., 2017).

PROJECT OVERVIEW

Raising Resilient Families: Empowering Parents with Cognitive Challenges has been a multi-phase project which was funded through a College and Community Social Innovation Fund (CCSIF) grant by the **Social Sciences and Humanities Research Council (SSHRC)**. The overall objective of the project has been to identify gaps in support and determine the best practices required to improve the current model of support for parents with cognitive challenges.

'**Cognitive Challenges**' (CC) is meant to encompass those who have a diagnosis of intellectual disability or in the borderline range, as well as acquired brain injury. This may also include those who received remedial special education, who self-identify as a slow learner, or who have not received a formal diagnosis. The steering committee chose to use this term as it reflects a broader range of the population that would



PARENTS AND MEMBERS OF THE RESEARCH TEAM AT A CO-PRODUCTION SESSION.

not otherwise be captured under the label of 'intellectual or developmental disabilities'. The goal has been to forge early intervention strategies with community partners that honour the strengths of families, eliminating the need to remove a child from their family and cultural community.

STEERING COMMITTEE

From the outset of the project, the researchers engaged a diverse steering committee of key stakeholders, inclusive of fellow academics, parents with lived experience, and service providers who support parents with CC, to help shape and guide every step of the research process.

With the goal of developing a model of support that truly meets the needs and lived realities of parents with CC, it is crucial that their voices be included throughout all stages of the research process. Too often, research is conducted *on* individuals to develop solutions for them, without their input or expertise. The goal was to instead conduct research *with* parents, to amplify their voices and develop innovative solutions. Centring parents' voices is crucial not only for respecting their dignity and worth as individuals, but to ensure that the research process and outcomes accurately reflect their lived experiences.

RESEARCH QUESTION:

What best practices are required to develop a model of support for parents with intellectual (ID), developmental (DD), and cognitive challenges (CC) that is proactive and reduces the impact of social issues such as trauma, stereotypes, institutionalization, and violation of human rights, based on their lived experiences?

OVERVIEW OF PHASES

The project was conducted over three distinct phases:

PHASE ONE:

The research team conducted one-on-one interviews with parents with CC and service providers who support these parents. The interview questions focused on their unique perspectives of the barriers and challenges to support, as well as identifiable gaps in services.

80%
FELT THEIR PARENTING DECISIONS
WERE QUESTIONED BY OTHERS

PHASE TWO:

82%
OF SERVICE PROVIDERS HAD NO PRIOR
TRAINING IN SUPPORTING PARENTS
WITH COGNITIVE CHALLENGES

The steering committee hosted a 3-day training on the Step-by-Step (SBS) Parenting Program led by Dr. Maurice Feldman in January–February of 2023, with the intent to build service provider capacity within the Durham Region to support parents with CC. Additionally, a half-day orientation was hosted to raise awareness about this evidence-based program. In October 2023, SBS training was implemented using infant simulators with expectant parents. SBS sessions continued post-birth to provide ongoing support and evaluate whether parents generalized the skills they developed to care for their own baby. This training was delivered again in June 2025 to an additional 13 service providers. Along with the goal of continuing to increase capacity, Vicky Caruana of the Starfish Parent Support Program was brought on to co-facilitate, enabling her to continue this training with her own staff at her organization.

PHASE THREE:

Researchers hosted 5 co-production sessions including parents with lived experience and service providers who support parents with CC. In these sessions, participants worked together to design four innovations to support parents with cognitive challenges. During follow-up working sessions, parents and service providers further developed the innovations from the co-production sessions, ultimately developing four practical interventions that can be implemented across Durham Region. In addition to the interventions, the co-production sessions facilitated interagency collaboration to better support parents with cognitive challenges in the community.

05
CO-PRODUCTION SESSIONS
WERE HELD, DEVELOPING FOUR
PRACTICAL INTERVENTIONS

RESEARCH SUB-QUESTIONS

1. What are the experiences of parents with cognitive challenges and service providers in the access and availability of appropriate services within Durham Region? (Phase 1)
2. What is the perception of service providers in the Durham Region of the efficacy of an evidence-based training program designed to build their capacity in supporting the needs of parents with cognitive challenges? (Phase 2)
3. What is the perception of parents with cognitive challenges of the efficacy of an early intervention model using infant simulators to teach proactive parenting skills? (Phase 2)

PHASE 1: QUALITATIVE SEMI-STRUCTURED INTERVIEWS

THE RESEARCH TEAM INTERVIEWED PARENTS WITH COGNITIVE CHALLENGES, AND SERVICE PROVIDERS WHO SUPPORT THOSE PARENTS. INTERVIEW QUESTIONS FOCUSED ON THEIR OWN PERSPECTIVES OF THE BARRIERS AND CHALLENGES TOWARDS SUPPORT, AS WELL AS GAPS IN SERVICES.

OVERVIEW

During Phase 1, the steering committee conducted **semi-structured, qualitative interviews** with parents with CC and service providers who support them. Interviews were conducted 1-on-1 and were designed to capture the lived experiences of both groups, from their own perspectives.

The research team sought to hear from parents, in their own words, about their lived experiences. Part of empowering parents with CC includes eliciting and **amplifying their voices**. In addition to this, the research team wanted to build upon the existing strengths and valuable insight from each parents' lived experience.

Beginning the project in this way helped to ensure that a **strengths-based perspective** was applied rather than a deficits-based one. Additionally, this qualitative approach allowed researchers to

learn from participants and what their perceptions were of the barriers, goals, needs, and best practices within the Durham region. This step in the project helped shape the **model of support** for parents with CC.

METHOD

The research team interviewed **10 parent participants** between March 1st–April 8th, 2022. These semi-structured interviews were up to **1.5 hours long**, and were offered in either **virtual or in-person** format. Interview questions asked about parents' personal and health history, their pregnancy and parenting experiences, their involvement with community and social services, and their overall experience of being a parent with CC.

Additionally, a total of **19 service providers** were interviewed between March 10–June 2, 2022. These semi-structured interviews were up to **1 hour in length**, and were primarily **conducted virtually**. Interview questions asked about service providers' roles within their organization, their current involvement with parents with CC, and their opinions on the systemic treatment of parents who face such challenges.

All interviews were **transcribed verbatim and anonymized** by Research Assistant(s) before analysis.

ANALYSIS

- Research Assistants (RA) worked in pairs to divide transcripts and thematically analyze all interviews. Both pairs met regularly to debrief on the coding process and discuss the definitions of codes.
- Inter-rater-reliability was achieved by the RA pairs switching to cross-code interviews completed by the other pair.
- In May of 2023, the research team engaged the steering committee in two sub-groups (parents and service providers) for a member checking process, to confirm that the themes and sub-themes aligned with their lived experiences.



RESEARCH TEAM, LEFT TO RIGHT: STEPHANIE WILSON & HOLLY PEDNAUD (RAs), AMANDA CAPPON & KAY CORBIER (PROJECT LEADS), MCKENNAH MAAS & NADIA SIFRI (RA/PLACEMENT STUDENTS)

PARENT INTERVIEW THEMES

*sub-themes are bolded

BARRIERS AND SOCIAL ISSUES

Parents with lived experience reported having a **lack of confidence in their own parenting abilities** which was related to their historical experience of **discrimination and bias** (stereotypes and stigma based on their disabilities).

