



# Comprehensive and Systemic Sexuality and Relationship Education for Young Adults with Autism

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# About me

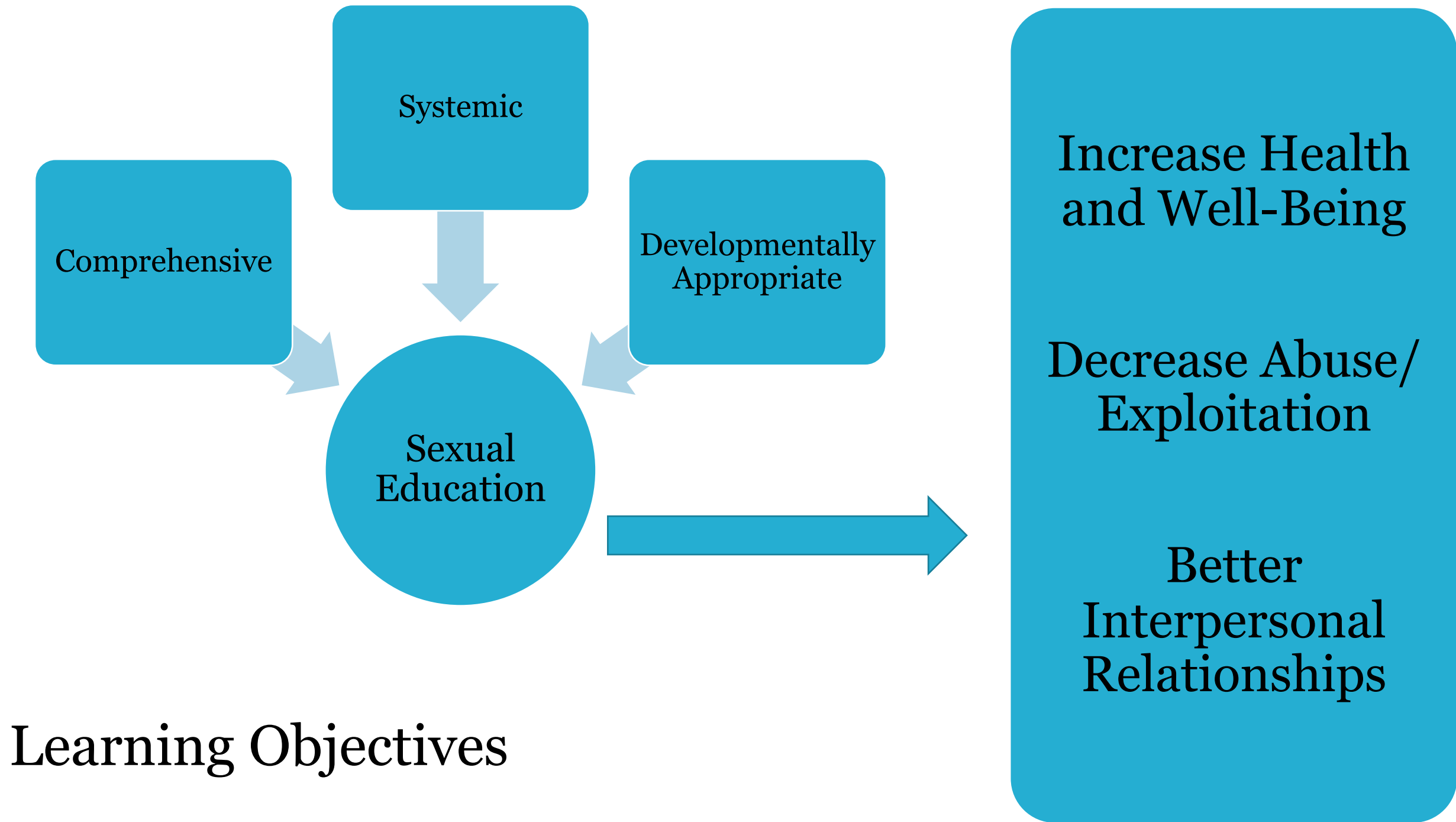
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# SEXUAL EDUCATION



# I/DD and the Education Gap

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**56% of students with mild ID received no sex ed**

**84% of students with moderate/profound ID received no sex ed**

**Estimates of around 40-60% of individuals with ASD leave High School with no sex education**

**60% of teachers believed students with ID could benefit from sex ed**

- Opt-out policy for those in special education
- Lack of “real-world” opportunities to learn
- Difficulties integrating information from movies, porn, etc.



