Navigating Consent & Body Autonomy in Early Autism Intervention

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BC-ABA Conference

March 9, 2019

Who Am I?

- MA in Special Education from UBC
- Board Certified Behavior Analyst (BCBA)
- Registry of Autism Service Providers – Category A Behaviour Consultant
- Completed Sexual Health Educator Certification Coursework & Practicum through Options for Sexual Health
- Certified Sexual Health Educator status pending practicum teaching review

Learning Objectives

- Review why it is important to consider and teach the concepts of consent and body autonomy within the context of early autism intervention
- Identify some potential practices that could be counter to the goal of teaching consent and body autonomy
- Identify some potential changes in practice that can be used to teach consent and body autonomy

WHY IS CONSENT & BODY AUTONOMY IMPORTANT

Sexual Abuse: What Is It?

- **Non-Contact**
  - exposing child to sexually explicit materials
  - online luring
  - invite to sexual touching (on/offline)
  - voyeurism
  - asking sexually intrusive questions or making sexually explicit comments to children
  - encouraging or forcing a child to masturbate or watch others masturbate
  - exposing child to sexually explicit acts
  - exposing genitals/flashing child

Sexual Abuse: What Is It?

- **Contact**
  - touching or fondling a child's genitals
  - touching or fondling child's breasts
  - encouraging or forcing a child to touch another's genital area
  - oral sex with a child
  - vaginal or anal intercourse with a child
  - vaginal or anal penetration of a child with an object or a finger

Sexual Abuse: What Do We Know?

- 1 in 10 children will be a victim of sexual abuse before they turn 18 (Canadian Centre for Child Protection)
  - 1 in 3 girls
  - 1 in 6 boys (Badgely Commission, 1984)

Sexual Abuse: What Do We Know?

- Who commits child sexual abuse
  - 30-40% - family member
  - 35% non-parent family member
  - 15% friends/peers
  - 13% step fathers
  - 9% biological fathers
  - 9% family acquaintances
  - 5% partner of a biological parent
  - 5% biological mother
  - 2% stranger
  - (Canadian Incidence Study (CIS) of Reported Child Abuse & Neglect – 2003: Major Findings; Minister of Public Works & Government Services Canada, 2005, p. 52 – via Little Warriors)

Sexual Abuse: What Do We Know?

- Signs of Sexual Abuse (CCCP, 2014; Isham, 2018)
  - Changes are typically sudden
  - quiet, sullen, sad
  - sleep challenges (nightmares, fear of dark)
  - unusually anxious or fearful
  - avoiding social situations
  - afraid of being alone with a particular person
  - irritability
  - physical behaviour directed towards others

Sexual Abuse: What Do We Know?

- Signs of Sexual Abuse (CCCP, 2014; Isham, 2018)
  - acting our sexual behaviour between dolls, stuffies, or other children
  - using sexual language or knowing information outside of age range
  - withdrawn/clingy
  - secretive
  - regression to younger behaviours (thumb sucking, bed wetting)
  - changes in eating
  - excessive masturbation

Sexual Abuse: What Do We Know?

- Statistics broken down by "disability" type are difficult to find
  - Those with **ID** are victims of sexual assault at 7 times the rate of those without ID (~7 out of 10) (NPR – US Department of Justice)
  - 12% of children with **ASD** experience sexual abuse (Mendell et al, 2005)

Sexual Abuse: What Do We Know?

- 25% of women with a **cognitive disability** will be sexually abused before age 15 (StatsCan)
  - 80% of women with **disabilities** will be sexually abused in their lifetime (Ontario Women's Justice Network)

Sexual Abuse: What Do We Know?

- Gil-Llario et al., 2019
  - Prevalence of sexual abuse in adults with **ID**
  - Self-Report
    - 6.10% (9.4% in women; 2.8% in men)
  - Professional Report
    - 27.8% (27.8% in women; 29.4% in men)

Sexual Abuse: What Do We Know?

- Review by Byrne (2018) of sexual abuse in **ID** populations
  - Prevalence is difficult to accurately establish
  - need a better operational definition of sexual abuse
  - variety of methods and populations studied makes comparisons difficult

Sexual Abuse: What Do We Know?

- Review by Byrne (2018) of sexual abuse in **ID** populations
  - psychological and behavioural effects of abuse
    - some research finds no differences; some does
    - reporting sources vary
    - causal links cannot be made
    - no single diagnostic trajectory

Sexual Abuse: What Do We Know?

- Risk Factors and Reporting Challenges in ASD (Edelson, 2010; Sevlver et al. 2013)
  - verbal reporting ability
  - knowledge deficits
  - social skills deficits
  - lack of privacy
  - inappropriate sexuality = deviance
  - stereotypy dismissed as sign of ASD

Sexual Abuse: What Do We Know?