Additionally, parents who were interviewed reported **difficulty with entry into services** such as accessing financial aid, being placed on **lengthy waitlists**, and **gaps in services**. In some cases, parents reported being **denied service** or **receiving misinformation** which led to a **violation of their human rights**.

Parents described the impact of **mental health concerns** on their experience as parents. Parents also described the impact of **traumatic experiences** both childhood and as a result of their experiences with health and social services. Additionally, parents identified **social isolation** as a source of stress.

Quote from parent:

"I had a ... worker come in and say I was doing it wrong, and she didn't know about autism. And finally I just, like, she kept coming in and I was like, what am I doing wrong? What am I screwing up as a parent? ... I was getting frustrated because ... nothing was good enough."

EXISTING BENEFICIAL SUPPORTS

Parents were also directly asked about existing forms of support that they have received and that were perceived as beneficial. The sub-themes represent a list of commonly referred to services in this regard:

- **Formal Support** was identified as resources provided by institutions or community professionals
- **Social Support** included any reference to non-paid supports (family, friends, adoptive parents, etc.).
- **Financial Support** included references to passport funding, ODSP, financial trustees and income tax benefits.

PARENTING STRENGTHS

Parents were asked a series of questions around their perceived **resilience and self-efficacy** as a parent. Sub-themes included reference to **values**, as well as **parenting skills and strategies**. Parents also described themselves as being the "voice for **their child(ren)**" and expressing love and joy in their role as parent.

Quote from parent:

"It's good to ask for help if you need it. And sometimes asking for that help, it can't do anything for you."

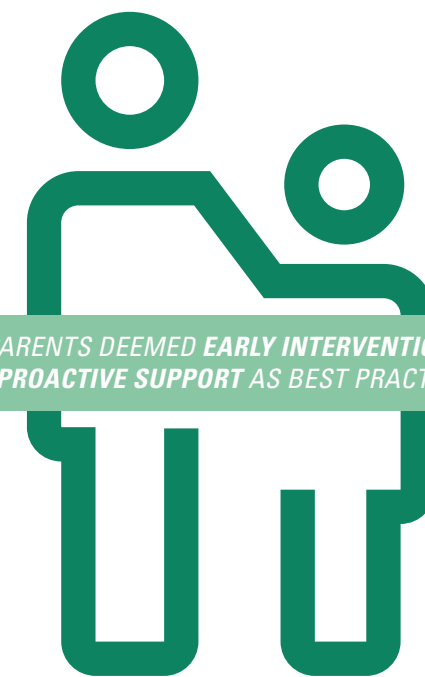
BEST PRACTICES

Parent participants were directly asked about their experiences with supports that they have found useful in their role as a parent.

The sub-themes below represent those useful services and supports:

- **Modeling & Coaching**
- **Advocacy**
- **Early Intervention**
- **Proactive support**

PARENTS DEEMED **EARLY INTERVENTION & PROACTIVE SUPPORT** AS BEST PRACTICE



PARENT INTERVIEW THEMES

*sub-themes are bolded

EXPERIENCE WITH SERVICE PROVIDERS

Parents were directly asked what supports they felt were and were not beneficial in their experience. These questions led to the above themes/sub-themes, and additionally led to the sharing of **positive and negative personal experiences** with various services.

Quotes from parents:

“I felt that any decision I made was being questioned. Any decision and they would take into account my husband’s opinion, my kids’ opinion, but I felt, probably not true, but I felt they weren’t listening to me and my opinions.”

“It was very hard for me ‘cause a worker came in and said, ‘No matter what, we’ll find a way to take your baby.’”

GOALS AND NEEDS

Parent participants reported a need to be treated with **respect and equality** and **not judged for their disabilities**. They also identified a need for help with their **emotional and mental well-being** and for **advocacy**.

In terms of practical skills, parent participants reported working on goals of cleaning, cooking, and shopping, among other activities of **daily living**. A number of references were made to a **need for respite**, especially if the participant had a child (or children) with special needs.

IMPACT OF SOCIAL ISSUES

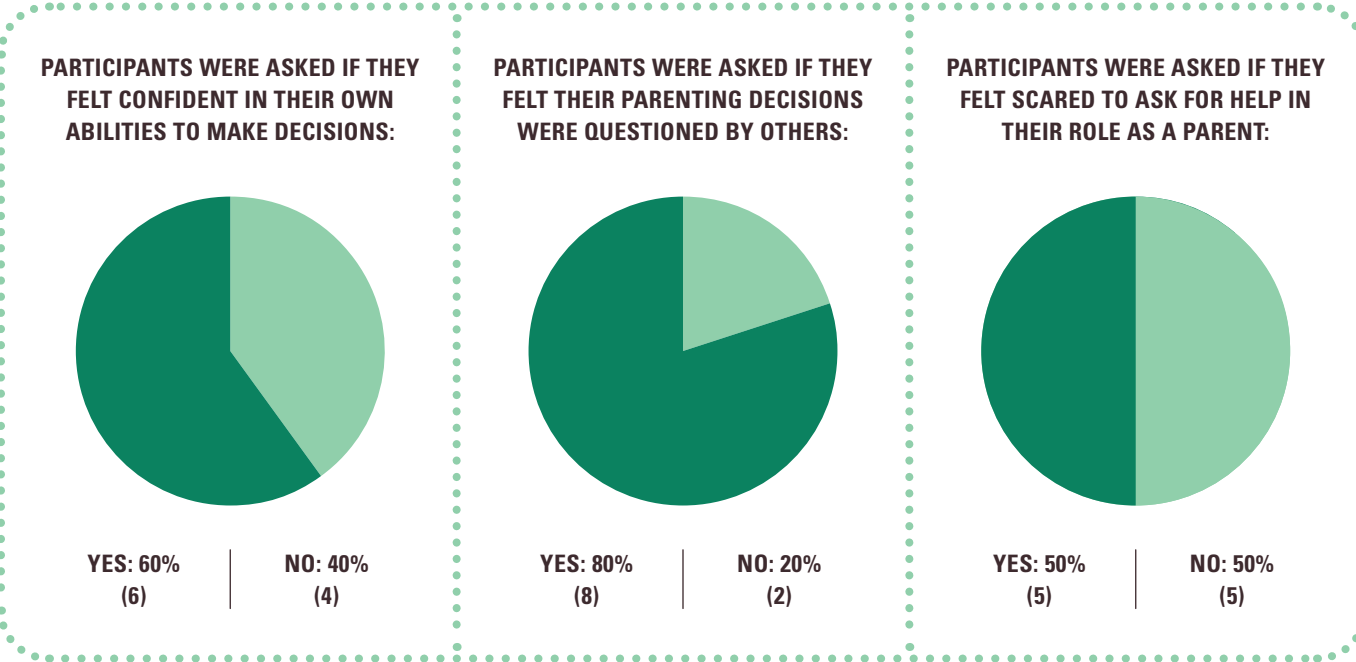
Parent participants reported on the impact of social issues. This theme captured reference to any noted outcome that the parent participants perceived as resulting from beliefs, opinions and viewpoints of others (formal and informal supports).Sub-themes included impact on the parents’ **mental health**, impact of **traumatic experiences** with health and social services, and how their experiences negatively impacted their sense of **self-efficacy and confidence**.

Quote from parent:

“... and it was emotional; like every night I cried, every day I was terrified [of losing custody of their child].”

