



Focus on Research II – April 23, 2021

Supporting Early Social & Communication Development through Parent Coaching

Web Streamed from Vancouver, British Columbia

Presented by

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and other members of the PACE Coaching team.



Acknowledgements

ACT – Autism Community Training thanks our presenters for enabling us to present the second of the two Focus on Research events we are holding this month to make up for having to cancel last year's presentation, because of the pandemic. ACT has held a Focus on Research event annually since 2005 as a way of ensuring that we promote the latest in evidence-based information.

As we all struggle to keep our communities healthy, we appreciate that ACT can offer this workshop online while maintaining the safety of attendees, staff, and our presenters. Many thanks to the Sheraton Wall Centre and XE Live for supporting our work.

Our sincere thanks to all members of the Parent And Child Early Coaching project (PACE) for sharing valuable information and the lessons learned from this project, conducted in collaboration with child development centres and Aboriginal agencies in 16 BC communities from 2018-2020. We are very grateful to all who enable us to share this necessary research with families, autistic individuals, community professionals and researchers, around British Columbia, across Canada and internationally.

Over the years, those who have attended ACT events know that we depend on community collaboration and support to sustain our work. ACT deeply appreciates the many parents and professionals across British Columbia who volunteer their time and support, donate funds, and help spread the word - especially during these challenging times.

Free Resources from ACT

ACT's Coronavirus (COVID-19): Resources for the Autism Community - ACT has gathered resources specific to those who are neurodiverse, and useful general resources related to COVID-19: www.actcommunity.ca/covid-19-resources

Autism Videos @ ACT (AVA) – Over 65 quality online videos available free – without a log-in, thanks to our sponsors. www.actcommunity.ca/videos

ACT's Autism Information Database (the AID) – Like Google for Autism but better! Keyword search nearly 1,400 curated AID records for evidence-informed, practical information resources useful to families and community professionals. www.actcommunity.ca/aid

ACT's BC Community Resources Database – Search by your postal code for professionals and service providers throughout BC. www.actcommunity.ca/aid-search/community

ACT's Autism Manual for B.C - 13 chapters! www.actcommunity.ca/autism-manual-for-bc -

ACT's Monthly News Round-Up & Event Alerts - Sign-up to keep in touch with developments affecting the special needs community. www.actcommunity.ca/updates

ACT's Facebook - ACT carefully sources interesting, insightful stories to inform our 8,000 plus followers. www.facebook.com/autismcommunitytraining



Parent Coaching: Why? Who? How?

ACT-AUTISM COMMUNITY TRAINING CONFERENCE

APRIL 23, 2021

PAT MIRENDA, PAOLA COLOZZO, VERONICA SMITH,
WENDY UNGAR, KAREN KALYNCHUK, AND FRIENDS

Welcome!



LIVE HEALTHY
& SAFE

Land Acknowledgment

This project was conducted on the traditional, ancestral, and unceded territories of many First Nations, including:

- the Musqueam, Squamish, and Tsleil-Waututh nations
- the Tsawassen, Semiamhoo, Kwantlen, and Katzie nations
- the Stó:lō nations, including the Se'math and the Matsqui
- the Ktunaxa nation
- the Kwakiutl and Wei Wai Kum nations
- the Cowichan Tribes
- the members of Treaty 8 and the Doig, Blueberry, and Halfway nations
- the Lheidli T'enneh nation
- the Syilx people of the Okanagan nation
- the Tsimshian nation
- the Haisla nation
- the Secwepemc nation
- WSÁNEĆ territory, home of the Lekwungen, Songhees and Esquimalt people of the Coast Salish nation

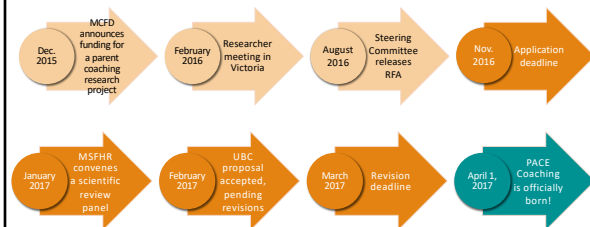
Parent And Child Early (PACE) Coaching Project

Goal: To identify promising practices with respect to implementing parent coaching as a model of service delivery for children up to 36 months of age who were at risk for ASD

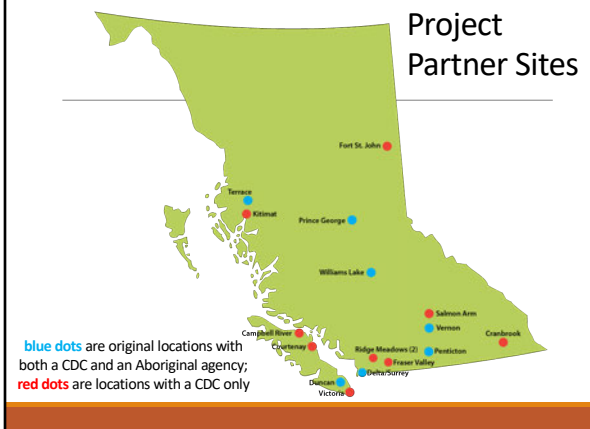
Housed at UBC, with research partners from University of Alberta, Hospital for Sick Children (Toronto), Emory University, University of California-Davis M.I.N.D. Institute

Conducted from 2017-2020

The PACE Coaching Story



Project Partner Sites



Today We Will Talk About

Session 1: Background and rationale

- What is social communication and why is it important?
- What does it mean if social communication is delayed?
- How is social communication related to parent coaching?
- How is parent coaching different than other types of parent-child support?

Today...

Session 2: PACE Coach training

- Who we trained
- How we trained
- What we found (outcomes, facilitators and barriers)
- What our partners had to say



Today...

Session 3: Research studies (PACE Coaching and Parent-Child Connections)

- What we did
- What we found (outcomes, facilitators and barriers)
- What our partners had to say

Session 4: Moving forward

- Costs of training, coaching and service use
- Understanding the breadth of services families use
- Implementation: what did we learn and what is required?
- Wrap up and final words

Let's Start at the Beginning...

What is Social Communication
and Why is it Important?



Social Communication...

Group of skills that include:

- **Watching, listening** and anticipating what people will do
- Initiating and responding to **social interaction**
- **Nonverbal** communication
 - Eye gaze, facial expression, gestures
- Communicating with **sounds**

Social Communication...

These skills allow the child to:

- Get your **attention**
- **Communicate** what they do and don't want
- Let you know how they feel
- **Share** what they interests them
- **Understand** other people's communication

Begins to develop before a child can talk

- sets the stage for learning how to talk, and
- later school success



Parent/Caregiver Role

Social communication requires **two people**

Develops primarily during **interactions** between young children and their parents/caregivers throughout the day



Baby Navigator

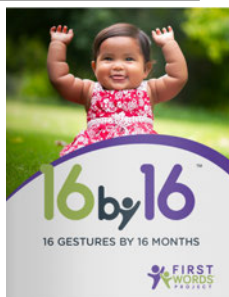
https://www.youtube.com/watch?v=urJs4aw_O3w

Social Communication Development

Social communication **develops over time**

Children should be using at least **two new gestures** each month from 9 to 16 months, so they have at least **16 gestures by 16 months**. They gesture to **communicate** and for **social reasons**, such as sharing interest by showing, pointing to something

See <https://firstwordsproject.com/16-gestures-by-16-months>



Social Communication Development

They should also be learning at least **two new actions** per month from 9 to 16 months, so they have at least **16 actions with objects by 16 months**

They do some actions just because they are fun but they also do many for **social reasons** – like getting a *reaction* from another person

See <https://firstwordsproject.com/16-actions-with-objects-by-16-months/>



What if Social Communication Development is Delayed?

When social communication development is delayed, children **miss out on opportunities to learn from social interactions with parents/caregivers**



Parents/caregivers, in turn, **have fewer opportunities to respond and follow the child's focus**, which limits later language learning and social connectedness

Why a Delay?

Sometimes, a delay is just...a delay, and the child just needs a bit more time

Sometimes, a delay is associated with a known condition

- e.g., Down syndrome, cerebral palsy, prematurity

And sometimes, a delay is a sign of autism spectrum disorder (ASD)

What to Do?

Find out more

The *Baby Navigator* has many resources specifically aimed at parents and caregivers
<https://babynavigator.com/resources/>

- Social communication growth charts 7 to 24 mos
 - what to expect for language, play, social interaction, etc.
- Consider signing up for a Social Communication Checkup: <https://babynavigator.com/soco/>

What to Do?

