

ASD and Disruptive Behaviour: Family Impact and Opportunity for Capacity Building

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Overview

1. Intro to autism spectrum disorder (ASD)
2. Pilot work: Family impact of ASD and disruptive behaviours
3. Capacity building: The JACC project

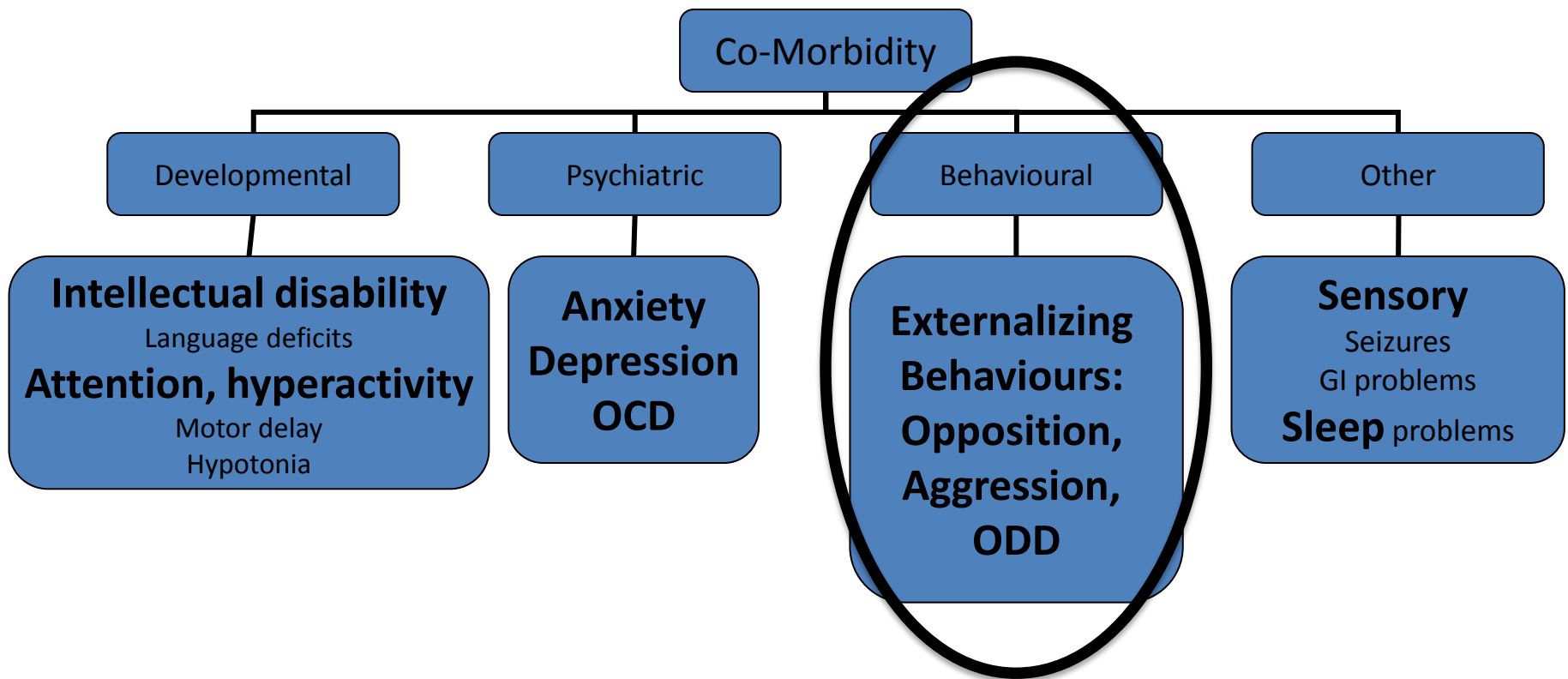


Autism Spectrum Disorder (ASD)



- Core features (DSM-V, 2013):
 - 1) Social/communication deficits
 - 2) Fixated interests and repetitive behaviours
- 1-2% of school-aged children (Anagnostou et al., 2014; Blumberg et al., 2013)
 - 4 males : 1 female
 - 67,000 people 3-20 years old in Canada
 - Co-morbidities are common

