

PROJECT OVERVIEW

The project

A community-based intervention project that was funded by the BC Ministry for Children and Family Development (MCFD) from 2017-2020, with ACT-Autism Community Training responsible for financial oversight.

The goal

To design, implement, and evaluate the effectiveness of a parent coaching intervention for children aged 15-36 months at risk for autism spectrum disorder (ASD), in partnership with community service providers.

Implementation team

Researchers, project manager, training facilitators, and research assistants.

Participants



23 Child Development Centres and Aboriginal agencies in small, medium, and large population centres across BC. Administrative leaders, coaches, support staff, and families from these partner agencies.

How it worked

- 1** Research team **INTRODUCED THE PROJECT** to partner agency staff.
- 2** Training facilitators **TRAINED COACHES** nominated by partner agencies.
- 3** Partner agency staff **SCREENED TODDLERS** with social communication delays to see if they were at risk for ASD.
- 4** A PACE Coaching **RESEARCH STUDY** was conducted with agency families in the communities where they lived.
- 5** **PARENT-CHILD CONNECTIONS**, a more flexible version of parent coaching, was offered to Indigenous families.
- 6** Research team met with partner agency staff to get **FEEDBACK ABOUT THEIR EXPERIENCES**.

What made the project unique



COACH TRAINING

What we did

We trained coaches in Child Development Centres (CDCs) and Aboriginal agencies as parent coaches.

Coaches were infant development consultants, early childhood educators, speech-language pathologists, occupational therapists, behaviour consultants or interventionists, child and family resource workers.

How we did it



1ST Coaches learned how to support social communication skills in young children with ASD.

3-day workshop and 12 weeks practice with a child in the community



2ND Coaches learned how to coach parents to use support strategies in daily routines at home.

3-day workshop and 16-20 weeks practice with a parent and child in the community

How it went

39 → **31**
COACHES STARTED TRAINING COMPLETED TRAINING

WITHDRAWALS were primarily because of high caseload demands at the partner agency.

Strengths

A **GOOD MATCH** between agency needs and values and the focus of training

STRONG SUPPORT of the coaches by agency leaders

READINESS FOR CHANGE on the part of coaches

Coaches & leaders said:

*“This has been such powerful learning, the gift that we give our families when we are successful is **the most powerful thing** I’ve ever seen in my work.”*

*“[You’re] **building that parent capacity** [so parents can] build those strategies into...daily routines that are already happening. So you’re not...doing a pull-out therapy session and saying ‘here’s your hour of therapy.’”*

*“The whole model was very different but...it’s **literally been a game changer** for me of how I practice.”*

*“This was **hands-down... the best inservice training** I’ve ever had.”*



Barriers

CASELOAD DEMANDS and **TIME REQUIRED FOR TRAINING.**

Even though agencies were reimbursed for the time coaches devoted to training, it was often impossible to find staff to backfill the time required.

RESEARCH STUDY

How it worked

Research staff helped partner agencies identify children between 15-36 months of age with social communication delays. Across all agencies, **they identified 285 children.**

Clinicians with autism experience helped parents complete a screening measure to assess autism risk. Across all agencies, **they screened 142 children.**

Parents whose children were at risk for autism were **invited to join the research study.** Across all agencies, parents of 92 at-risk children were invited. Some did not agree to join the study.

Agency clinicians assessed parents and children **before the study began.**

Parents and their child were **assigned at random** to a Parent Coaching or an Assess & Monitor group.



32 PARENTS were to receive parent coaching for 24 weeks from a coach who was trained in the project.



30 PARENTS were to be assessed and then monitored for 24 weeks.

Both groups could receive services from the partner agency and others in the community. All parents received access to **online learning modules** about how to support their child's social communication development and a guide book written by subject matter experts.

Agency clinicians assessed parents and children **when the study was finished.**

What happened

24 parents in the **Parent Coaching group** completed the study.

25 parents in the **Assess & Monitor group** completed the study.

Most parents who withdrew did so because of family issues that interfered with study completion.



AT THE BEGINNING OF THE STUDY, children and parents in both groups were very similar.

BY THE END OF THE STUDY, children in the parent coaching group were **able to understand more words** than children in the other group.



BY THE END OF THE STUDY, parents in the parent coaching group had a **better quality of life,** were **more satisfied** with the services they received, and **said that they had learned more** than parents in the other group.

Child change was related to parent change in interaction skills – that is, children whose social communication skills improved more had parents whose interaction skills improved more.

PARENTS WHO WERE COACHED SAID:

“Our child is a completely different person! Our child communicates, asks for help, plays with others, does everything we hoped he would do and were so worried that he would never do.”

“I feel like he’s a different kid. Part of it is age/maturing/going to preschool, but a large part is the communication development due to PACE – i.e., I can hold his hand when we’re out, not hang on to his wrist for dear life.”

*“My child and I grew and bonded so close thanks to the guidance of the program. **We are truly grateful** for this opportunity! It’s something we will remember and cherish.”*

“This study is the best thing I could have done for him. I have learned skills that will help us for years to come.”



“The changes my child has experienced through PACE are mind blowing. He has grown in every single aspect that we worked on and more. Plus, I now have the tools and confidence to help him and his younger brother...”

*“Gave me more confidence to carry out daily tasks in a way that is most beneficial to his learning. **He has made SO much progress** in so many areas, it blows my mind. It’s amazing.”*

*“When we started the study he wouldn’t let me touch any toys he was playing with. He would take anything I touched and look me in the eye and drop it on the floor. Last week at preschool he was independently taking turns with another peer. **It’s absolutely amazing how much he has progressed.** He is a happy and bright young boy who has benefited immensely from his involvement in the PACE study. Thank you from the very bottom of my heart!”*

“PACE really helped our family connect. We learned how to best support both of our children....My child has grown exponentially throughout this study and I’m so sad it’s over.”