Any time anyone is concerned about a child's social communication development, it is important to

- **Seek a general developmental assessment** from a pediatrician or early childhood professional
- Infant-Toddler Checklist:
<https://brookespublishing.com/wp-content/uploads/2012/06/csbs-dp-itc.pdf>
- Ages and Stages Questionnaires
<https://agesandstages.com/>

What to Do?

If a developmental assessment indicates a delay, the pediatrician or early childhood provider will likely use another tool to **screen for ASD**

- Modified Checklist for Autism in Toddlers-Revised with Follow-up (M-CHAT-R/F)
<https://mchatscreen.com/>

What to Do?

If ASD seems possible, **ask a physician or pediatrician for a referral** to the BC Autism Assessment Network (BCAAN) for a diagnostic assessment

<http://www.phsa.ca/our-services/programs-services/bc-autism-assessment-network>

Contact the **Autism Information Service of BC** (AIS-BC) for information and support

<https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/special-needs/autism-spectrum-disorder>

Delay → Diagnosis?

The early signs of autism begin to unfold between 9-16 months of age

By age 2, a diagnosis by an experienced professional can be considered very reliable

However, in 2015, among Canadian children diagnosed before age 17

- Only 19% were diagnosed by age 3, and
- **Only 56% were diagnosed by age 6**

<https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018.html#a2-4>



Act Early

NOT addressing a concern only delays the assessment and diagnostic process

- The current wait time for a diagnostic assessment through BCAAN is **78 weeks – 1 year 6 months!**

In BC, parents cannot access autism funding for early intervention without a diagnosis

- While children are on the diagnostic waitlist, limited therapy services are available to them

Early identification = early intervention = better outcomes

The Bottom Line

"Wait and see" is not a good option

"DO and see" is a better choice!

The first step: seek support from the health unit, CDC, or Aboriginal Friendship Centre in your region



What Does This Have to Do with Parent Coaching?

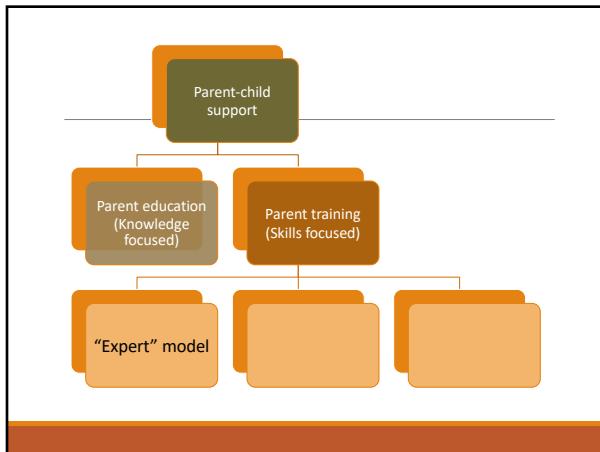
Coaching supports parents to use evidence-based strategies in daily routines, to support a child's social communication development

This can be effective

- For any child with a social communication delay
 - Down syndrome (Meadan et al., 2014)
 - Rett syndrome (Simacek et al., 2017)
 - Fragile X syndrome (McDuffie et al., 2016; Vismara et al., 2019)
- For children who are waiting for an autism diagnostic assessment (Rogers et al., 2012, 2014)
- After an autism diagnosis (Dawson et al., 2010)

What is Parent Coaching?





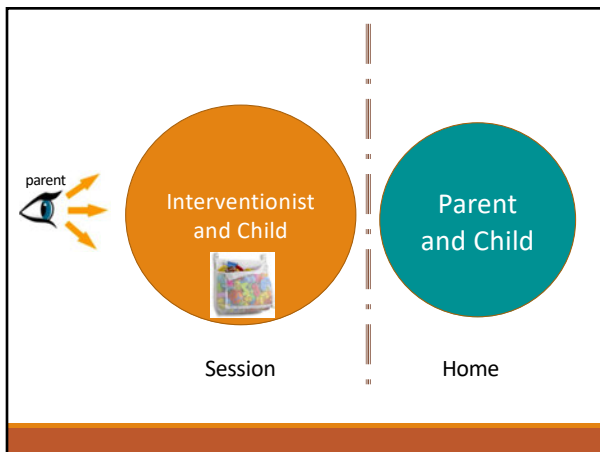
"Expert" Model

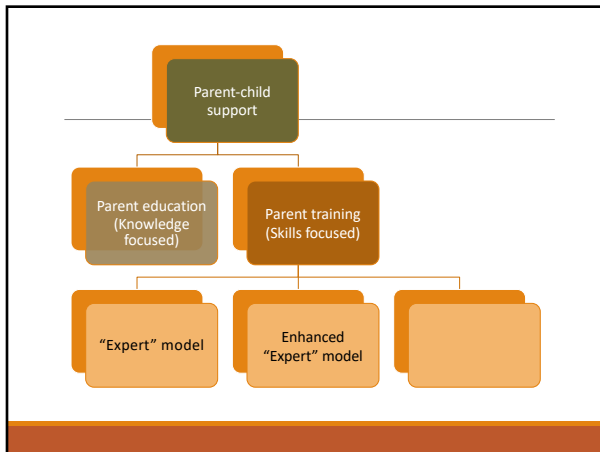
Interventionist *identifies a new behaviour* that the child needs to learn, sometimes with parent input

Interventionist *explains a teaching strategy* to the parent (verbally and/or in writing)

Interventionist interacts with the child *to model the strategy* while the parent watches; child engages in the new behaviour

Interventionist *encourages the parent* to try the strategy over the next time period





Enhanced “Expert” Model

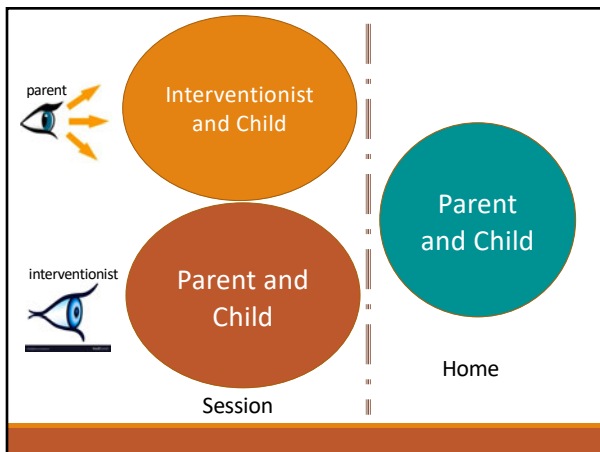
Interventionist *identifies a new behaviour* that the child needs to learn, sometimes with parent input

Interventionist *explains a teaching strategy* to the parent (verbally and/or in writing)

Interventionist interacts with the child to *model the strategy* while the parent watches; child engages in the new behaviour

Parent *tries (rehearses)* the strategy with the child

Interventionist *provides feedback* to the parent



Expert-Guided Practice is Not Enough

Interventionist's lament:

"I've been working with this parent for months, and every time I see them, we practice this skill together. I don't know why they can't do it themselves by now!"



Why?

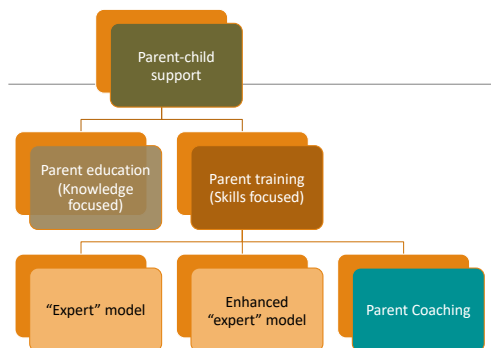
Interventionist is still in the role of "expert"

Interventionist **modeling** is still included as a **core teaching strategy**

Parent might be **reluctant to practice** in front of the interventionist

- Concern about "doing it wrong"
- Worry about being "judged"





Parent Coaching



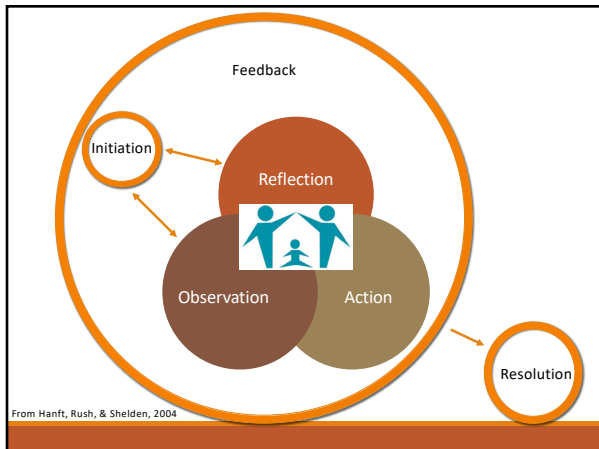
Coach and parent are *equal partners*

Coach focuses on the *parent's priorities and goals*

During parent-child interactions, coach *observes* what the parent does and *reinforces success*

Coach supports the parent to *reflect* on the interaction *and try new skills* as needed

- Emphasis is on *guided practice* by the parent, with *coach feedback*
- Coach modeling is *limited and used only when essential*



What Does the Research Say?