KEY FINDINGS

■ YES ■ NO



SERVICE PROVIDER THEMES

*sub-themes are bolded

BEST PRACTICES

Service Providers reported that checking for understanding, **providing clear explanations and communicating** different roles at different agencies was useful when supporting parents with cognitive challenges. In addition, service providers also reported that advocacy is imperative as is working from an **anti-oppressive** lens and addressing personal **bias**.

Providing **support before child apprehension** in hopes to prevent need for apprehension was a notable goal. This would further require a change in attitude to **empathy and understanding** of parents with cognitive challenges skills and abilities to parent.

Service provider responses demonstrate agreement on the need for **collaborating with other agencies**, developing ways to model skills, **coach and support** parenting skills tailored to those with cognitive challenges. With this, service providers recognize the importance of **building rapport** through empathy and understanding of individual parent and family needs.

SYSTEMIC ISSUES AND BARRIERS

Service providers were directly asked about broader, systemic barriers to supports for parents with ID/DD/CC. The sub-themes below are a list of examples that were referred to numerous times:

- Strengths-Based and Empowerment Approach
 - Interdisciplinary Collaboration
 - Advocacy
 - Accessible Communication
 - Anti-Oppressive and Equity-Based Practice
- Flexibility and Tailoring to Parent Needs
 - Rapport Building and Empathy
 - Changing Attitude and Awareness
 - Modeling and Coaching
 - Early Intervention and Proactive Support

PARENT GOALS AND NEEDS

Service providers shared various goals which align with needs that they were actively working on with parents on their caseload. For example, “**parent-child attachment**” might be a goal following apprehension and regaining custody and “**parenting skills**” would be a need in order to retain **custody**.

“**Skill development**” was coded to any response around the development of independence, life-skills, organization, time management, self care and education; which was differentiated from “**parenting skills**.”

Quote from Service Provider:

“... the goal whenever possible is for the parent to resume care, resume full care [of their child]. So, when that does not [happen], when that’s not a likely outlook or outcome, then I have to look at, ‘How do I preserve that relationship in such a way that there’s still some contact, that there’s still something?’”

SERVICE PROVIDER BARRIERS

Service providers were able to respond to questions about the barriers that they, themselves, face in their roles.

As per the sub-themes, there were a number of references toward **limitations within agencies** which may result from a **lack of specific training** and **not having enough time** to provide adequate support - such as to provide accessible form of communication to meet unique needs of parent(s).

PARENT STRENGTHS

Service providers were directly asked about the positive aspects of parents with cognitive challenges **relationship to their children**. The sub-themes represent a summary of these positive aspects.

Examples of beneficial **parenting skills/strategies** identified by service providers included: parents **advocating for themselves directly and/or for their child(ren)**, demonstrating love and attention, and eagerness to be involved with their child(ren).

EXISTING BENEFICIAL SUPPORTS

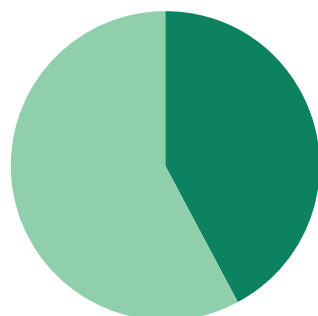
Examples of existing beneficial supports which align with the above best practices were reported to include **financial aid supports**, such as OW/ODSP/DSO/Passport and tax benefits especially for parents.

Service providers also report that having **helpful resources** within their organization such as electronic resources, literature and training are also useful when supporting parents with cognitive challenges.

KEY FINDINGS

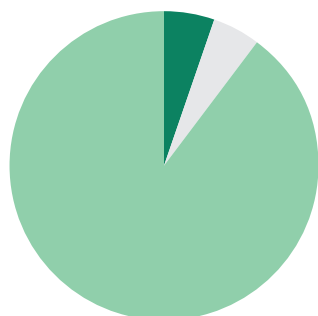
☐ YES ☐ NO

PARTICIPANTS WERE ASKED IF THEY BELIEVED THERE WAS BIAS WITHIN THEIR ORGANIZATION TOWARDS PARENTS WITH GC:



YES: 58% (11)	NO: 42% (8)
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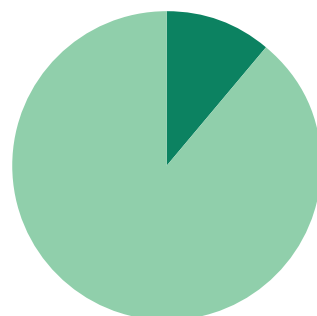
PARTICIPANTS WERE ASKED IF THEY BELIEVED PARENTS WITH CC WERE OFTEN JUDGED ON THEIR PARENTING ABILITIES:



YES: 89% (17)	NO: 5% (1)
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*5% (1) PREFERRED NOT TO ANSWER

**PARTICIPANTS WERE
ASKED IF THEY BELIEVED THEIR
ORGANIZATION COULD DO BETTER
TO SUPPORT PARENTS WITH CC:**



YES: 89% (17)	NO: 11% (2)
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RECOGNIZING DR. MAURICE FELDMAN



Dr. Maurice Feldman's work in supporting parents with learning difficulties has been applied globally, and his expertise played a key role in shaping the early intervention design of this research project. **The Step-by-Step Parenting Program**, developed by Dr. Feldman and his colleagues at Surrey Place in the 1980s, aims to reduce the risk for child neglect due to parenting skills deficits and to promote family preservation (Feldman, 2025). Implementation of his program was vital in Phase 2, where it guided efforts to strengthen service providers' capacity in the Durham Region.

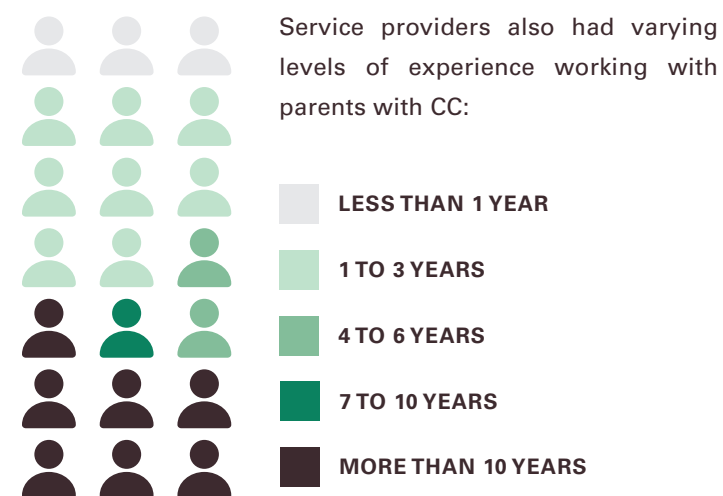
For more information on the Step-By-Step Parenting Program, visit: www.stepbystepparentingprogram.com.

PHASE 2: BUILDING CAPACITY AND SUPPORTS

TO ENHANCE THE CAPACITY OF SERVICE PROVIDERS IN THE DURHAM REGION TO BETTER SUPPORT PARENTS WITH CC, THE RESEARCH TEAM PARTNERED WITH DR. MAURICE FELDMAN FROM BROCK UNIVERSITY. THIS PHASE INVOLVED A THREE-DAY, EVIDENCE-BASED TRAINING IN THE STEP-BY-STEP (SBS) PARENTING PROGRAM, .