How it worked

In the partner agencies, **10 Indigenous children** were at risk for autism and their caregivers were invited to participate in the project. All ten caregivers agreed.

Research staff and training facilitators **consulted with Indigenous advisers** to modify coaching for these families. All families received:

**MORE FLEXIBLE
PARENT COACHING**

+

MORE TIME

+

**CULTURAL
SAFETY**

What we learned

Indigenous parents are eager to learn strategies for supporting children's social communication development.

Building a trusting relationship with caregivers takes additional coach time and flexibility.

Designing a model for coaching Indigenous parents must involve co-construction during the planning stage and throughout, in partnership with Indigenous advisers.

What happened

Of the ten families who joined the project, **four completed parent coaching**. Caregivers who withdrew did so because of family issues that interfered with completion.

Child and caregiver change varied for the four families who completed coaching.

Caregiver-child interactions were more balanced and most children could say and/or understand more words.

Overall, caregivers endorsed the experience:

"[Coach's name] was very good at pointing out my child's strengths and showing me how to bring them out and have more fun."

"Being proactive in helping the child in my case was very positive for both of us. The many techniques available to support and encourage the child so that their learning style and abilities could be developed and grow."

"My child's interest in other people has improved tenfold. He never used to acknowledge the presence of other people. Now he seeks interaction with others."



COMPARATIVE COST ANALYSIS

How it worked

Research partners at the Hospital for Sick Children in Toronto compared resource use and costs for families who received parent coaching (PC families) and those who did not (Assess & Monitor families).

Data were collected from parent coaches, training facilitators, and parents:

- Activities and costs of coach training
- Activities and costs of parent coaching
- Amounts and types of services parents sought for their children from the Ministry of Children and Family Development (MCFD) and the Ministry of Health (MoH)

Key messages

An investment in parent coach training would be an important addition to an **EARLY INTERVENTION WORKFORCE.**

Early parent coaching may lead to **SAVINGS AND BETTER OUTCOMES IN THE LONG-TERM** for children with suspected autism who receive subsequent therapy, but this requires study.

Coach training: What happened?



The average cost of formal parent coach training was **\$11,822** per coach: 41% of this cost was for coaches' time spent in training (workshops & practice), travel and accommodation, and 59% was for the time and travel of training facilitators. We estimate that, following the initial period of training and mentorship, a full-time coach could coach up to 40 families per year, on average.

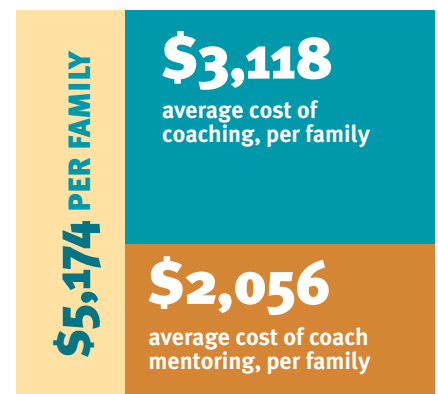
Parent coaching: What happened?

The average cost of coaching per family was \$3,118, consisting of the cost of coaches' time directly coaching parents, preparing for coaching sessions, providing parent support by telephone, consulting with training facilitators, and completing administrative tasks. After formal coach training, coaches were mentored by training facilitators during the research study at an average cost of \$2,056 per family. The total cost was **\$5,174** per family.

During the study, all families accessed a wide range of health and community services funded by government. The most frequently used services were from speech-language pathologists, occupational therapists, physiotherapists, pediatricians, and audiologists.

Children in PC families used fewer services compared to those in A&M families. The average savings to MCFD related to reduced service use in PC families was **\$724** per child.

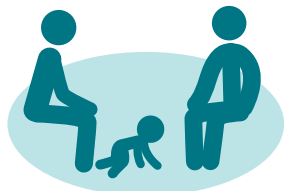
Although service use and costs were lower in the PC group, they did not offset the costs of coaching and mentoring. When coaching costs were included, the net cost to MCFD was **\$4,350** more per PC family compared to A&M families. This cost would likely decrease as coaches become more experienced and require less mentorship and support.



OVERALL LESSONS LEARNED

Parent coach training

Community professionals both **with and without graduate degrees** can learn to provide coaching supports to parents and caregivers of young children.



Parent coach training requires **considerable hands-on practice** both during and following initial workshops, combined with opportunities to reflect and receive feedback from an experienced training facilitator.

Parent coach training requires a financial **investment to supplement existing services** and to reduce current caseload demands by hiring additional staff.

There is a **need for additional investment** in technology infrastructure and technology training in CDCs and Aboriginal agencies.

An investment in parent coach training is likely to yield long-term impacts of services to families and **long-term professional development benefits**.

Parent coaching

Parent coaching

is a promising practice that should be included as an **early intervention option** for parents



of young children with social communication delays in general (e.g., those with Down syndrome and other disorders that affect early development), not just ASD.

A **parent coaching approach** to supporting families may have a long term empowering impact.

A modified, **culturally safe version of parent coaching** has potential for Indigenous families who choose a relatively intensive level of support.

Early autism awareness

CDCs would benefit from resources aimed at helping them to **ESTABLISH STRONGER CONNECTIONS** with other community service providers.

There is a need for **INCREASED AWARENESS TRAINING** about the early signs of ASD, the availability of screening tools, and the importance and potential effectiveness of early intervention.

COMMUNITY PROFESSIONALS (physicians, public health nurses, infant development consultants, speech-language pathologists, and others) would benefit from training aimed at helping them to engage in **“THE AUTISM CONVERSATION”** with families of young children who might be at risk for ASD.