Parent coaching may not be the best “fit” for all parents and all children, but it should be one of the available options (Siller, Hutman, & Sigman, 2013)

Parent coaching requires a **different skill set** from the coach than other forms of parent training (Friedman & Woods, 2012; Sone et al., 2021)

- *Not* “just another name” for the same thing
- Parent coaching *is* “real therapy”

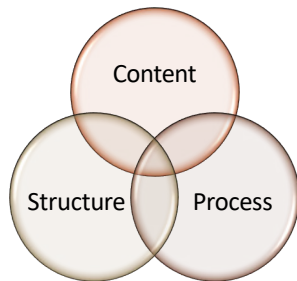
One More Time...What About Children Who Don't Have Autism?

Parent coaching is not just effective for children at risk for or diagnosed with autism! It has also been used successfully with parents/young children with other social communication delays

- Down syndrome
- Rett syndrome
- Fragile X syndrome
- Others



Next up...Parent Coach Training



Resources

Ages and Stages Questionnaires: <https://agesandstages.com/>

Autism Information Service of BC (AIS-BC): <https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/special-needs/autism-spectrum-disorder>

Baby Navigator: <https://babynavigator.com/resources/>

BC Autism Assessment Network (BCAAN): <http://www.phsa.ca/our-services/programs-services/bc-autism-assessment-network/>

First Words Project: <https://firstwordproject.com/16-gestures-by-16-months/> and <https://firstwordproject.com/16-actions-with-objects-by-16-months/>

Infant-Toddler Checklist: <https://brookespublishing.com/wp-content/uploads/2012/06/csbs-dp-1tc.pdf>

Modified Checklist for Autism in Toddlers-Revised with Follow-up (M-CHAT-R/F): <https://mchatscreen.com/>

References

Autism Spectrum Disorder among Children and Youth in Canada 2018: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018.html#a2-4>

Dawson, G., Rogers, S., Munson, J., & Smith, M. (2010). Randomized, controlled trial of an intervention for toddlers with autism: Early Start Denver Model. *Pediatrics*, 125, 17–23.

Friedman, M., & Woods, J. (2012). Caregiver coaching strategies for early intervention providers. *Infants & Young Children*, 25, 62–82.

McDuffie, A., Oakes, A., Machalicek, W., Ma, M., Bullard, L., Nelson, S., & Abbeduto, L. (2016). Early language intervention using distance video-teleconferencing: A pilot study of young boys with Fragile X syndrome and their mothers. *American Journal of Speech-Language Pathology*, 25, 46–66.

Meadan, H., Angell, M., & Stoner, J. (2014). Parent-implemented social—pragmatic communication intervention: A pilot study. *Focus on Autism and Other Developmental Disabilities*, 29, 95–110.

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Rogers, S. J., Vismara, L., Wagner, A. L., McCormick, C., Young, G., & Ozonoff, S. (2014). Autism treatment in the first year of life: A pilot study of Infant Start, a parent-implemented intervention for symptomatic infants. *Journal of Autism and Developmental Disorders*, 44, 2981–2995.

Siller, M., Hutman, T., & b Sigman, M. (2013). A parent-mediated intervention to increase responsive parental behaviors and child communication in children with ASD: A randomized clinical trial. *Journal of Autism and Developmental Disorders*, 43, 540–555.

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References (Con't)

Sone, B., Lee, J., & Roberts, M. (2021). Comparing instructional approaches in caregiver-implemented intervention: An interdisciplinary systematic review and analysis. *Journal of Early Intervention*, 1–22.

Vismara, L., McCormick, C., Shields, R., & Hessl, D. (2019). Extending the parent-delivered Early Start Denver Model to young children with Fragile X syndrome. *Journal of Autism and Developmental Disorders*, 49, 1250–1266.



Coach Training

ACT-AUTISM COMMUNITY TRAINING CONFERENCE
APRIL 23, 2021

PRESENTERS: PAT MIRENDA, PAOLA COLOZZO,
VERONICA SMITH, WENDY UNGAR, AND FRIENDS

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In This Session

PACE Coach training


- Objective: to train community service providers as parent coaches, using a modified version of the Early Start Denver Model
- Who we trained
- How we trained
- What our partners had to say



2

Who Were the Coaches?

- **39 individuals** nominated by their respective CDCs and Aboriginal Friendship Centres
- Infant development and Aboriginal infant development consultants
- Early childhood educators
- Speech-language pathologists
- Occupational therapists
- Family support workers
- Behaviour interventionists/consultants



3

Coach Demographics

Women, average age 44 years

Approximately one-third in each of small, medium, large population centres

Many different cultural/ethnic groups

- 7% were First Nations or Metis
- 19% spoke English and one or more additional languages



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Coach Demographics

Most had 6-10 years of experience with

- Early intervention
- Children with ASD
- Working with families



56% had diploma or Bachelor degrees

- (A)IDP consultants, early childhood educators, behaviour interventionists

44% had graduate degrees

- SLP, OT, others

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What Motivated Them?

"I just really see this as a huge opportunity for us to get some much needed skills and education."

"You know, children are part of a family and if they learn the skills to help their children, then that's when we'll see the progress."

"...to contribute to a knowledge base [in] a way that only strict research [can]...[and] to use this knowledge to advance...our actual service delivery in our province..."

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Training Facilitators



Janet Harder



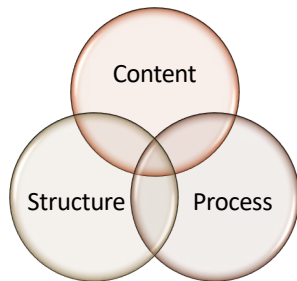
Michaela Jelen



Mary McKenna

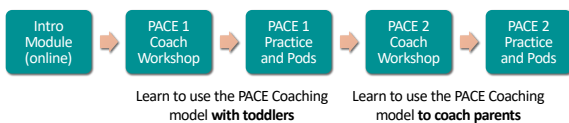
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Coach Training

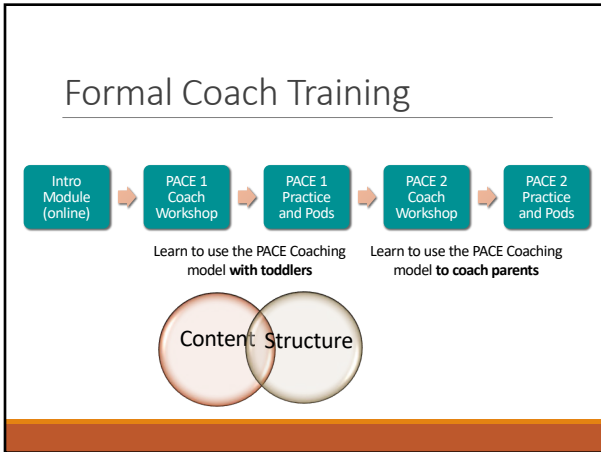


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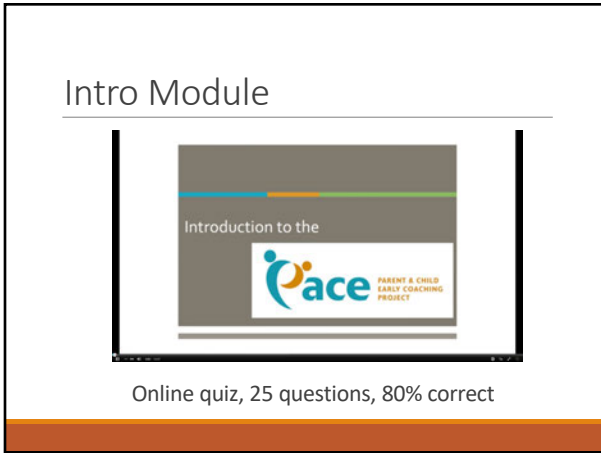
Formal Coach Training



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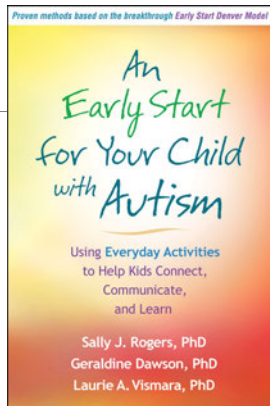