PART I: 3-DAY TRAINING

21 service providers from organizations across the Durham Region participated in a **3-day training program**. They held various roles, including: family support worker, direct support worker, parent educator/trainer, behaviour analyst, adult community services worker, executive director, behaviour consultant, child protection worker, and supervisor.



METHOD & ANALYSIS

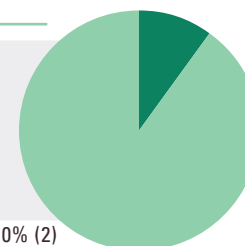
☒ YES ☐ NO

On day one, the researchers administered an anonymous pre-training survey which asked service providers about their experiences in supporting parents with CC, their opinions on the ability of these individuals to raise their children, and their perception of the barriers faced by them. The survey also included open-ended questions on how parents could be better supported.

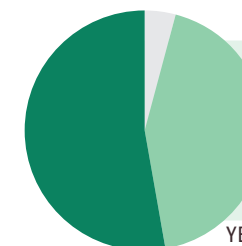
On day three, a post-training survey was administered to measure any changes in service providers' confidence and skills when supporting parents with CC.

PRE-TRAINING FINDINGS

Q: "HAVE YOU ATTENDED ANY PREVIOUS TRAINING SPECIFIC TO SUPPORTING PARENTS WITH LEARNING DIFFICULTIES?"



NO: 90% (19) | YES: 10% (2)



Q: "DOES YOUR AGENCY OFFER ANY SUPPORT SPECIFIC TO WORKING WITH PARENTS WITH LEARNING DIFFICULTIES?"

YES: 53% (11) | NO: 43% (9) | NO ANSWER: 5% (1)

Q: "HOW MIGHT YOUR WORKPLACE IMPROVE THEIR SUPPORTS FOR PARENTS WITH LEARNING DIFFICULTIES?"

- “Talk. Listen. Include parents (caregivers) in planning.”
- “Increased advocacy with MCCSS [Ministry of Children, Community and Social Services] to fund ongoing support to parents with developmental disabilities.”
- “Often our clients have to utilize their passport funding to pay for parenting support. It would be helpful if we had funding to pay fee[s] for service parenting support.”
- “Ongoing training like this workshop.”

Q: "WHAT ARE SOME AREAS THAT THE HUMAN SERVICES SECTOR IN THE DURHAM REGION COULD IMPROVE ON IN SUPPORTING PARENTS WITH LEARNING DIFFICULTIES?"

- “Being less judgemental of some parents. Support parents instead of supervise, and not being influence on parents disorders etc.”
- Providing case workers to parents ... service navigators who can assist them in identifying and applying for services, and help them address barriers.”

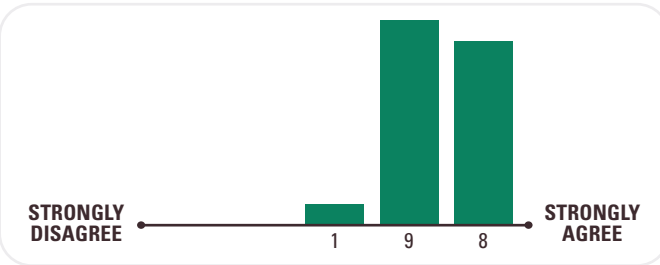
SERVICE PROVIDERS IDENTIFIED THE FOLLOWING “NEEDS” TO IMPROVE SUPPORT FOR PARENTS WITH COGNITIVE CHALLENGES:

- Reducing physical/social barriers and stigma
- Providing support and guidance tailored to the learning abilities of the parent
- Funding to hire supporters to teach skills and provide long-term support
- A focus on education and equality when developing policies, procedures and programming

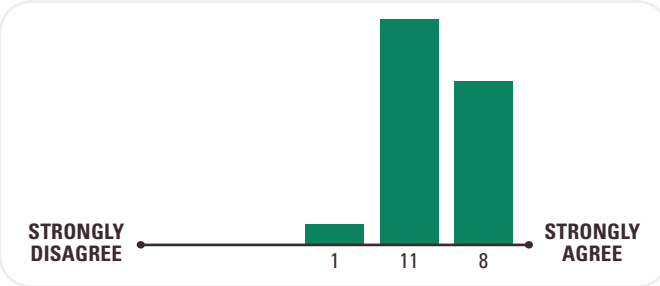
- Increasing opportunities and access to housing
- Support groups that focus on parenting with CC
- Increasing resources and training for support workers

POST-TRAINING FINDINGS

Q. "I AM CONFIDENT THAT THE TRAINING COVERED CRITICAL CONTENT NECESSARY FOR THE ACQUISITION OF THE SKILLS REQUIRED TO SUPPORT PARENTS/ EXPECTANT PARENTS WITH LEARNING DIFFICULTIES."



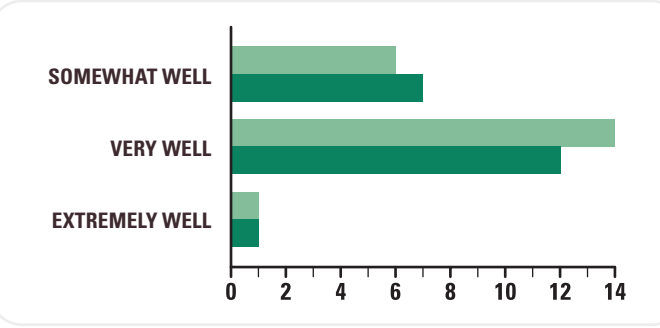
Q. "I AM CONFIDENT THAT I DEVELOPED THE SKILLS AND COMPETENCIES TO SUPPORT PARENTS/ EXPECTANT PARENTS WITH LEARNING DIFFICULTIES."



COMPARING PRE & POST-TRAINING SURVEYS

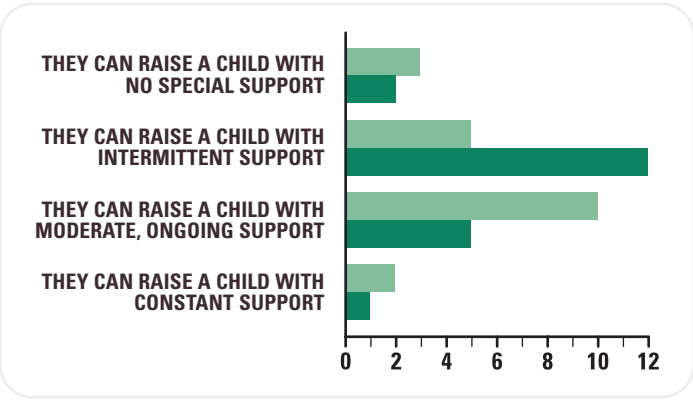
PRE POST

1. In both surveys, respondents were asked: "How well do you think you know how to work effectively with parents with learning difficulties?"



*In both the pre and post training surveys, zero respondents indicated: "Not very well" or "Not well at all".

1. In both surveys, respondents were asked: "What is your opinion regarding parents with learning difficulties?"



*In both the pre and post training surveys, zero respondents indicated: "Parents with CC should not have children."