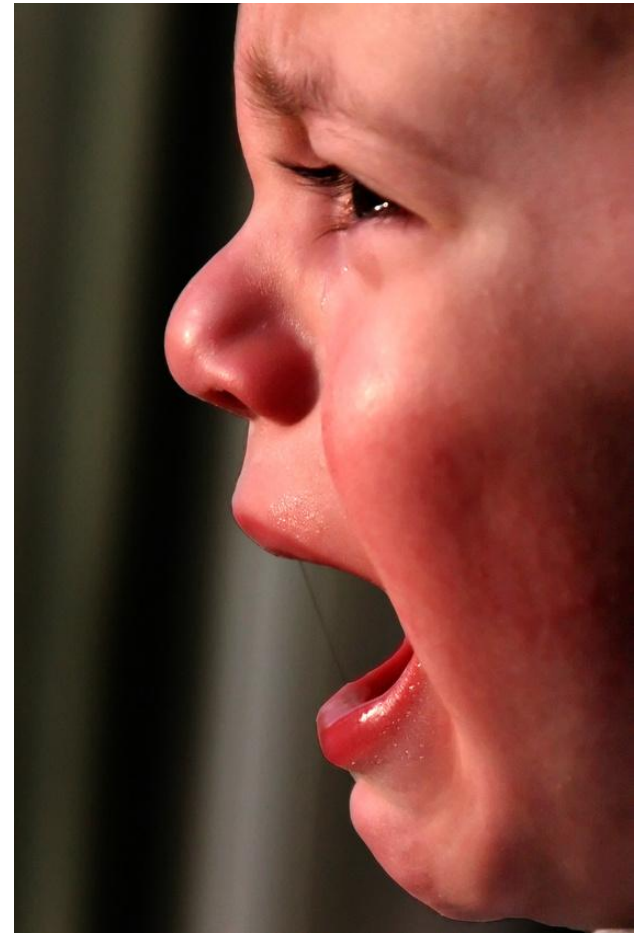
Co-Morbid Conditions



ASD and Disruptive Behaviour

- Aggression to others \cong 20-70%
- Self injury \cong 20%-33%
- Tantrums \cong 50%
- Meet ODD criteria \cong 40%

- Adaptive skills often developmentally younger than child's actual age, BUT, physical development often age-appropriate.
 - major physical risk challenges to parents, school staff, and others, along with the child himself.