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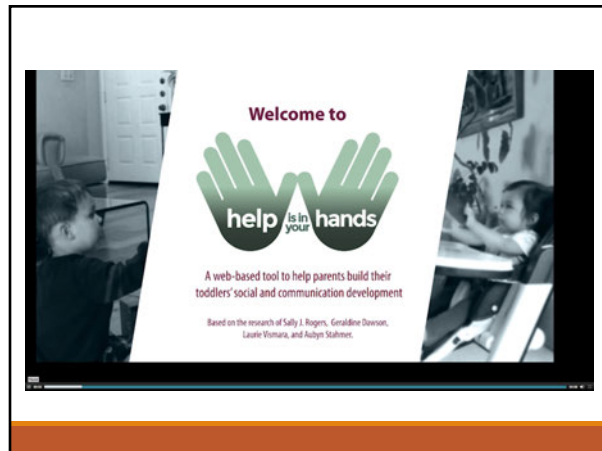


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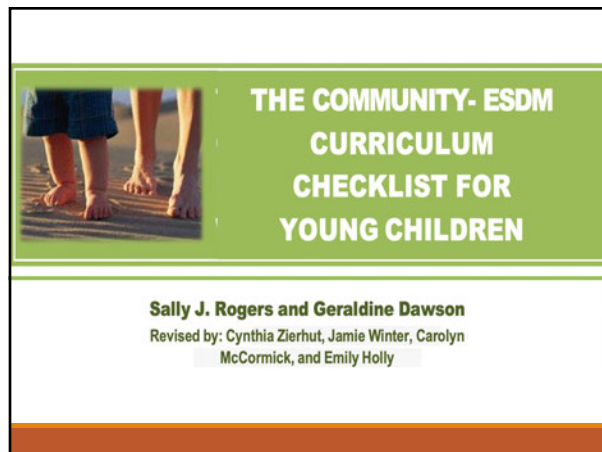
PACE 1 Tools



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15



16

Checklist Domains

Receptive communication

- Understanding early gestures
- Understanding speech

Expressive communication

- Gestures
- Vocal/verbal communication

Joint attention

Social skills

- Dyadic engagement

Imitation

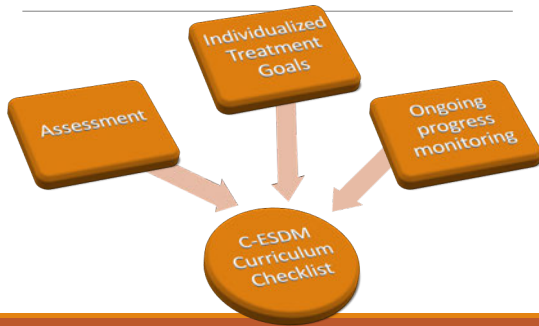
Cognition

- matching, sorting, etc.

Play skills

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Three Uses of the Checklist



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PACE 1 Content and structure

Coaches learned to use key ESDM strategies to **support social-communication development** in toddlers who were already diagnosed with autism and were not part of the research study



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Positioning

Position oneself within the child's "cone of attention"



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Environmental Arrangement



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Follow the Child's Lead

Use the **child's interests** to enhance motivation

Provide choices among toys and activities

Adapt activities to **accommodate sensory needs**

Use **instructional strategies** such as

- Modeling
- Prompting
- Imitating the child's actions
- Contingent ("if-then") reinforcement

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Joint Activity Routines (JARs)

| 1 Setup | 2 Theme | 3 Variations | 4 Close |
|---|--|--|---|
| <ul style="list-style-type: none"> Develop the theme | <ul style="list-style-type: none"> Take turns Teach objectives | <ul style="list-style-type: none"> Increase play complexity Expand child's repertoire Target multiple objectives Build flexibility | <ul style="list-style-type: none"> Organize Transition to next activity |

24

Pace 1 Checklist: 24 Items

C-ESDM
Therapist Practice Checklist

What to consider:
Using this rating tool will help you understand whether a therapist is learning new skills, and to identify skills that may need more coaching.
Use **1** if the therapist uses the skill well or pretty well during the activity.
Use **2** if the therapist could still use some support and feedback using the skill.
Use **3** if there was no opportunity to use the skill during the activity.

For each item rate if the therapist...

1) Warm-up/Attention

| | |
|--------------------------|---|
| <input type="checkbox"/> | Positions self inside the child's peripheral zone to face & close enough to touch |
| <input type="checkbox"/> | Controls the materials well |
| <input type="checkbox"/> | Manages distractions well (e.g. & ignores off-camera distractions) |
| <input type="checkbox"/> | Anticipates child's movements & actions that need to be done |
| <input type="checkbox"/> | Provides choices and allows child a choice |
| <input type="checkbox"/> | Reacts, responds and makes positive comments to the child |
| <input type="checkbox"/> | Acts opportunistically to increase child's interest & extend |
| <input type="checkbox"/> | Is sensitive to face, attention, sounds, textures etc. the child seems to dislike |

2) Anticipation/Communication

| | |
|--------------------------|---|
| <input type="checkbox"/> | Looks for attention, vocalization, eye contact or facial expression before responding |
| <input type="checkbox"/> | Responds to child's demands, vocalizations, eye contact and/or facial expression |
| <input type="checkbox"/> | Labels or describes things, concepts, feelings and actions |
| <input type="checkbox"/> | Follows the "rule" of turn-taking (alternates 1-2 words longer than your child's) |
| <input type="checkbox"/> | Acts opportunistically to extend length and frequency |
| <input type="checkbox"/> | Thinks turns leading and following the child with words, sounds and actions |

3) Active play/Problem Solving

| | |
|--------------------------|--|
| <input type="checkbox"/> | Introduces child's interest into an activity or action that the child prefers |
| <input type="checkbox"/> | Anticipates activity before it becomes repetitive, by introducing new materials, actions or ways |
| <input type="checkbox"/> | Does what the child does |
| <input type="checkbox"/> | Looks for a safe and healthy structure (Set-up, Theme, Variations, and Closing/Transition) (circle specific areas that need feedback or support) |

4) Play/Play

| | |
|--------------------------|--|
| <input type="checkbox"/> | Introduces at least two teaching goals |
| <input type="checkbox"/> | Provides child appropriate level of help, using wait to most prompting, then prompts |
| <input type="checkbox"/> | Does not over-respond to the child or respond to second demand before |
| <input type="checkbox"/> | Provides teaching opportunities about every 30 seconds |
| <input type="checkbox"/> | Does not |
| <input type="checkbox"/> | Identifies goal of interaction and teaches an alternative behavior to meet same goal |
| <input type="checkbox"/> | Reacts through and moves away from the child's response to each interaction |

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Coach "Pods"

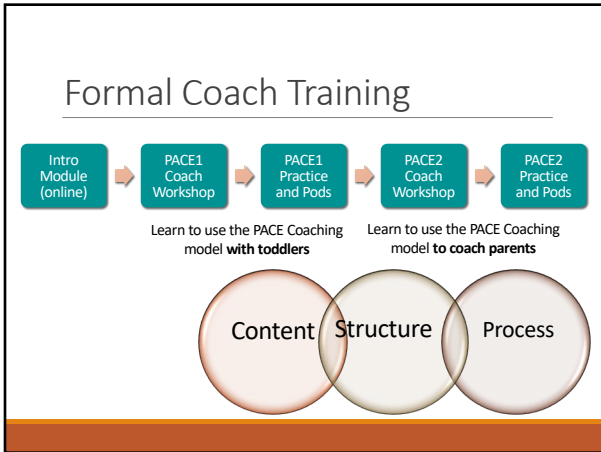


To support a community of practice, coach trainees meet online periodically in regional "Pods" with their trainer, via our online platform, Teleroo

- To provide mutual support
- To share information about coaching strategies that have been effective
- To brainstorm and troubleshoot
- To celebrate progress



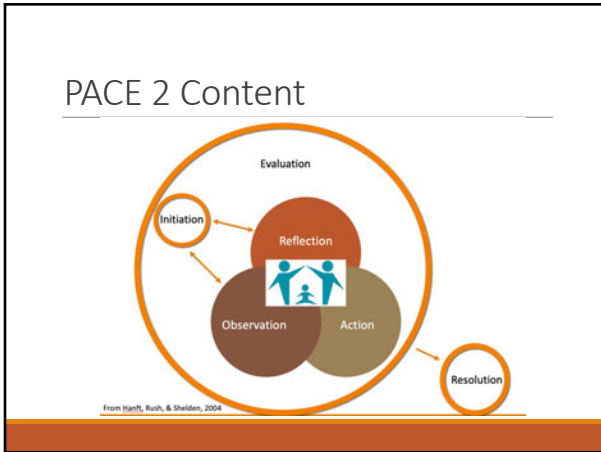
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Hot Off the Press!