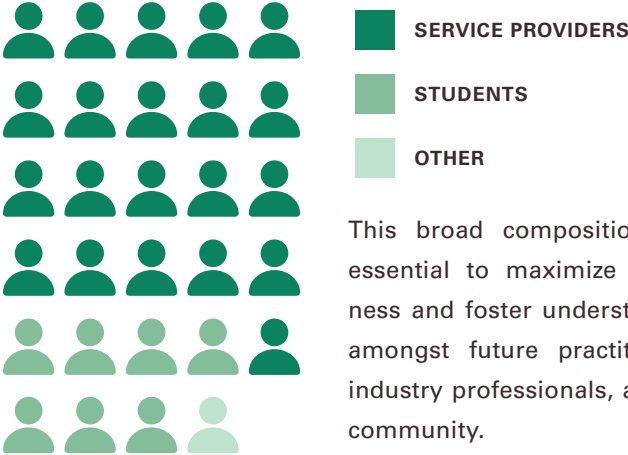
**Levels of support are defined as follows:
Special: any support beyond what most families will access.
Moderate, ongoing: 1-2 weekly home visits until child is 18 years old.
Intermittent: weekly home visits for first 1-2 years, then as needed.
Constant: nearly 24/7 support.

KEY FINDINGS:

- Service providers' perceptions of parents with CC shifted from the pre-survey to the post-survey.
- Service providers reported higher confidence in the abilities of parents with CC with intermittent support.

HALF-DAY ORIENTATION

A half-day orientation session was held to introduce the Step-by-Step (SBS) Parenting Program. This session was open to post-secondary students, service providers, and community members, each with varying levels of experience in supporting parents with CC:



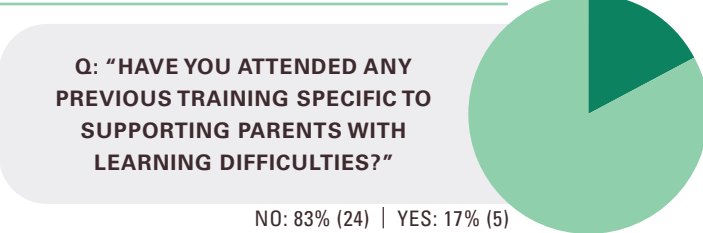
This broad composition was essential to maximize awareness and foster understanding amongst future practitioners, industry professionals, and the community.

METHOD & ANALYSIS

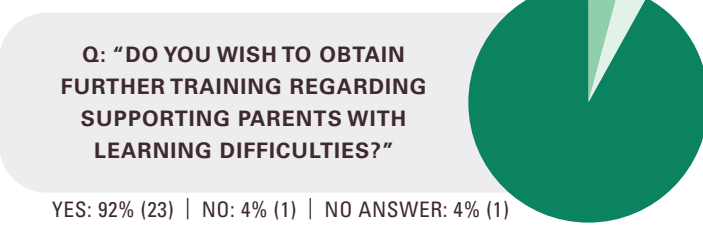
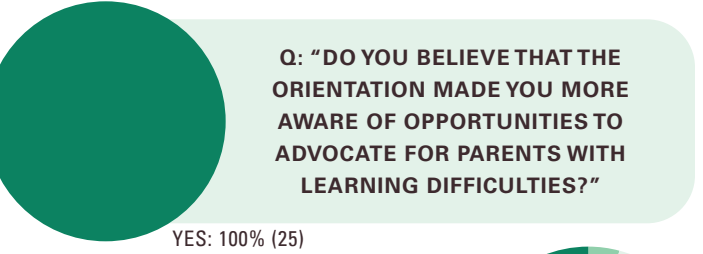
YES NO

Anonymous surveys were administered to evaluate changes in attitudes and beliefs regarding the parenting capabilities of parents with CC. To maintain anonymity, overall results were analyzed to assess any shift in the participants' perceptions.

PRE-SURVEY FINDINGS



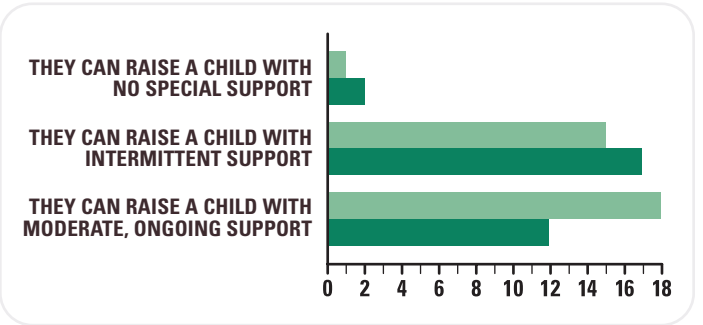
POST-SURVEY FINDINGS



COMPARING PRE & POST-TRAINING SURVEYS

PRE POST

1. In both surveys, respondents were asked: "What is your opinion regarding parents with learning difficulties?"



*In both the pre and post training surveys, zero respondents indicated: "Parents with CC should not have children" or, "Parents with CC can usually raise a child, but will need constant support".

PART II: STEP-BY-STEP PARENTING PROGRAM

With the disproportionate representation of parents with CC in the child welfare system (DeZelar and Lightfoot, 2018; McConnell et al., 2011; Kendrick, 2024; LaLiberte et al., 2017; Rebbe et al., 2021), it is evident that these families are at particular risk of being accused of child neglect. As such, early intervention is critical.

During part II, early intervention was implemented to help build parenting skills aiming to increase the chance that newborns will stay with their parents..To support this work, the research team collaborated with Dr. Maurice Feldman and Dr. Kendra Thomson from Brock University.



SERVICE PROVIDER PRACTICING ON AN INFANT SIMULATOR DURING TRAINING.

METHOD & ANALYSIS

2 parent educators certified during the 3-day SBS training worked with 2 expectant parents with CC. The parent educators used a single-case experimental design that included baseline assessments using the SBS checklists across several selected skills, which helped determine the cause-and-effect relation of the training and the subsequent skills developed by parents. Checklist scores from each skill's observational sessions were recorded across 4 stages: baseline, training, follow-up with the infant simulator, and follow-up with the actual babies when born.

Surveys were also conducted to examine the parents' satisfaction and confidence in the skills they learned.

KEY FINDINGS:

- All parents increased, maintained, and generalized the skills they learned with their own babies.
- All parents retained custody after birth.

PHASE 3: CO-PRODUCTION

AS CLOSS AND LANDRY (2020) EMPHASIZE, A CO-PRODUCTION APPROACH—DISTINCT FROM A PURELY CONSULTATIVE ONE—ENSURES THAT THE TRUE NEEDS OF INDIVIDUALS WITH LIVED EXPERIENCE ARE RECOGNIZED AND ADDRESSED. THIS PHILOSOPHY UNDERPINNED OUR SESSIONS’ DESIGN AND FACILITATION.

The steering committee hosted **5 co-production sessions** aimed at developing a more effective **model of support** for parents with CC. To ensure inclusive and participatory research, participants were asked what format they would like the sessions to occur in. Based on this feedback, the following in-person sessions were held:

- Two sessions exclusively with parents with CC
- Two sessions exclusively with service providers
- One combined session with both groups



A CO-PRODUCTION SESSION WITH THE SERVICE PROVIDER GROUP, CO-FACILITATED BY DENISE MAREK AND STEPHANIE WILSON.

During each session, the steering committee presented findings from Phases 1 and 2 of the project. Then, they adapted the **Institute for Research and Innovation in Social Services’ (IRISS) co-production tools** (IRISS, 2017) to guide meaningful discussions. These tools were instrumental in fostering a safe, respectful, and encouraging environment where all participants could contribute openly.