- Risk Factors and Reporting Challenges in ASD (Edelson, 2010; Sevlver et al. 2013)
  - participate in multiple environments
  - deficits in daily living skills
  - overlap in behavioural signs of sexual abuse and behavioural manifestations of ASD

Sexual Offending in ASD

- A note on sexual offending (see Sevlever et al., 2013 for more)
  - exact prevalence in ASD population is unknown
  - over-representation in the forensic system but *specific offenses* are unclear
  - possible risk factors
    - social skills deficits (reciprocity; empathy)
    - impulsivity
    - access to other vulnerable individuals

Sexual Abuse: What To Do

- It is NOT our job to determine whether or not sexual abuse is occurring/has occurred
- It is our *legal, moral, and ethical* obligation to report any suspicion or disclosure of sexual abuse
- Call 1-800-663-9122

WHAT ARE WE DOING

WHAT CAN WE DO DIFFERENTLY

Common Practices Which May Impact Consent and Body Autonomy

- Physical Prompting
- Escape Extinction
- Don't Ask Questions
- Teaching Self-Care Skills
- Teaching Body Parts
- Instructional Control
- Treatment Selection/Social Validity

What Might Be Done – Physical Prompting

- Manual guidance on some part of a child's body
- May be done even when a child resists
- Prompting v. Restraint v. Force
- Common Uses:
  - lack of imitative repertoire
  - difficulty with joint attention
  - more with early learners

What Might Be Done Differently – Physical Prompting

- ASK "can I help you by touching your hand?"
  - interpret verbal and physical cues as consent to prompting
- TELL child you are going to help them by touching them
  - "I am going to help you play and touch your hand"
- CHOICE options "do yourself" or "help"

What Might Be Done Differently – Physical Prompting

- Interpret physical resistance as removal of consent
- Assess/re-assess effectiveness of different prompts
- Re-assess reinforcement

What Might Be Done Differently – Physical Prompting

- Systematic Fading
  - Even if child accepts/consents
- Don't use if less intrusive prompts work
- Creating children who are accepting of their bodies being physically manipulated is dangerous
- Use shaping
  - Requires no physical touch
  - Requires ↑ monitoring

What Might Be Done – Escape Extinction

- **Extinction** – withholding reinforcement that was previously available for a behaviour
- **Escape Extinction** – not allowing escape from a task/demand, often as a result of interfering/inappropriate behavior

What Might Be Done – Escape Extinction

- This can/has looked like:
  - blocking a child from leaving a bathroom until hands are washed
  - blocking a child from getting up from the table until a task is completed
  - physically 'prompting'/'forcing' a child to complete a puzzle after they throw pieces and try to leave the table

What Might Be Done – Escape Extinction

- This can/has looked like:
  - putting appropriate escape behaviours on extinction
    - saying "no"
  - Using escape extinction alone as a strategy to reduce interfering behaviour

What Might Be Done <u>Differently</u> – Escape Extinction

- Antecedent strategies – avoid need to use escape extinction
  - Instructional control/Demand Fading
  - High-preference activities
  - Non-contingent reinforcement
  - Choice
  - Curricular revisions
  - Differential Reinforcement
- Geiger, Carr, Leblanc (2010) for review of function-based treatments for escape-maintained behaviour

What Might Be Done Differently – Escape Extinction

- Operationally define removal of consent
  - verbal or non-verbal "no"
  - reinforce these when appropriate (more to come)
- Clearly defined termination criteria
- "Minimize the Win"
  - remove demand; re-assess reinforcement; re-present the demand at a later time with additional supports

What Might Be Done – Don't Ask Questions

- One of the first lessons for new front line workers:
  - **"don't ask a question if it is an instruction"**
  - "can you sit down?" vs. "sit down"
  - a question gives the learner a chance to say "no"
- New staff may be given specific, corrective feedback about this in training and ongoing supervision
  - Asking questions to child is punished
  - Not asking questions is reinforced

What Might Be Done Differently – Don't Ask Questions

- Give the learner opportunities to say "no" and have it be reinforced
  - Program this specifically if you have to
- Save **must-follow** instructions for safety skills
  - Escape extinction necessary
- Use pairing and instructional control to create a teaching relationship where the learner wants to answer "yes"

What Might Be Done Differently – Don't Ask Questions

- Change staff evaluations/training
  - Provide reinforcement for appropriate question asking in sessions
  - Provide feedback on when to deliver instruction v. question

What Might Be Done – Teach Self Care Skills

- Self Care Skills
  - Hand washing
  - Teeth brushing
  - Bathing
  - Toileting
  - Menstrual hygiene

What Might Be Done – Teach Self Care Skills

- Taught in a public setting
- Taught by a wide variety of support staff
- Observed by various support staff/ professionals
- Not prioritized in treatment plan

What Might Be Done Differently – Self-Care Skills

- Train family members to support this skill whenever possible
- Have a single support worker be responsible for assisting whenever possible
  - a consistent "back-up"
  - allow choice

What Might Be Done Differently – Self-Care Skills

- Limit support people present to 1
  - what messages does having multiple people there send?
  - if you have to have multiple people, how can you maximize dignity and privacy
- Teach skills that can help with independence in **private** routines
  - follow visual schedule
  - follow audio prompts