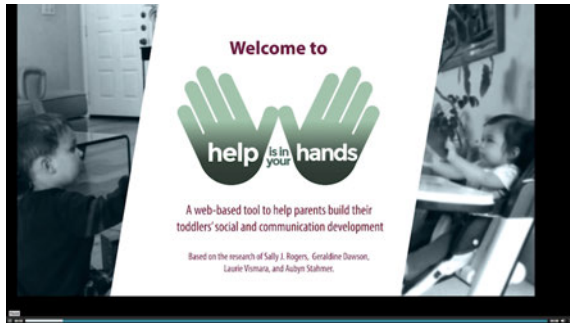
Coaching Parents of Young Children with Autism

Promoting Connection, Communication, and Learning



Sally J. Rogers, Laurie A. Vismara, and Geraldine Dawson

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"Refrigerator Lists"

Refrigerator List: Module 4 - Lesson 4

Positioning

Goal: Face-to-face and close enough to touch.

- Find your child's spotlight of attention; then step inside.
- Have materials between you and your child.
- Control the materials yourself.
- Use materials to make a bridge for eye contact.
- Manage distractions.
- Try not to let others interrupt an activity.




Refrigerator List: Module 4 - Lesson 4

B is for Behavior

Goal: Identify target behaviors to teach.

- Decide what you want your child to be able to do/learn. Write down your goal for your child.
- Observe your child's behavior during target activities.
- What to your child doing to achieve his or her goal? Is it what you want?
- Write down a behavior your child could learn to do in a few weeks on the way to the goal you identified.



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Parent-Led JARs

Parent provides opportunities for social communication during daily routines and activities



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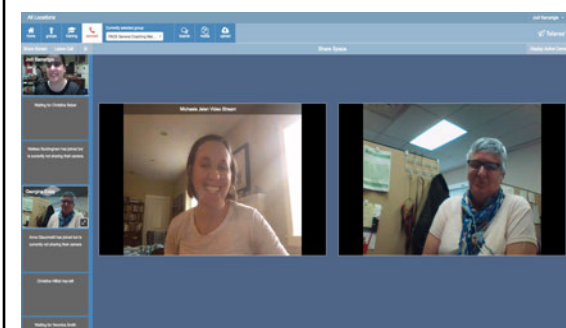
PACE 2 Structure

| SESSION PLANNING SHEET | | |
|------------------------|--|--------------------------------|
| Time | Activity | Notes |
| 0-5 min | Check-in about last session's focus (include any parent concerns for ending discussion) | Set the Plan Share the Plan |
| 5-10 min | Warm-up play - reflection and discussion: "Share what you have been doing." | |
| 10-15 min | Discuss new topic or continue with current topic based on parent progress and goals | Practice the Plan |
| 15-30 min | Practice 1 - Observed, coaching for success, reflection ("How was that for you?") | |
| 30-45 min | Practice 2 - Observed, coaching for success, reflection ("What went well during that activity?") | Wrap up the Plan |
| 45-60 min | Review parent progress (today's activities, parent sets goals for week, discuss next topic, notes and discuss parent concerns) | |

Additional Notes:

40

Pod Meetings



42

Coaches' Hardest Lesson



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Coaches' Most Important Lesson



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Pace 2
Checklist:
40 Items

| C-ESDM Coaching Checklist | |
|--|---|
| Activities of the Session | |
| A. Opening and Closing. This is a brief phase that moves quickly into action. | |
| <input type="checkbox"/> | The coach opens with a question that invites a brief description of the week's progress. |
| <input type="checkbox"/> | The parent provides a snapshot of the week, progress and challenges. |
| <input type="checkbox"/> | Parent identifies their focus with child for the past week and goals for current session. |
| <input type="checkbox"/> | Coach acknowledges parent efforts over the week. |
| <input type="checkbox"/> | Coach focuses on what parent has shared thus far for session goals and facilitates a smooth transition into parent-child warm up activity. |
| <input type="checkbox"/> | Total number checked: _____ |
| B. "Warm up" parent-child and activity. This phase allows the coach to observe and evaluate parent-child progress based upon what was discussed and practiced in the last session. | |
| <input type="checkbox"/> | The focus of the interaction emerges from the parent's sharing of the week's activities and theme. |
| <input type="checkbox"/> | An uninterrupted parent-child activity occurs that allows parent and child to move into action and allows the coach to gauge progress and complete ratings. |
| <input type="checkbox"/> | After the activity, the coach invites the parent to reflect on the activity, to evaluate the extent to which the parent's goals were realized. |
| <input type="checkbox"/> | The coach then shares reflections and comments constructively in a way that reinforces parental use of learned techniques and feedback for any parent technique and/or child skill in need of further support. |
| <input type="checkbox"/> | There is a smooth transition into the next phase. |
| <input type="checkbox"/> | Total number checked: _____ |
| C. Introduction of the topic of the day. This phase sets the main topic for the session. This is usually the topic of the video the parent reviewed that week. If the parent didn't review the video, the coach and parent may watch it together. It may be a previously introduced topic if further practice would benefit the parent. | |
| <input type="checkbox"/> | The coach: |
| <input type="checkbox"/> | discusses the video topic in language and flow that fits the parent's understanding well, including use of needed multimodal teaching strategies (print materials, verbal explanation, visual demonstration and checks understanding, answers any questions or clarifies areas the parent did not understand in the video); |
| <input type="checkbox"/> | discusses the relationship among target child behaviors, main parenting strategies, and effects on child behavior; |
| <input type="checkbox"/> | invites the parent to parent goals for the child and to give examples from the session or other examples that illustrate the target behavior and/or parental strategies; |
| <input type="checkbox"/> | in event of timing time and adjusts the length to meet the parent's attention and understanding of content; |
| <input type="checkbox"/> | Manages and/or facilitates can occur |
| <input type="checkbox"/> | Total number checked: _____ |

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Ongoing Training

After *formal* coach training was completed (PACE 1 and PACE 2), training continued during the research study

- Peer support via Pods or locally, when possible
- Mentorship by training facilitators

This proved to be an important component of the training and was endorsed by both coaches and CDC leadership

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In the End...



The project trained 31 coaches from all over BC, most of whom went on to coach between 1-3 families each

- Training was described as “hard,” “humbling,” but “worth it”
- Training required considerable local resources
- The project reimbursed agencies for all coach time and expenses

Coaches and leadership personnel described the training as facilitating a “paradigm shift” in how they deliver services to families

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Scalable Model for Coach Training

Our data suggest that PACE Coaching is likely to be a **scalable model** for parent coach training that

- Is community-based
- Was strongly endorsed by our partners
- Is applicable to both infant development/early childhood consultants and graduate-level clinicians
- Includes strategies for evaluating quality and impact

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Next Up...

The research studies

- Who was involved
- What we did
- What we found



53

Selected Resources

Hanft, B.E., Rush, D.D., & Shelden, M.L. (2004). *Coaching families and colleagues in early childhood*. Baltimore, MD: Paul H. Brookes Publishing Co.

Rogers, S. J., & Dawson, G. (2010). *Early Start Denver Model for young children with autism: Promoting language, learning, and engagement*. New York: Guilford.

Rogers, S. J., Dawson, G., & Vismara, L. M. (2012). *An early start for your child with autism: Using everyday activities to help kids connect, communicate, and learn*. New York: Guilford.

Rogers, S. J., & Stahmer, A. (2021). *Help is in Your Hands* [online modules]. <https://helpisinyourhands.org>.

Rogers, S. J., Vismara, L. M., & Dawson, G. (2021). *Coaching parents of young children with autism: Promoting connection, communication, and learning*. New York: Guilford.

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The Research Studies

Research Studies

There were two research studies in this project:

- A randomized controlled trial
- A sub-project for Indigenous families called Parent-Child Connections

We will talk about both of them in this session

Research Study Objectives

We wanted to answer four questions in these studies:

1. Was there change in children's social-communication skills during the study?
2. Was there change in parents' quality of life or stress, and/or in parent-child interactions during the study?
3. Were changes larger in parents and children who participated in parent coaching, compared to those who did not?
4. What predicted child change when it occurred?