CO-PRODUCED INNOVATIONS

At the conclusion of the co-production sessions, the steering committee, participating service providers, and parents co-created **4 practical strategies** to implement within the community. These key innovations form the foundation of this project’s outcome and meet the expressed needs of parents with CC.

1. Post-Birth Plan

The Post-Birth Plan is a document that can be shared with healthcare providers to support expectant parents with CC. It outlines their wishes for medical care (both prenatal and postnatal), labour and delivery. It may also include a schedule of medical appointments, health concerns being monitored, precautions being taken during pregnancy, birth preferences such as whether they wish to have an epidural, who they would like to be present during delivery, and any concerns they want their healthcare providers to be aware of.

Importantly, the plan also includes a list of the supports and resources the parent already has in place, as well as their plans for the baby’s healthcare. This might include vaccination and check-up schedules, the names of doctors or hospitals they will use, and emergency contacts.

The purpose of the Post-Birth Plan is to provide parents with a clear, written document that communicates their healthcare and infant care plans to their medical team. It is intended to reduce the number of babies apprehended after birth in hospital settings by making health providers aware of the parent’s existing support network and care plans. The ultimate goal is to prevent unnecessary referrals to child protection and reduce the trauma of separation for both parents and children.

2. Community Presentation

The Community Presentation is a series of workshops and presentations designed to be delivered and tailored to students and service providers across a range of sectors that may work with parents with CC. This includes developmental services, early childhood educators, social services, adult protective services, child welfare, social workers, teachers, nurses, and doctors.

The purpose of these presentations is to raise awareness about the lived experiences of parents with CC by highlighting their strengths (such as coping and parenting skills, personal strategies, and resilience), as well as the barriers and challenges they face (such as discrimination and bias, mental health concerns, trauma, and complex service

systems). The ultimate goal of these presentations is to reduce the stigma and bias surrounding parents with CC by increasing the community’s understanding of:

- The barriers they face
- Their human rights
- The importance of keeping families together
- The importance of maintaining parent-child contact
- The existence of tailored, evidence-based supports and training (or lack thereof)
- The effectiveness of supports and training that is already available to them

3. Parent Support Group

The Parent Support Group is designed to help parents with CC build social connections, share their experiences in a safe space, and receive support on a variety of parenting topics.

The group provides opportunities for parents to share their skills and strategies with one another and raise concerns with others who may be navigating similar challenges—all within a supportive, non-judgmental environment.

The plan includes **two types** of support groups:

1. A closed group, where a group of parents work through a series of session topics together to foster stronger rapport, relationship-building, and psychological safety.
2. A drop-in group, where parents can attend as often as they wish, offering flexibility and accessibility to those who may not be able to attend a closed group format.

Both groups should be **co-facilitated** by at least one:

- **Peer mentor**, with lived experience as a parent with CC (compensated for their time).
- **Service provider**, experienced in group facilitation and supporting parents with cognitive challenges.

There is an opportunity to involve post-secondary students in Developmental Service Work, Social Service Work, and Social Work. To further reduce barriers to participation, on-site childcare should be provided during sessions.



STEPHANIE WILSON, RA

DENISE MAREK, RA/PLACEMENT STUDENT



DR. MAURICE FELDMAN (STANDING) TRAINING SERVICE PROVIDERS.

4. Early Intervention and Ongoing Support

This innovation focuses on increasing the capacity and availability of service providers trained in the SBS Parenting Program to deliver individualized, tailored support through an evidence-based approach.

The project *Raising Resilient Families: Empowering Parents with Cognitive Challenges* has contributed to the goal of building local capacity by **training and certifying 21 service providers** across the community in the SBS Parenting Program. In addition, the diverse steering committee and co-production sessions fostered inter-agency collaboration, creating more opportunities for seamless referrals and improving access to SBS-trained service providers.

Parenting is a journey of evolving challenges—and as children grow, families’ needs and goals often change, too. As such, ongoing, adaptable support throughout the child’s lifetime is essential for true efficacy and sustainability.

Importantly, early intervention should begin before the baby is born. Expectant parents benefit from support that helps build parenting skills in advance, increasing their confidence and preparedness. This early intervention component was piloted during phase 2 of the project, with expectant parents practicing and learning parenting skills using infant simulators. After birth, **these skills were successfully transferred to real-life parenting, with all participating parents retaining custody of their babies**—highlighting the power and impact of proactive support.



NOTE. ADAPTED FROM *RAISING RESILIENT FAMILIES: SUPPORT MODEL FOR PARENTS WITH IDD* BY CORBIER, 2024.

DISCUSSION & MOVING FORWARD

PARENTS WITH CC OFTEN FACE HIGH RATES OF CUSTODY REMOVAL, CAUSING TRAUMA FOR BOTH THE PARENT AND CHILD (MCCONNELL ET AL., 2011; KENDRICK, 2024; LALIBERTE ET AL., 2017). THIS RESEARCH AIMED TO IDENTIFY BARRIERS, ADDRESS SERVICE GAPS, AND CO-DEVELOP A PROACTIVE MODEL OF SUPPORT THAT REDUCES THE NEED FOR CHILD REMOVAL.

OVERVIEW

The *Raising Resilient Families: Empowering Parents with Cognitive Challenges* research project highlights the importance of **early intervention, community collaboration, and support systems** rooted in respect and dignity. By reflecting the **lived experiences** of parents, the project’s goal has been to influence **lasting change** that promotes the well-being of families and **prevents unnecessary disruption**.

KEY FINDINGS

PHASE 1

Phase 1 grounded the research in the voices of those most impacted— especially parents, whose perspectives are too often overlooked, yet essential to shaping a strengths-based and responsive approach. Several key lessons emerged and directly influenced the phases that followed.

- Parents and service providers identified barriers such as bias, discrimination, mental health, trauma, and navigating systems. Repeated negative experiences frequently led to decreased self-confidence in parents.
- Service providers believed parents experienced bias and judgement, including bias within their own agencies. Many believed agencies could do more to support parents with CC—reinforcing the urgent need for systemic change.
- Both groups identified best practices such as advocacy, modelling, and coaching in supporting parents with CC.
- Both groups emphasized the strengths of parents with CC, including strong relationships with their child, resilience, and a deep commitment to parenting.

PHASE 2

Phase 2 focused on building capacity by strengthening the skills, knowledge, and confidence of parents with CC and the service providers who support them.

- A key takeaway is the need for more training opportunities like the training provided on the SBS Parenting Program, as the majority of service providers had no prior training specific to supporting parents with CC.
- Attendees felt confident in the efficacy of the 3-day training. Increasing access and funding for such programs could greatly enhance capacity.
- Respondents unanimously agreed the orientation increased their awareness in advocating for parents with CC, and many expressed an interest in further training. Raising awareness can shift attitudes and challenge bias—laying the groundwork for inclusive and informed practice.
- Implementing the SBS Parenting Program demonstrated the benefit of prenatal early intervention. Both of the expectant parents who participated improved their parenting skills and maintained them post-birth with their babies. **To date, both parents have retained custody of their children.**

PHASE 3

The insights from Phases 1 and 2 played a critical role in shaping the innovations co-designed by parents and service providers in Phase 3.

During the co-production sessions, participants were presented with the key findings from previous phases, giving them a shared foundation of lived experience and evidence. This allowed them to draw on the realities of parenting with CC, along with the demonstrated value of training and tailored support, to develop practical, strengths-based solutions for an overall model of support.