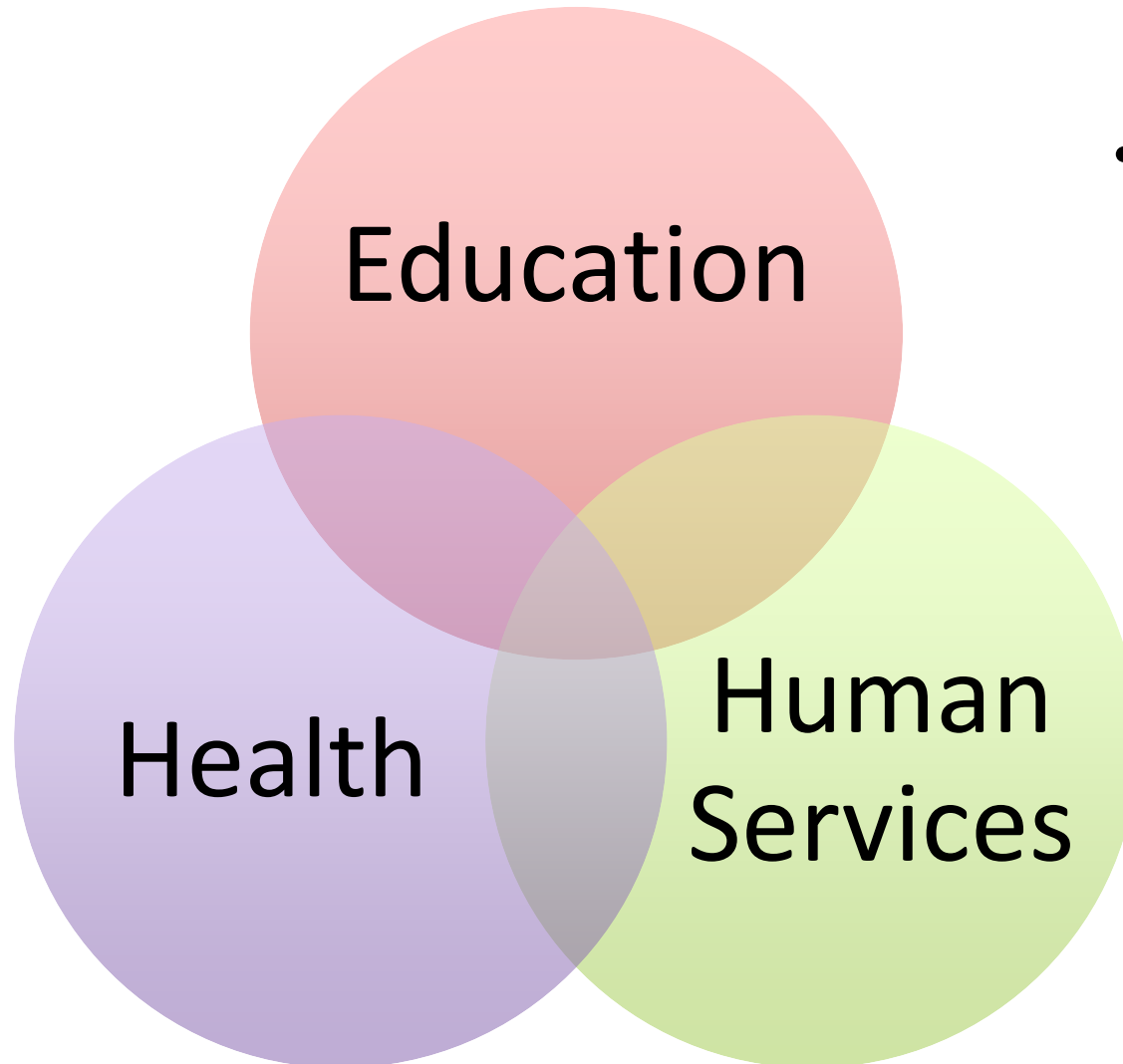


Families Living with Autism

- ↓ social support
- ↓ parenting satisfaction
- ↓ parenting confidence
- ↓ family QoL
- ↑ stress
- ↑ depression
- ↑ marital discord
- Significant out-of-pocket expenses
- Loss of income due to care needs



Which Ministries May Be Involved?



- *Costs are shared across ministries and needs often blur lines*

Research Study: Families Experiences Navigating Systems of Care

1. Identify strengths, gaps and family impact of current systems of care
2. Identify child, family and/or service variables that predicted enhanced outcomes



Pilot Work

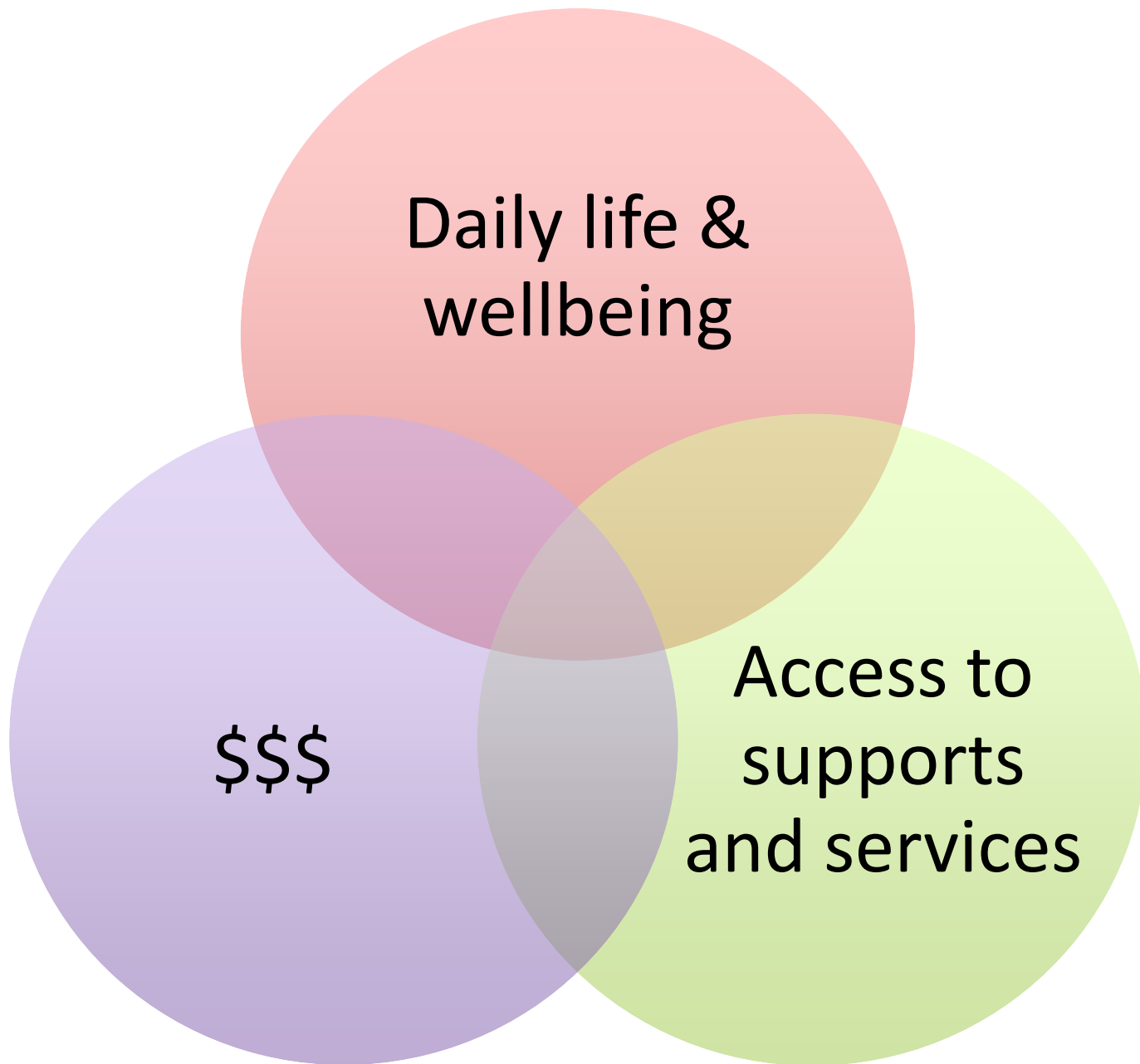
Home Sweet Home? Families' Experiences With Aggression in Children With Autism Spectrum Disorders