Screening

The goal: to determine if child is at risk for autism



The “Qs”



Introducing: the “Qs” -- qualified clinical specialists in ASD

- Graduate level clinicians; one at most sites
- They were our project ambassadors, multi-taskers, and problem solvers!
- Completed several online training modules to take on numerous research tasks

Q Responsibilities

- **Identify** eligible children and **invite** parents for screening
- **Administer and score** the screening tool
- **Invite** parents of children at risk for ASD to the project
- **Conduct** baseline and post-intervention assessments



Family Recruitment

Children age 15-36 months with a social-communication delay; some exclusion criteria

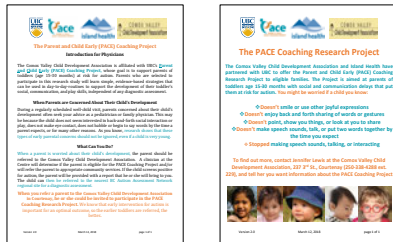
Parent/caregiver who can communicate in English, unless a family translator was available

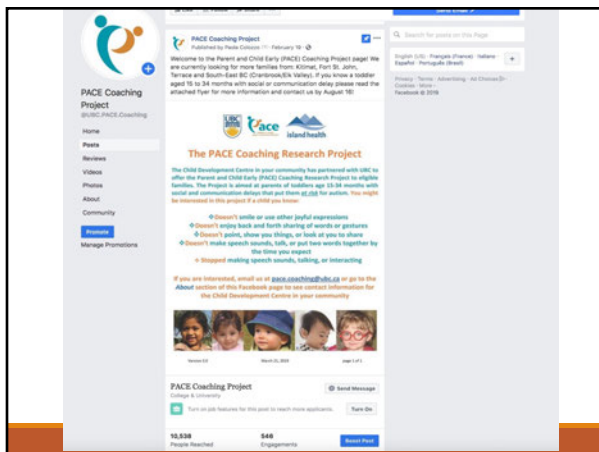
- We wanted family diversity, so were were very few parent exclusion criteria
- Parents decided for themselves if they wanted to participate



Recruitment: Community Outreach

One-page intros and 4,000 flyers were distributed to physicians, Health Unit professionals, other community agencies





Screening: M-CHAT-R/F

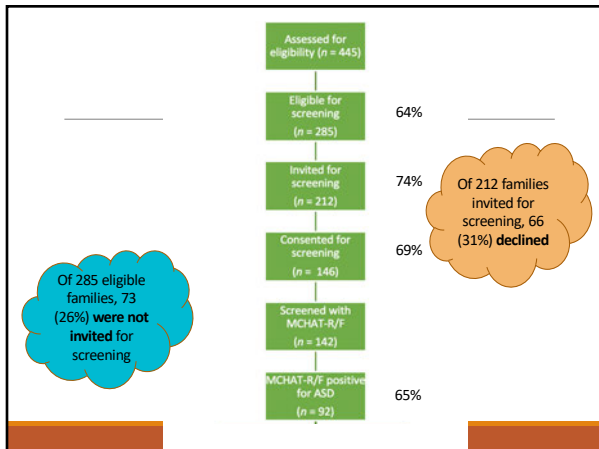
M-CHAT-R/F: Modified Checklist for Autism in Toddlers - Revised with Follow-up (Robins, Fein, & Barton, 2009)

- Use of the M-CHAT was specified by our funder

20 yes/no questions about the child

Scores above the cutoff indicate autism risk





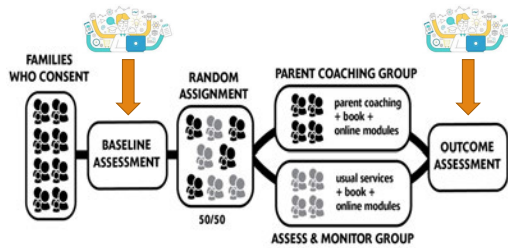
Research Studies

Parents of at-risk children were invited to participate in a Randomized Controlled Trial (RCT)

Indigenous families were also provided with another option, called Parent-Child Connections



RCT



What Did We Measure?

Child development, words understood, words said

Parent distress, quality of life, and (at T2) satisfaction and self-efficacy

Parent-child interactions, from videotaped play sessions with toys provided by the project

Parent Coaching (PC) Group

Parents received coaching for 24 out of 30 weeks

- One, 60 min. face-to-face session per week
- One, 15-30-min. online or phone follow-up per week
- + *An Early Start for Your Child with Autism* book
- + *Help is in Your Hands* online modules
- + any local services except speech-language therapy

32 families started in this group and 24 completed the study

- Most withdrawals were a result of family circumstances that prevented continuation

Assess & Monitor (A&M) Group

Parents and children received the supports they would ordinarily receive for 24 out of 30 weeks

- + *An Early Start...* book
- + *Help is in Your Hands* modules

30 families started in this group and 25 completed the study

- Most withdrawals were a result of family circumstances that prevented continuation

Who Were the Children?

At the start (Time 1, T1), PC and A&M **children were quite diverse**

- Age: 16-36 months
- M-CHAT-R/F score: 3-18
- Number of words understood: 0-383
- Number of words said: 0-375
- Children who spoke 5 words or less: 7-8
- Developmental age: 5-24 months



But, on average, the two groups were similar

Who Were the Parents?

At T1, PC and A&M **parents/caregivers were quite diverse**

- Age: 23-62 years, all women
- Parent education: some secondary school – graduate degree
- Number of languages spoken at home: 1-3 (mostly English)
- Annual household income: less than \$30,000 - more than \$100,000
- Distress score: 1-6 ("Everything is fine" to "We have to work extremely hard every moment of every day to avoid having a crisis")
- Quality of life score: 4-14 (poor to high)

But, on average, the two groups were similar

Analysis of the Child and Parent Measures

We wanted to answer these questions:

1. Did children change from T1-T2?
2. Did parents change from T1-T2?
3. Were changes larger in the PC group than the A&M group?
4. What predicted change when it occurred?



T1 Compared to T2

We used various statistical tests to compare the *average scores* for the PC group to the *average scores* for the A&M group

- Not individual scores – average group scores
- If an average score changed from T1 to T2, we wanted to know *if the change was more than was expected* (i.e., if the change was “*significant*”)

What Did We Find?



Child Change

There was **no significant** change in developmental age scores from T1-T2

Children in **both groups** could say **significantly more words** at T2

Children in **both groups** were **significantly more engaged** with their parent/caregiver during play interactions at T2

- But there was a **trend toward larger engagement effects for PC children**

PC children understood **significantly more words** than A&M children at T2

Understanding More Words is Important



Children who understand more words when they are very young are more likely to develop speech (Yoder, Watson, & Lambert, 2015)

and

Speech communication by age 5 is the best predictor of later outcomes in adaptive skills, school achievement, and independence in adulthood (Lord, Risi, & Pickles, 2008)

Parent Change

There was no significant change in family distress from T1-T2

Parents in **both groups** were **significantly more engaged** with their children during play interactions at T2

- But there was a **trend toward larger engagement effects for PC parents**

PC parents had **significantly higher quality of life** than A&M parents at T2

PC parents were **significantly more satisfied** with the services they received than A&M parents at T2

PC parents had **significantly higher self-efficacy scores** than A&M parents at T2

What Predicted Child Change?

Parents whose **interaction scores improved** from T1-T2 had children whose **interaction scores improved** from T1-T2







In the spirit of the 2015 Truth and Reconciliation Commission report, and with the advice of our Indigenous advisers, we committed to three main principles in this project



The Genesis of Parent Child Connections...

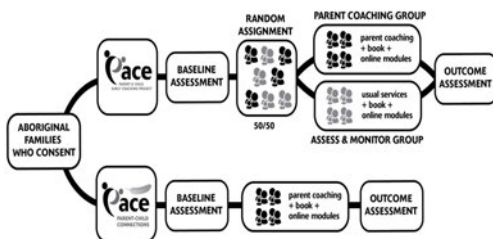
We engaged in a consultative process with Indigenous knowledge holders to deepen our understanding

- Advisors on our Advisory Committee
- Reached out to invite AIDP consultants and met with them in their communities
- Sought feedback from coaches who served Indigenous communities

The result was **Parent-Child Connections** 

- Modified PACE Coaching to be more flexible
- Name and logo suggested by Indigenous collaborators

P-CC Choice



P-CC

Same basic coaching model as in the RCT, **but more individualized, according to caregiver preferences:**

- Frequency
- Length
- Location
- Who attended
- Structure and focus

Assessments proposed were the same as in the RCT, **but** caregivers could choose to opt out of any or all assessments

10 families started (all chose P-CC) and four completed

What Did We Learn?



Case Studies

Because there were so few families, we did not use statistics to examine the outcomes

"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."

"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."

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

We Are Part Way There...