SERVICE PROVIDER USING AN ASSET MAP, ONE OF THE IRISS (2017) TOOLS USED DURING THE CO-PRODUCTION SESSIONS.

IMPLICATIONS FOR POLICY AND PRACTICE

Across all research phases, several key barriers emerged that require **changes to policy and practice**.

Lack of Proactive Support and Early Intervention

This research project aimed to develop a **proactive** model of support to reduce the impact of social issues such as trauma, stereotypes, institutionalization, and violation of human rights. Yet, the results of this research revealed that supports offered to parents are often **reactive—typically provided only after a crisis, such as custody loss or family separation, has already occurred**.

A proactive and strengths-based approach which offers support and builds upon parents’ existing skills and resources before a crisis or separation occurs may therefore help mitigate this harm, benefiting both parents and children. Responses from participants in this study suggest that few early interventions are available during pregnancy or early parenting. Those that do exist are often difficult to access due to factors like long waitlists, restrictive eligibility criteria, or a lack of awareness.

To address this, policies should be developed that **prioritize and fund early, proactive, and strengths-based supports, particularly during pregnancy** and early parenting years. These supports must also be **ongoing**, adapting to children’s developmental milestones and parents’ evolving needs and goals.

Insufficient Training for Service Providers

Phase 2 revealed a significant gap in training for service providers specific to supporting parents with CC. These parents often experience unique barriers and challenges resulting from the intersections of disability and systemic social inequities (Kendrick, 2024; LaLiberte et al., 2017).

Supports for these parents must therefore recognize this context, be responsive to parents’ individual goals, and be delivered in ways that align with their preferred learning styles (Rebbe et al., 2021). Training for service providers specific to engaging with and supporting parents with CC may play a key role in reducing their overrepresentation in the child welfare system (LaLiberte et al., 2017). Phase 2 of this study demonstrated that training can positively shift service providers’ attitudes and increase their confidence

in supporting parents with CC, highlighting its potential to challenge bias and reduce stigma.

Therefore, a key recommendation is to **integrate specialized training into core service provider education** and professional development, and to offer this type of **training on an ongoing basis**. This requires increased funding dedicated to training opportunities and a commitment from agencies to prioritize and sustain them.

Stigma, Bias, and Discrimination

Stigma, bias and discrimination emerged as significant recurring issues for parents with CC, and service providers reported that they believed **bias existed within their own agencies**. This finding was further bolstered when parents reported they often felt judged and as if their parenting decisions were questioned. Tied to these experiences—and due to the overrepresentation of their children in the child welfare system (Feldman et al., 2025; Kendrick, 2024; LaLiberte et al., 2017; McConnell & Llewellyn, 2002; Proctor & Azar, 2013; Rebbe et al. 2021)—many parents also expressed a **fear of asking for help due to the risk of child apprehension**. Systemic change is necessary to disrupt these patterns.

There is a dire need to address the ongoing impact of bias, discrimination, and stereotypes to ensure that parents with CC can receive support with equity and dignity. Central to this is the use of an **anti-oppressive lens** that acknowledges the impact of systemic inequalities, rather than a parent’s CC in isolation. For example, parents with CC are disproportionately more likely to experience issues which may affect their experience as parents, such as poverty, social isolation, or a history of abuse or neglect themselves (Kendrick, 2024; LaLiberte et al., 2017; Lightfoot et al., 2010). Viewing parents from this broader social context is therefore crucial for service providers to provide more holistic and fair support, contextualized within parents’ individual experiences and responsive to their needs and goals. Such a perspective may help to reduce the likelihood of unjust blame or penalties, such as custody loss, that can arise from systemic barriers rather than parenting ability.

A key recommendation is to **integrate human rights based, anti-oppressive, and anti-stigma frameworks into policy and training**—within agencies and across broader levels of government. These frameworks must actively challenge stigma and discrimination to promote equitable treatment

of all parents. Furthermore, parents themselves should have the opportunity to share their lived experiences and offer recommendations based on their needs.

The success of the co-production sessions, in which parents and service providers collaborated to design 4 practical strategies, demonstrates the value of including those directly impacted in policy and program development. Involving parents in this way brings a crucial perspective that helps ensure policies and supports are not only relevant, but grounded in real-world experience. Therefore, an additional recommendation is for policy-makers to actively and meaningfully **include the voices of parents with CC in the design and evaluation of programs, services, and policy decisions**.



LEFT TO RIGHT: VICKY CARUANA, 2 OF THE PARENTS, KAY CORBIER & AMANDA CAPPON, STANDING NEXT TO THE RESEARCH PROJECT POSTER.

System-Level Service Gaps

While some tailored services to support parents with CC do exist, this research revealed that there are often significant barriers, such as: long waitlists, inflexible eligibility criteria, complex system navigation, or a lack of awareness of their existence. As a result, many parents are unable to access support that could benefit them and their children.

These systemic barriers must be addressed from **multiple levels**. At an administrative level, more funding is needed to increase the availability of these supports and services, and the complexity of application and **intake processes should be simplified wherever possible**. At the agency level, policies and programs that **promote interagency collaboration** could be highly beneficial. The co-production part of this research study demonstrates the potential benefits of such collaboration, providing a space for service providers to begin building interagency relationships, become aware of existing resources

and programs, and identify ongoing gaps in services. The network created by such collaboration may enable agencies to work together to fill service gaps and improve access to individualized support—overall helping prevent parents with CC from falling through the cracks.

LIMITATIONS

As with any research project, there are limitations that must be considered when interpreting the findings and planning for future research.

First, a convenience sample of parents connected to agencies represented on the steering committee was used to recruit participants for interviews in Phase 1. As a result, the sample may not be representative of the broader population of parents with CC—**particularly those who have not received formal support** and those who may have different experiences and perspectives.

Additionally, Phase 2 used a **snowball recruitment method** for the training and orientation. The research team began with members of the steering committee, who then shared the opportunities with colleagues and contacts at other agencies. 32% of orientation participants were post-secondary students, primarily from 2 institutions—Durham College and Trent University. Future research should aim for **more diversity in participants** and/or more open and widely **accessible recruitment strategies**.

The co-produced strategies and model of support are still in the **early stages**. While they show strong promise, not all have been fully implemented—making it premature to discern their effectiveness. Future research could focus on **evaluating the impact** of these strategies and **refining them based on outcomes**.

Geographically, this was a project focused on the Durham Region in Ontario, primarily suburban in nature. As such, the findings may not be transferrable to other areas and could differ between rural, urban, and suburban contexts. Future research would benefit from **greater geographical diversity and comparative regional analysis** to explore how context influences experiences and outcomes.

Despite these limitations, the findings of this research provide valuable insights and a strong foundation for future work.

MOVING FORWARD

This project has made significant impact and taken important steps towards developing a better model of support for parents—but **the work is far from over**. To fully address the service gaps, discrimination, and lack of tailored proactive support, change is still needed across all levels: from **one-on-one interactions** with individual parents, to the **training and practices within agencies**, to broader **interagency collaboration**, and finally, the **systemic barriers and deep societal biases** that continue to shape how parents with CC are perceived and treated.