Sandra Hodgetts, PhD¹, David Nicholas, PhD²,
and Lonnie Zwaigenbaum, MD¹

- In-depth interviews with 15 families
 - 9 talked about the influence of aggression...
despite NEVER ASKING!

“How has your child’s diagnosis of autism affected your social life?”

“What challenges have you had accessing supports and services?”



Daily life &
wellbeing

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Access to
supports
and services

Family Life & Wellbeing

Isolation

- *"You don't want to go visit friends...you spend your whole time keeping your kid out of trouble."*
- *"We don't want [our extended family] to see that side of him"*

Exhaustion

- *"Never ending"*

Safety

- *"He can't even be in the same room as [his sister]. We can't eat dinner together."*
- *"War zone"*

Formal Supports and Services

Respite

- Not qualified to deal with disruptive behaviours

Behavioural Services

- In-adequate
- Excluded

Long-Term Planning/Housing

- *“It’s not a degenerative condition... We’re going to have a dependent for as long as we live”*
- *“We just pray he dies before we do.”*

Larger Study: Predictors of Unmet Service Needs, Mother's Ability to Work, and Mother's Wellbeing

- ☑ Disruptive Behaviours
- ☑ System Fragmentation: Discontinuity of care



Capacity Building

Joint Action for Children Committee (JACC)

- About 5 years ago, JACC focused its collaborative, cross-ministerial efforts to develop a multifaceted plan for better supporting this population
- One recommendation: develop specialized training for the adults involved with children with ASD

Prevention Strategy: Education

The goal of training was:

(1) to reduce the frequency / severity of behavioral outbursts at home and school

(2) to build the capacity of parents to feel effective in dealing with their child's challenging behavior

Workshop Design

- Used an intensive Positive Behaviour Support (PBS) approach
 - focuses on prevention and environmental modifications to decrease the child's need for negative behaviors to get his/her way, while still challenging them to develop academic and daily living skills
- Trained teams of caregivers (including parents) wrapped around children with moderate-severe behavior problems that are at risk for escalating

Workshop Design

- Teams met for 3.5 days over 6 - 7 weeks to learn PBS approach and to develop an individualized plan for each child



- ❖ JACC covered costs of workshop/manual development (Authors – Shane Lynch, Shane Hewitt, Shawn Reynolds)
- ❖ Trainers initially provided by GRH; ongoing training supported by partner agencies
- ❖ Parents were compulsory members of each team
- ❖ Teams were supported by their employing agency to participate

Delivery and Uptake?

- 3.5 years of workshop delivery
- 11 school divisions involved
- 20 workshops provided
- 94 teams trained
- 58 additional professionals received training on sharing PBS strategies with their teams
- Total: **414 Different participants trained**