Coach training:

- Successful **in engaging** Aboriginal agencies
- Successful **in engaging** coaches to serve Indigenous families
- Difficulty **retaining** AIDP sites and coaches

We Are Part Way There...

Parent Coaching:

- Successful in **connecting** with Indigenous families
- Difficulty with **maintenance**
 - Families withdrew for many complex reasons, not all well understood

We learned that, despite our efforts, what we offered to families was **not always the best “fit”**

In particular, we learned that **time** was often a limiting factor

Parent Coaching Has Potential

A parent coaching model has **potential for supporting** Indigenous **families**

Considerations looking ahead:

- **Co-construction** with Indigenous partners
- **Time**
- Organizational support
- Interdisciplinarity



Autism Only? NO!

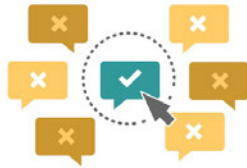


Next Up...

Cost analysis

Factors related to implementation

Wrap-up and final words



References

Lord, C., Risi, S., & Pickles, A. (2008). Trajectory of language development in autistic spectrum disorders. In M. Rice & S. Warren (Eds.), *Developmental language disorders: From phenotypes to etiologies* (pp. 7-29). Mahwah, NJ: Lawrence Erlbaum Associates.

Robins, D., Fein, D., & Barton, M. (2009). *The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F)*. Retrieved from <https://mchatscreen.com/>.

Truth and Reconciliation Canada (2015). *Honouring the truth, reconciling for the future: Summary of the final report of the Truth and Reconciliation Commission of Canada*. Winnipeg, MB: Truth and Reconciliation Commission of Canada.

Yoder, P., Watson, L., & Lambert, W. (2015). Value-added predictors of expressive and receptive language growth in initially nonverbal preschoolers with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 45, 1254-1270.



Moving Forward: Coaching Costs, Implementation Outcomes, and Final Words

Moving Forward

- Understanding the costs of coaching
- Understanding the breadth of services families use
- Considerations for planning and implementation
- Implications for service delivery in BC
- Key messages and lessons learned



Understanding the Costs of Coaching

WENDY UNGAR, PH.D., CO-INVESTIGATOR
THE HOSPITAL FOR SICK CHILDREN, TORONTO



Land Acknowledgement

We would like to begin by acknowledging the land on which SickKids operates. For thousands of years it has been the traditional land of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit River. Today, Toronto is home to Indigenous Peoples from across Turtle Island. SickKids is committed to working toward new relationships that include First Nations, Inuit, and Métis peoples, and is grateful for the opportunity to share this land in caring for children and their families.

Why study costs?

Coaching

Use of services

Coverage

Lost time

Inform Policy

- Toddlers at risk for autism may benefit from parent coaching but the costs of delivering coaching to families are unknown
- Families with a child with suspected autism seek a wide range of services in the community before, during, and after a diagnosis
- What services are paid for by the government or private insurance can influence which services parents seek out
- Families can incur out-of-pocket costs for uninsured services
- Parents miss time from work or other usual activities to attend to care or services for their child and to provide coaching
- A good understanding of use of services in families with children at risk for ASD, the cost of these services, and the cost of coaching is important to inform future funding and policy decisions.

What did we want to know?

| | |
|----------------|--|
| Training | <ul style="list-style-type: none"> What are the costs to train coaches to deliver parent coaching? |
| Coaching | <ul style="list-style-type: none"> How much time do coaches spend on various coaching-related activities? What does parent coaching cost? |
| Service use | <ul style="list-style-type: none"> What kinds of services do parents seek? What is the difference in use of services and costs between the RCT PC and A&M groups? |
| Time Loss | <ul style="list-style-type: none"> How much time do parents spend attending to their child? What is the difference in lost days and the cost of lost time between the PC and A&M groups? |
| Cost to payers | <ul style="list-style-type: none"> What are the total and incremental costs of parent coaching to the public sector? |

Our research methods



Training and coaching costs

| |
|--|
| Training phase |
| <ul style="list-style-type: none"> Trainer and coach time to travel to and attend workshops Trainer and coach travel expenses for workshops |
| Coaching during the Randomized Controlled Trial (RCT) |
| <ul style="list-style-type: none"> Time spent by trainers to support coaches, including reviewing videos and documents Time spent by coaches to receive trainer support Time spent coaching parents: direct coaching, parent support (telephone follow-up), session preparation, post-session documentation, administrative tasks |
| The dollar value of time was determined by applying wage rates to hours reported for each activity |

Use of services and resources

Service use and time loss reporting

- Service use and out-of-pocket costs for services and other resources were collected from parents or primary caregivers using the Resource Use Questionnaire for Toddlers (RUQ-T)
- The RUQ-T captures service use across multiple sectors, including health, education, community, and child and youth services
- Time losses for both parents from work and from usual activities related to caring for their child were reported

Service use, out-of-pocket costs and time losses were collected from PC and A&M groups prior to start of coaching (baseline) and after 24 weeks of coaching

Services were priced using public fee schedules and time losses were valued by using average wages for Canadians of the same age and sex

What did we find?



Training costs

Three training facilitators provided training to 39 coaches who would deliver the coaching intervention to parents during the study

94% of training costs were time invested in workshops, coach support and travel

6% of costs were for travel expenses

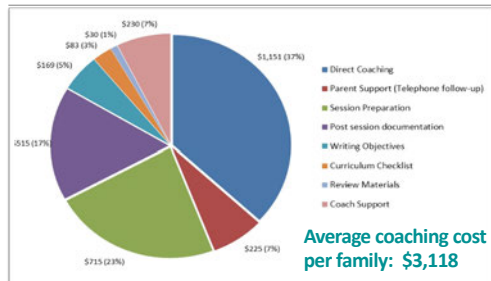
Average cost of training: \$11,822 per coach

Coaching during the RCT

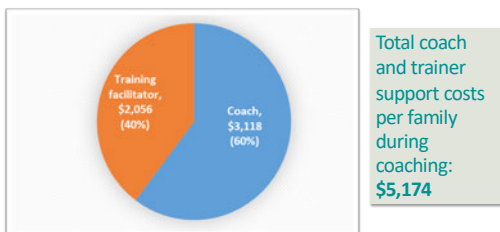
Time per family Over the 24 weeks of the RCT, coaches spent an average of 65 hours of coaching per family (range, 28 to 126 hours)

This is equivalent to 2.7 hours per family per week (range, 1.2 to 5.3 hours per week)

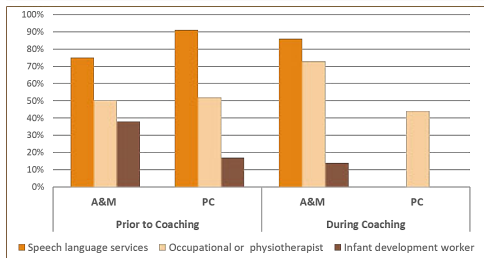
Coaching costs during the RCT



Total coaching costs per family



Use of services by group



During the intervention, the PC group reduced their use of MCFD services

Public payer costs

The average cost per family for additional MCFD services during 6 months of coaching was **\$199** in the PC group, compared to **\$923** in the A&M group

Average savings of **\$724 per family** to MCFD

Adding the cost of coaching, the net cost to the MCFD was **\$4,350 more per family** compared to usual care

Costs to families

Out-of-pocket costs were highly variable but not extensive

- In the 6 months prior to coaching, PC parents spent an average of \$63 per family (range, \$0-\$300) compared to \$194 per family (range, \$0-\$2,700) in A&M families
- In the 6 months of coaching, PC parents spent an average of \$188 per family (range, \$0-\$2,000) compared to \$55 per family (range, \$0-\$500) in A&M families

Money was most often spent on educational materials, learning and communication aids, and private OT/PT services

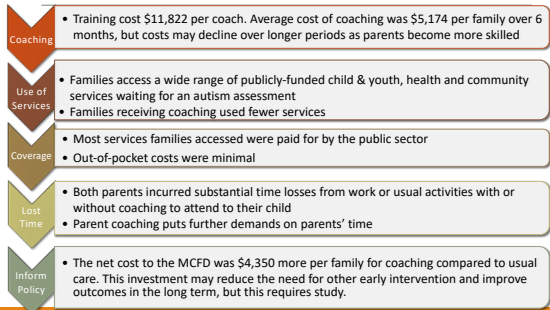
Parent time losses

64%-78% of parents reported time losses in the 6 months before and during coaching in both groups

- **50%-61%** of parents reported 10 or more days lost during each 6 month period
- The dollar value of parents' time losses were similar in the A&M and PC groups in the 6 month before coaching: \$6,871 vs. \$7,542

During the 6 months of coaching, PC families had greater time losses, resulting in greater productivity costs: \$9528 vs. \$4198

Key findings



Implementation: What Does it Take?