Too often, these parents are seen primarily through the lens of their diagnosis, rather than simply as parents (Bachrach, 2022; LaLiberte et al., 2017). However, all parents—not just those with CC—have needs and face challenges in parenting. All parents deserve to be treated with dignity and respect, and to be offered support free from bias, judgement, or the fear of negative

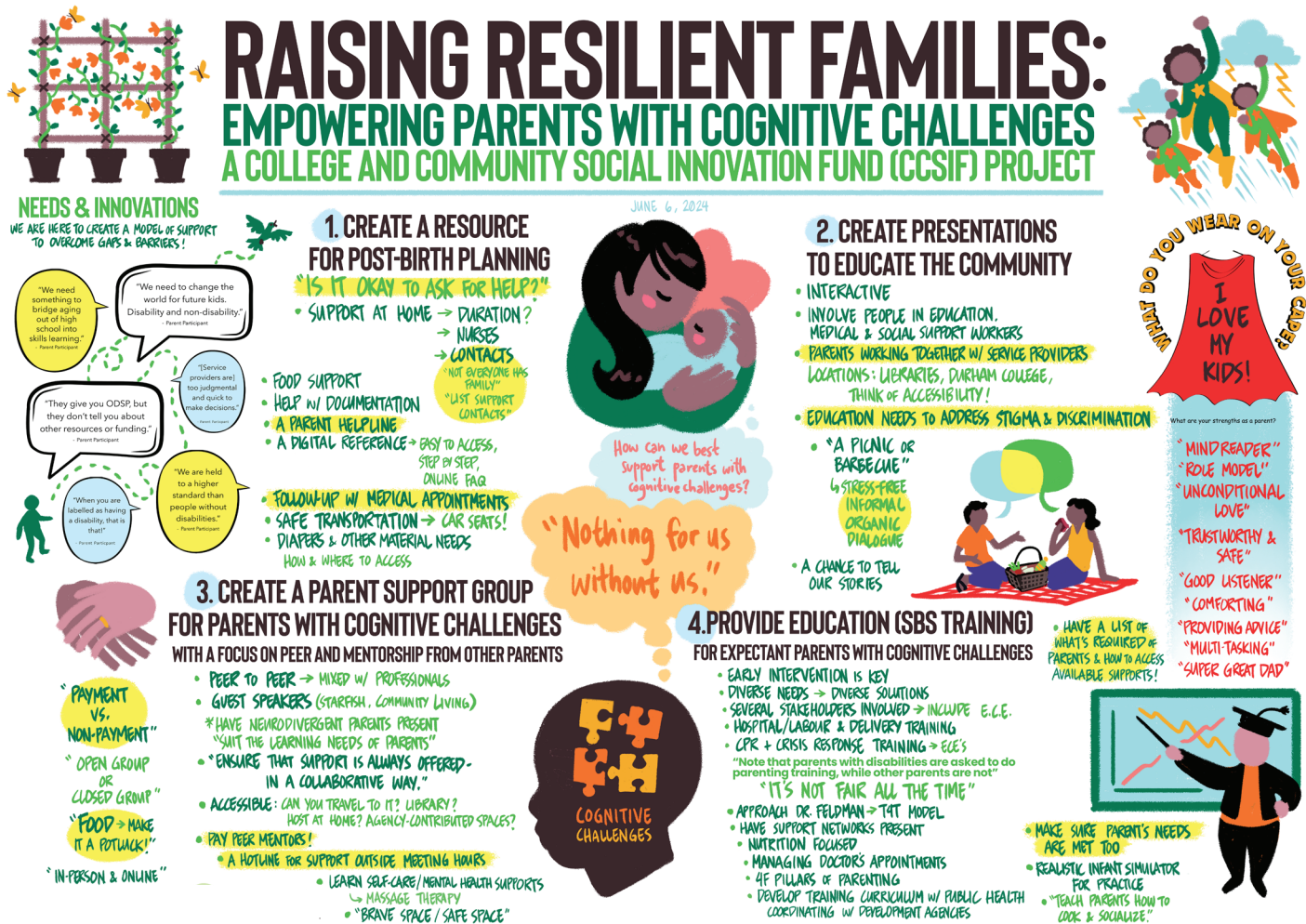
consequences for asking for help. **It is long past time that every parent, regardless of ability, is given an equal chance to be supported, to be valued, and to thrive.**

TRAINING THE TRAINER

In June 2025, research leads partnered with **Lake Ridge Community Support Services (LRCSS)** to train more local service providers in the SBS Parenting Program. This session—funded in part by a **Specialized Training and Equipment Fund (STEF)** through the **Ministry of Community, Children & Social Services (MCCSS)**—introduced a more sustainable and accessible model, allowing for long-term impact and scalability within the community. It also marked a significant advancement: **Vicky Caruana** of the **Starfish Parent Support Program** was certified as a trainer, enabling her to train her own team and further build regional capacity.



DR. FELDMAN & VICKY CARUANA (STANDING, LEFT TO RIGHT) TEACHING SERVICE PROVIDERS.



A LIVE GRAPHIC RECORDING DRAWN BY JAMES NEISH TO ILLUSTRATE THE 4 CO-PRODUCED INNOVATIONS.

OUR IMPACT

OVERVIEW

The research project *Raising Resilient Families: Empowering Parents with Cognitive Challenges* aimed to enhance support for parents by building capacity among service providers and fostering community collaboration. As a result, it had significant impact in the community and advanced a better model of support in several ways.

This innovative project focused on the lived experiences of parents with CC and actively involved them in the entire research process, rather than conducting research on them. It included two key components: an evidence-based program (SBS), and a qualitative approach using semi-structured interviews to gather lived experiences and elicit the voices of parents who are often unheard or undervalued. This is often due to the prevailing assumptions that these individuals cannot be parents, raise children safely, or even learn parenting skills effectively.

BEYOND OUR COMMUNITY

Through knowledge dissemination efforts, the research team successfully reached a wider audience beyond the Durham Region. Findings and insights have been shared through various channels, including presentations at community events (Durham College ORSIE Impact Expo, October 2024), academic conferences (Health and Wellbeing in Developmental Disabilities, February 2025; C2U Expo 2025, “Partners in Place,” May 2025), and a peer-reviewed journal publication (Feldman et al., 2025). This has ensured that this work contributes to ongoing discussions and improvements in support for parents with CC.



RESEARCH WAS PRIMARILY CONDUCTED AT THE DURHAM COLLEGE CENTRE FOR INNOVATION & RESEARCH IN OSHAWA, ON.



COMMUNITY HIGHLIGHT



For nearly 4 years, project leads Kay Corbier (not pictured) and Amanda Cappon (left) worked on this research project alongside **Vicky Caruana** (middle), **Executive Director and Founder of the Starfish Parent Support Program**. Starfish Parent Support is a unique agency supporting families with one or more parent with CC.

On March 6th, 2025, Caruana was honoured as a nominee for the **Paul Harris Fellow Award** at the **Rotary Club of Whitby**, put forward by former recipient and dear colleague, **Danielle Harder** (right). This award recognizes individuals who contribute, or have contributions made in their name, of \$1,000 to The Rotary Foundation

FINAL THOUGHTS

Ultimately, while this project was innovative in many aspects, it should not need to be. Parents with CC deserve the same grace and support as parents without such challenges. This project serves as a reminder that empowering and valuing all parents is not an exception—it is a necessity.

We leave this foundation of change in the hands of our community, to go forth and create even greater impact.

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