

# Neurodevelopmental Disorders and Puberty

The good, the bad, and the awkward

Dr. Melanie Penner – Developmental Paediatrician  
Clinician Investigator – Autism Research Centre

## Tips from #askingautistics

- “Periods are a sensory nightmare and hormones can cause more meltdowns” - @NeuroRebel
- “Think about the language you use and avoid using euphemisms...I’d add extra emphasis to the message that body changes are totally expected, it’s not possible to die from blood loss when you get your period, etc.” - @autgeek
- “I think some explanation on how hormones can affect the body would be useful. All I got was the talk about my period, but I didn’t understand why suddenly the boys were stronger and faster than me” - @Daria\_basically

## Outline

- Typical developmental tasks of puberty
- What is different about puberty in neurodevelopmental disorders?
- Mood/behavior changes in puberty
- Menstrual management
- Gender/sexuality



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## An overview of puberty

Variable	Early Adolescence	Middle Adolescence
Age (SMR)	10-13 (1-2)	14-16 (3-5)
Sexual	Interest > activity	Sexual drive surges
Cognitive/moral	Concrete operations, conventional morality	Abstract thought, questioning mores, self-centred
Self-concept	Concerned with changing body, self-conscious	Concerned with attractiveness, introspective
Family	Bids for independence, ambivalence	Struggle for autonomy
Peers	Same-sex, conformity, cliques	Dating
Society	Middle school adjustment	Gauging skill and opportunities

## An overview of puberty in NDDs

Variable	Early Adolescence	Middle Adolescence
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No boundaries

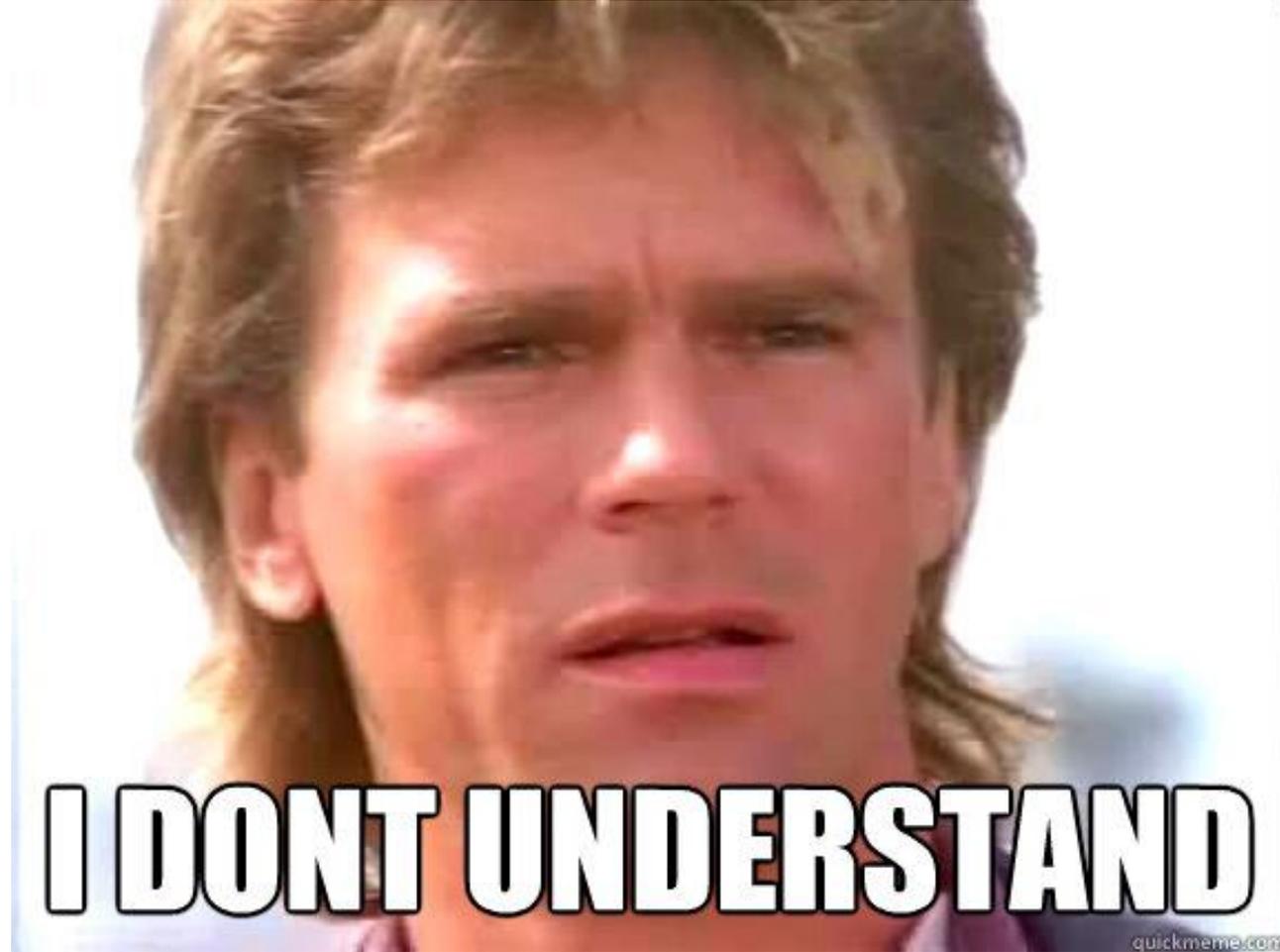
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## What does the research tell us?