Maintaining the Program

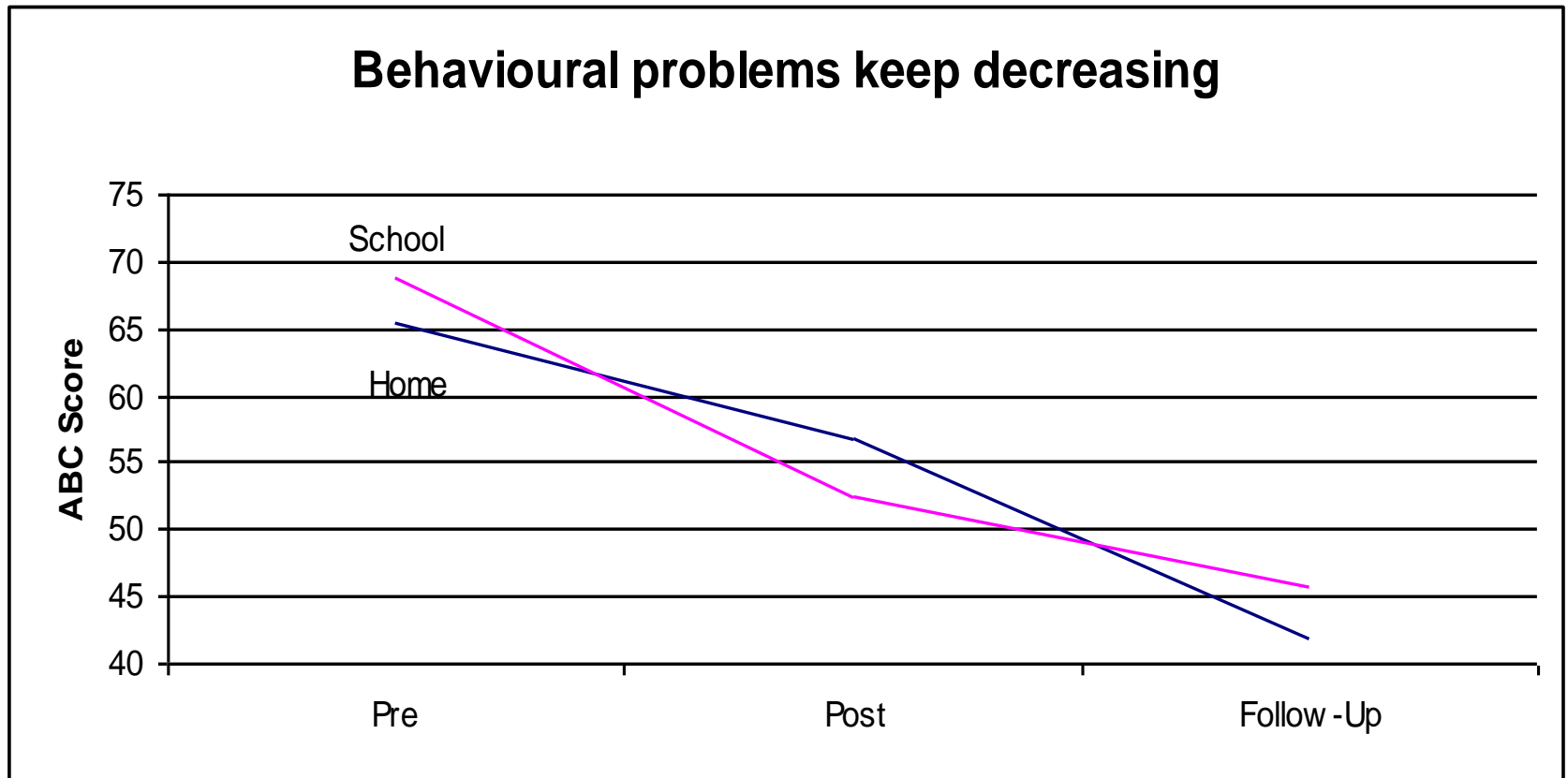
- Now, AHS coordinates training
- Support is provided by school districts
 - Co-facilitators
 - Hosting
 - Staff coverage for participants
- Anticipated satisfying demand in 2 years...but it is still high
- Meeting a need in the community to support challenging children...BUT, it's resource-intensive. **Is it worth it?**



Evidence

- Participants “liked” the workshops
 - Workshop evaluations (Average 3.53 on 1-4 scale)
 - Similar for experienced vs. newer facilitators (capacity building occurs when new)
- Participants kept coming back
 - Attendance after Day 1 > 90%
- Demand is still high
 - First two workshops this year are at/over capacity

Improvements in Behaviour Persist



Parents Also Maintain Changes



Conclusion

- Changes noted at home and at school.
- The improvements held over time.
- Preventative strategies can result in long-term improvements in challenging behaviours for children with ASD
- Cross-ministerial support can be effective in dealing with cross-ministerial challenges
- *A good model of a cross-ministerial approach to a complex challenge.*

Moving Forwards

- Significant Gaps:
 - Crisis services
 - Training and maintaining qualified respite care providers
 - Adequate housing for adults
 - Defragmentation of systems and increasing access to info
 - Meeting existing demand