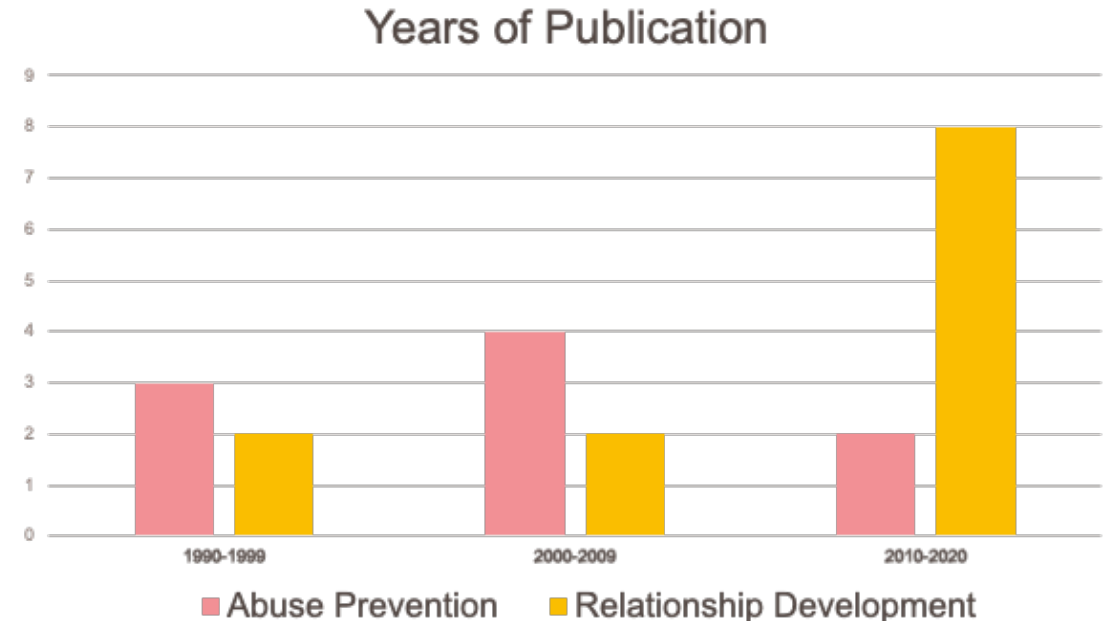


# Interventions and Outcomes

- When younger, focus is on anatomy/physiology
- For adults, focus is abuse prevention and relationship development
- Further alienation when combined with social skills concerns
- Sensory issues often not considered
- Adults lack initial sexual knowledge



- Sex education is a nuanced topic
- Often becomes a focus when it becomes an “issue”
- Myth of asexuality
- Myth of perpetual offender



# Healthcare Consequences

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Issues with basic hygiene, health maintenance, and health/reproductive advocacy

**1 in 3 women with a disability do not have a usual healthcare provider**

**1 in 4 women with a disability did not have a routine check-up in the past year**



Overinvolvement of guardians/caregivers

Unintended pregnancies

Amy



YA with ASD

Sensory issues related to  
giving birth and  
menstrual pain

Lack of access to  
healthcare

ASD and ID

Hysterectomy when 23  
without her consent

Linda





# IPV/SV Statistics

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	General Population	Disability
Sexual Violence	20% of women 2.6% of men	41.6%
Intimate Partner Violence	25% of women 10% of men	37.4%

People with IDD 7x more likely to experience abuse, women 12x more likely

# Disability Specific Abuse and Consequences

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Use of diagnoses to  
create connection and  
manipulate

One abuser manipulated  
a victim into staying in  
the relationship, stating  
“no one else would want  
her” because of her  
disability

Taking advantage of  
misreading social cues  
and sensory concerns

Using derogatory labels  
related to disability  
during arguments (e.g.  
“crazy” or “moron”)

Amplified mental health  
symptoms following  
SV/IPV experience (e.g.  
depression, self-harm,  
suicidal thoughts)