- Higher risk (small!!!) of early puberty in NDDs (Siddiqi 1999)
- No difference in pubertal timing in ASD (May 2017 JADD)
- Pubertal deterioration in ASD (Gillberg 1987) and Down syndrome
- Autistic adolescent girls may be more likely than other NDD groups to have behavior issues related to menses (Burke 2010 Journal of Pediatr Adolesc Gynec)
- Parent concerns high; most minimally verbal autistic girls coped well (Cummin, 2018)
- Classic symptoms of ADHD decrease; BUT risk of academic failure, substance abuse! (Wolraich, 2005)



No boundaries

**Bloorview**  
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## Her behavior is getting worse! Must be puberty...

- Something we hear frequently!
- OFTEN: the behavior hasn't changed, the child has gotten bigger
  - Hits harder
  - Can't physically stop the behavior (i.e. pick up and put in car)
- Important to go back to the ABC's
  - Antecedent: what has changed in the youth's environment?
  - Behavior: has it actually changed?
  - Consequence: school/home? What has changed?

His behavior is getting worse! It must be puberty.....yup

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## POND data – externalizing behavior in puberty

	Pre-puberty	Puberty
<b>ASD</b>		
Male	12.7	11.8
Female	10.4	12.4
<b>ADHD</b>		
Male	16.1	15.3
Female	13.8	15.8
<b>OCD</b>		
Male	9.3	8.4
Female	7	9
<b>TD</b>		
Male	3.2	2.4
Female	0.9	2.9

No boundaries



## POND data – internalizing behavior in puberty

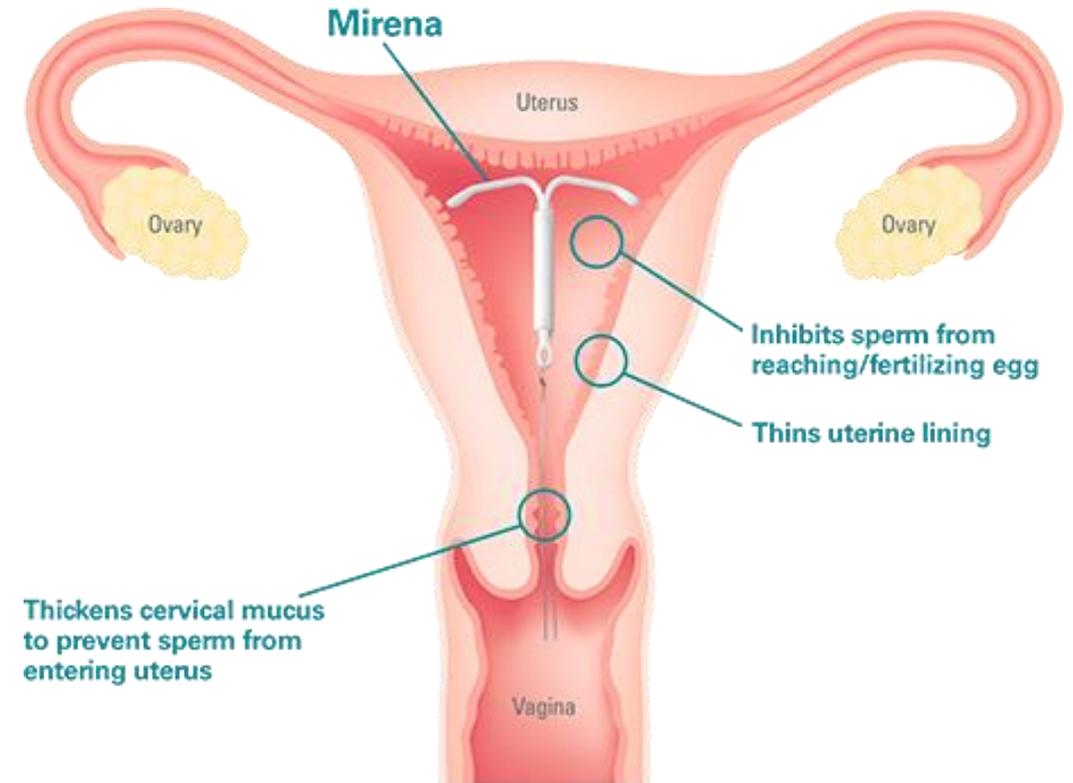
	Pre-puberty	Puberty
<b>ASD</b>		
Male	13.1	14.6
Female	11.9	15.9 ↑
<b>ADHD</b>		
Male	11.5	12.9
Female	10.3	14.3 ↑
<b>OCD</b>		
Male	15.3	16.8
Female	14.1	18.1
<b>TD</b>		
Male	3.4	4.8
Female	2.1	6.1 ↑