VERONICA SMITH, PH.D., CO-INVESTIGATOR
UNIVERSITY OF ALBERTA

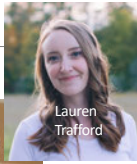
Land Acknowledgment

This project was conducted on the traditional ancestral, and unceded territories of many First Nations in British Columbia.

I acknowledge the lands where the University of Alberta is located, Edmonton or Amiskwaciwāskahikan Treaty 6 territory, a traditional meeting grounds, gathering place, and travelling route to the Cree, Saulteaux, Blackfoot, Métis, Dene and Nakota Sioux. The footsteps of many First Nations, Métis, and Inuit have marked these lands for centuries.



Angeliki Altani

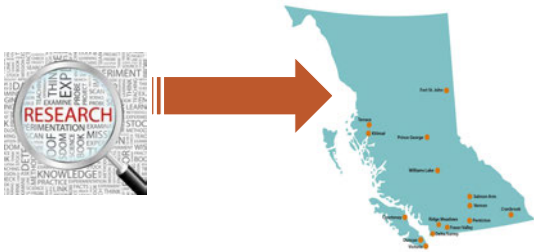


Lauren Trafford



Nick Denomey

Moving Research to Practice



Implementation: What Do We Know?



Implementation Research Aims

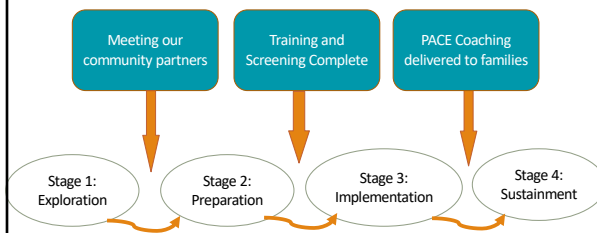
Our intent was twofold:

1. To **learn about local conditions and understand** barriers and challenges, in order to better support project participation, as it rolled out



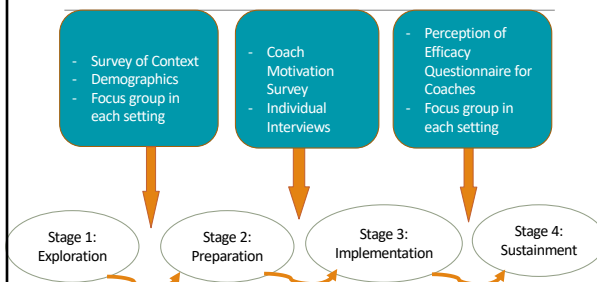
2. To **describe the conditions and contexts** that might support future implementation of the PACE Coaching model and **contribute to emerging research** on moving effective intervention to practice.

Staged Delivery of the Project



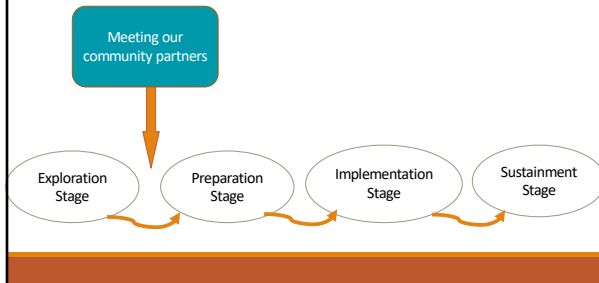
Metz, Naom, Halle, & Bartley, 2015

Implementation Data



Metz, Naom, Halle, & Bartley, 2015

Stage 1 – Exploration



Stage 1 – Exploration Findings

| Usable Practice ? | Enabling Context ? | Change Process ? |
|--|--|--|
| <ul style="list-style-type: none"> - Strong interest & motivation - Good match with values | <ul style="list-style-type: none"> - Inviting culture - Strong leadership - Plenty of space! | <ul style="list-style-type: none"> - Interest in participating in research - Interest in changing policy |
| <ul style="list-style-type: none"> - Worries about whether or not it would be a good fit for families | <ul style="list-style-type: none"> - Caseload demands - Low service to 18 – 36 month toddlers - Use of technology - Practice of receiving feedback | <ul style="list-style-type: none"> - Low or little technology access or use in intervention services |

How We Responded

Organized coach trainees **into pods**

Dedicated **resources to support technology learning**

Provided centre-based posters/advertisements to **encourage recruitment**

Reimbursed agencies for **actual time**

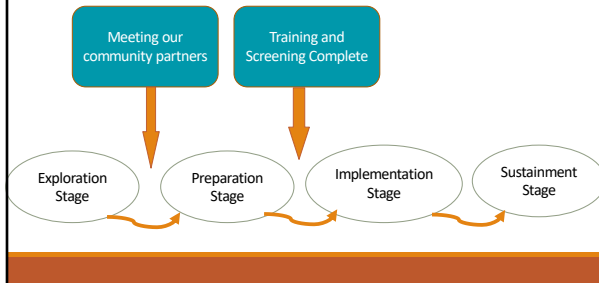
Provided **\$1,000** per agency for administrative costs

Provided **gift cards** to families for child care and mileage

Regular project **communications**



Stage 2 – Preparation



Stage 2 – Training Findings

| Usable Practice? | Enabling Context? | Change Process? |
|---|---|---|
| <ul style="list-style-type: none"> - Evidence of strength & quality - Valued approach - Felt empowered | <ul style="list-style-type: none"> - Centres provided a positive climate for learning | <ul style="list-style-type: none"> - Training was high quality and well laid out - 'PODS' provided a great context for change |
| <ul style="list-style-type: none"> - Highly complex - Concerns about adaptability | <ul style="list-style-type: none"> - Time intensive – impacted other responsibilities - Technology challenges | <ul style="list-style-type: none"> - Lack of 'big picture' of project - Coaches at different levels of readiness for change |

Stage 2 – Screening Findings

| Usable Practice? | Enabling Context? | Change Process? |
|------------------|--|--|
| | <ul style="list-style-type: none"> - Training for screening was thorough | <ul style="list-style-type: none"> - Screening process was easy to follow |
| | <ul style="list-style-type: none"> - No required touchpoints for children 18-60 months of age - "Autism hesitancy" | <ul style="list-style-type: none"> - Time constraint |

Responding to Stage 2 Findings

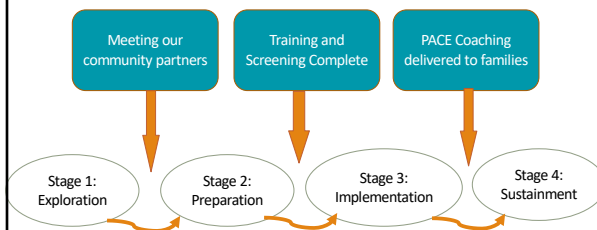
Continued support to use technology (in some cases updated technology)

Increased efforts to support recruitment – visit to the community, social media

Regular project communications



Stage 3: Implementation



Metz, Naom, Halle, & Bartley, 2015

Stage 3 – Implementation Findings

| Useful Practice | Enabling Context | Change Process |
|--|---|---|
| <ul style="list-style-type: none"> - Beneficial and valuable for families - Transformative - Fit with Family-Centred values | <ul style="list-style-type: none"> - Ongoing flexibility with leadership to support the program delivery - Ability to practice skills | <ul style="list-style-type: none"> - Creating a 'community of practice' essential - Access to coach trainers valuable |
| <ul style="list-style-type: none"> - Families need flexible schedules - Time intensive - More training needed | <ul style="list-style-type: none"> - Caseload demands - Struggles to get children into services earlier | <ul style="list-style-type: none"> - Ongoing struggles with technology - Strains with delivery and research |

Key Implementation Findings

PACE Coaching

- A good 'value' fit with early interventionists
- Training model transformative

Successful implementation strategies

- Exploration stage helped us to understand community context and engage in some co-construction with our partners
- Coach consultation / feedback beyond training
- Communities of practice to build and reflect upon skills

Key Implementation Findings

More work to be done

- Identifying and supporting families to seek services early
- Establish implementation leadership in centres and among Aboriginal early interventionists
- Contextual supports
 - Communities of practice that link centres
 - Policy and funding to support implementation



Wrapping Up: Final Words from Our Partners

Importance of the Project

Community-based research and study outcomes:
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MIND Institute, University of California, Davis



Leadership and Cost

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Ongoing cost of training and
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Indigenous Partners

Moving forward: Diana Elliott, AIDP Provincial
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Parent Empowerment

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Tawny, Parent

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