Feelings of physical and  
emotional isolation and  
mistrust of others—  
further abuse  
experiences

Substance  
abuse/”negative  
behaviors” increased

Overall health decline  
and physical injuries as  
component of SV/IPV  
experience

# Language and Misunderstanding

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Inability to discuss abuse experiences if you don't have the terms  
AAC users

Taylor

Abe

Maria

Clara

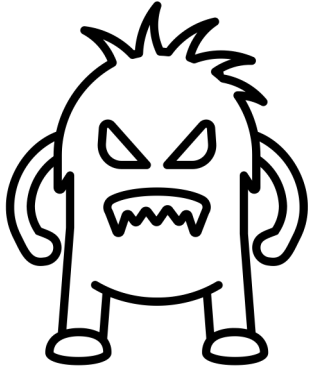




# What Next

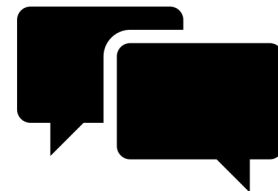
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Policy changes in order to make it more accessible—in the meantime, community programs and parent training programs are key



Change societal views of sex ed as the big bad monster

Don't have to know a lot about the topic, you just have to be open, honest, and willing to deal with a little discomfort



The background features a repeating pattern of interlocking puzzle pieces in a light yellow color. Overlaid on this is a large, semi-transparent heart shape. The heart is divided vertically: the left half is white, and the right half is a soft pink. The text 'Comprehensive Sex Ed' is centered over the heart.

# **Comprehensive Sex Ed**

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# Romantic Relationships

A desire for intimacy  
BUT  
Restrictive  
programs/policies/family  
rules

A desire for  
friendships/peers  
BUT  
Others in control of their  
social lives

A desire for a sexual  
identity and experiences  
BUT  
Family/staff/society  
expectations place barriers

Punished for intimate  
experiences  
Loneliness  
Sex as secretive  
Abusive experiences  
Focus on abuse  
prevention and not  
desire/positive  
experiences



# Comprehensive Sex Ed Topics

1

## Biological & Reproductive

- Anatomy/Physiology
  - Sex differences
  - Pregnancy
- Birth Control

Mike

2

## Health and Hygiene

- Hygiene
- Health and Wellness
- Alcohol and Drug Use
- STD/HIV Prevention
- STD Epidemiology
- Body and Disease

3

## Relationships

- Relationship/Social Skills
- Responsibility to Partner
- Family Types and Roles
- Feelings and Expressions
  - Dating and Marriage
  - Parenting
- Sexual Orientation

4

## Self-Protection/Self-Advocacy

- Protection against Abuse
  - Sexual Feelings
- Sexuality as Positive Aspect of Self
- Sexual Behavior other than Intercourse
- Appropriate and Inappropriate Touching
  - Decision Making
  - Safe Sex Practices
- Reduction of Fear and Myths
  - Personal Rights
  - Sexual Discrimination
- Saying “no”—sex/drugs/alcohol