No boundaries



# Menstrual management / Contraception

- From the Canadian Paediatric Society:
- **Long-acting reversible contraception (LARC)** is first-line
  - More effective than other hormonal methods
- Providers should work with youth to select the right method for them



# Menstrual management / Contraception

- From the adult Developmental Disabilities Primary Care Guidelines:

## **DISCUSS MENSTRUAL REGULATION**

- Discuss methods of menstrual regulation with women with IDD and their caregivers. In deciding together on a method, consider safety and effectiveness, the patient's health circumstances, and the patient's and caregiver's views on the benefits and burdens to the patient.<sup>184, 187</sup>

## Menstrual management in ASD

- Kirkham et al. (from Ontario!) 2013 – chart review for adolescents with developmental disabilities
- Caregiver concerns: menstrual suppression, hygiene, caregiver burden, menstrual symptoms
- Chosen methods:
  - Continuous OCP: 42.3%
  - Patch: 20%
  - Expectant management: 14.9%
  - DMPA (i.e. Depo-Provera): 11.6%
  - Levonorgestrel intrauterine system (i.e. Mirena): 2.8%

# Menstrual management

- Hamilton 2011: survey of adolescents w/ASD (mostly caregivers)
- 29% taking hormonal contraception
  - Of those, 35% taking continuously
- 1/3 had worsening of behavior around the time of menses
- Common hygiene issues: needing help with blood stains, reminders to change pad/tampon, disposing used products
- Most common treatments were ibuprofen and acetaminophen
- Authors conclude that hormonal treatments underused

# Considerations for choice of menstrual management

- From Kirkham et al.
- Degree of impairment and required assistance
- Menstrual-associated symptoms
- Contraindications to estrogen
- Concerns for bone density
- Comorbidities
- Route and frequency of administration
- Individual preferences

## Gender and NDDs

- Research has been limited to date, conflicting results re: higher rates of gender dysphoria in ASD
- Netherlands data: <1% of their ASD sample (n = 675) identified as something other than their biological sex (Dewinter, 2017)
  - 22% of women and 8% of men identified gender non-conforming feelings
- Link may also be present in other NDDs (ADHD)
- Regardless of link, children/youth with NDDs should receive same range of gender-affirmative interventions as their neurotypical peers

## Sexuality and NDDs

- People with NDDs experience sexuality!
- (for the most part) It's ok!
  - Caution re: flags for sexual abuse
- Masturbation:
  - Normal, expected
  - May be an issue if it is not occurring!
  - May need instruction re: privacy
- Resources: Hand Made Love, Finger Tips



## Sexuality and NDDs

- From the Netherlands: half of participants w/ASD in their sample\* were in a relationship, many lived with their partner
- Sexual orientation more varied c/w NT controls
- Higher proportion was not exclusively attracted to members of the opposite sex, esp. among women

Dewinter 2017

## Risk of abuse

### CPS Position Statement: The sexual abuse of young people with a disability or chronic health condition

- Children/youth with NDDs are at higher risk of abuse, including sexual abuse
- Maintain a high level of suspicion
  - Behaviour changes, sexualized behavior, somatic complaints, encopresis, avoiding specific caregivers or situations
- Discuss limits of confidentiality appropriate to developmental level
- Helpful practices:
  - Promote patient privacy, draping
  - Encouraging self-reporting in children and adolescents during histories
  - Chaperoning physical examinations/procedures
  - Appropriate information about healthy sexuality, anatomy, personal rights

## Take home points

- Behaviors may get worse in puberty
  - Similar to typical developmental tasks of puberty
  - Existing behaviours become more difficult to manage
  - Internalizing behavior may worsen, esp. in girls
- Many options for menstrual management, including expectant management
- There may be increased gender dysphoria in NDDs; increased awareness warranted
- People with NDDs experience sexuality, including non-hetero
- Increased vigilance and empowering practices needed re: abuse