What Might Be Done Differently – Self-Care Skills

- Prioritize self-care skills in early intervention
  - identify barriers to implementation with family and help address
  - seek additional support
  - reinforce importance for families

What Might Be Done – Teaching Body Parts

- Very common early intervention target
  - Receptively ("show me your _____")
  - Expressively ("what's this called?")
- Who has included private body parts in this program?
- Vulva, penis, breasts, nipples, bum/ buttocks are rarely included

What Might Be Done Differently – Teaching Body Parts

- Include identifying **private** body parts in early learning programming
  - match to sample
  - receptive identification on pictures and self
  - expressive identification on pictures and self
    - Including for AAC users

What Might Be Done Differently – Teaching Body Parts

- Knowing CORRECT names of body parts it one of the BEST protective factors in preventing sexual abuse
  - can disclose
  - signals to possible offender that they could disclose
  - learners with autism are already at a communicative disadvantage; decrease the barriers they have to reporting where we can

What Might Be Done – Instructional Control

- Front line staff are often instructed to pair with new learners
  - Delivery of reinforcement regardless of behavior or responding
  - Making sure that they as the teacher are paired with fun things
  - This may not be completed as an ongoing process or is not systematic
- Some elements of good instructional control are used and others are not or implementation is inconsistent

What Might Be Done Differently – Instructional Control

- Implement 7 Steps to Instructional Control (Schramm & Miller, 2014) Consistently
  - Be in control of reinforcers
  - Be fun – make the reinforcer better with you than without you
  - Say what you mean and mean what you say
  - Show them that following instructions is the easiest way to get what they want

What Might Be Done Differently – Instructional Control

- Implement 7 Steps to Instructional Control (Schramm & Miller, 2014) Consistently
  - Start by reinforcing all responses and then fade reinforcement schedule
  - Show the learner you know their priorities (what they like)
  - Show the learner ignoring instructions doesn't earn reinforcement

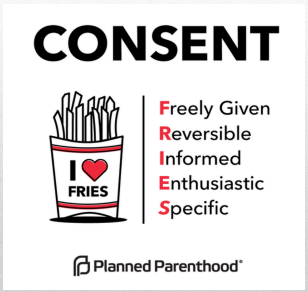
What Might Be Done Differently – Instructional Control

- BUT Think Critically about the 7 Steps
  - Show them that following instructions is the easiest way to get what they want
    - "do this, get this"
  - Show the learner ignoring instructions doesn't earn reinforcement
    - "if you don't do this, you won't get this"
  - Are we setting up learners to be accepting of these **possible grooming techniques**?

What Might Be Done – Treatment Selection/Social Validity

- Choice
  - common procedure used to reduce likelihood of interfering behaviour
- Asking clients for their input or opinion on treatment or elements of treatment is not widely adopted (less than 3% of published research in the field) (as cited in Hanley, 2010)
- We require consent, but for children this is generally given by parents/caregivers

Consent in Early Intervention



What Might Be Done Differently – Treatment Selection/ Social Validity

- Hanley, 2010 provides review and suggestions
- Treatment selection via preference assessments
- Use technology of stimulus control to assist those with limited language to be able to choose a treatment/response plan for interfering behavior
  - There is some research showing that recipients will choose punishment procedures and restraint in some cases

What Might Be Done Differently – Treatment Selection/ Social Validity

- Ask those who are capable to choose or rate their preferences
  - create ways for those with more limited language skills to do the same

Key References

- Byrne, G. (2018). Prevalence and psychological sequelae of sexual abuse among individuals with an intellectual disability: A review of the recent literature. *Journal of Intellectual Disabilities, 22*(3), 294-310.
- Canadian Centre for Child Protection (2014). Child sexual abuse: It is your business. Retrieved from: https://www.protectchildren.ca/pdfs/C3P_ChildSexualAbuse_ItIsYourBusiness_en.pdf
- Edelson, M.G. (2010). Sexual abuse of children with autism: factors that increase risk and interfere with recognition of abuse. *Disability Studies Quarterly, 30*(1).
- Geiger, K.B., Carr, J.E., & LeBlanc, L.A. (2010). Function-based treatments for escape-maintained problem behavior: A treatment selection model for practicing behavior analysts. *Behavior Analysis in Practice, 3(1)*, 22-32.

Key References

- Hanley, G.P. (2010). Toward effective and preferred programming: A case for the objective measurement of social validity with recipients of behavior-change programs. *Behavior Analysis in Practice, 3(1)*, 13-21.
- Isham, K. (2018). *Body smart right from the start*. Ryane's Press: Qualicum Beach, BC.
- Mandell, S. & Walrath, M. (2005) Characteristics of children with autism spectrum disorders served in comprehensive community-based mental health settings. *Journal of autism and developmental disorders, 35*(3), 313-321.
- Sevlever, M., Roth, M.E., & Gillis, J.M. (2013). Sexual abuse and offending in autism spectrum disorder. *Sex and Disability, 31*, 189-200.