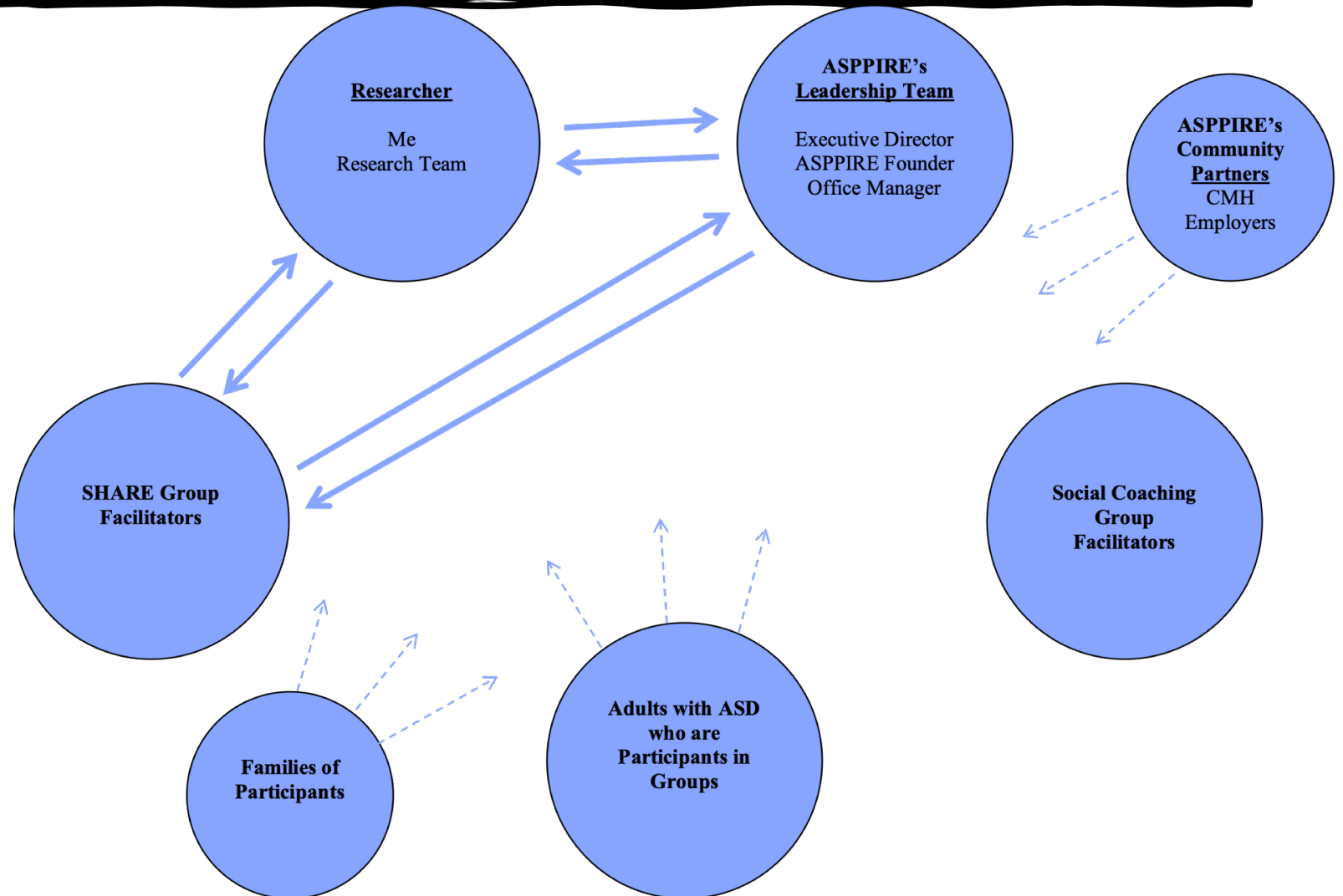
Claire & Nate

Katie

# SHARE Curriculum Review



- Employment skills, social coaching, and sex education
- 18+, mostly ASD
- Small groups, small program



# Curriculum Review

What are mutual friends?  
What category under relationships  
would they fall under?

Can you force a friendship to  
become a romantic relationship?

Does the mother get scratched  
when giving birth by the baby?

Burning question

Is it right to date someone  
at least 10 years older/younger  
than you?

Does sex need to be central  
to a relationship?

Questions:

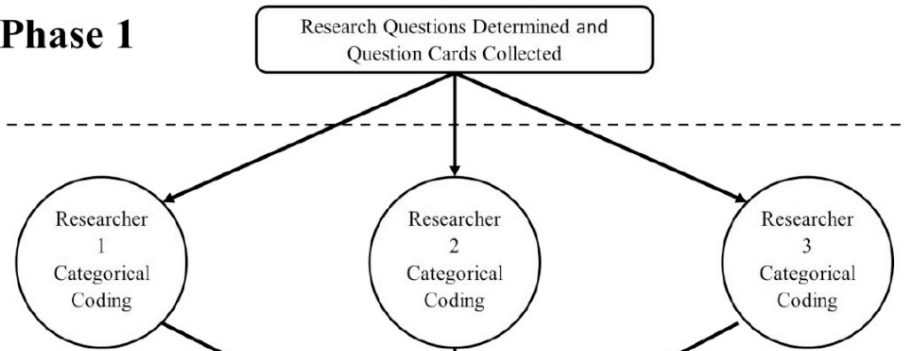
Is there any Guy Birth Control  
(Pill)

During ovulation ~~to~~ how much does  
the woman's temp. go up?

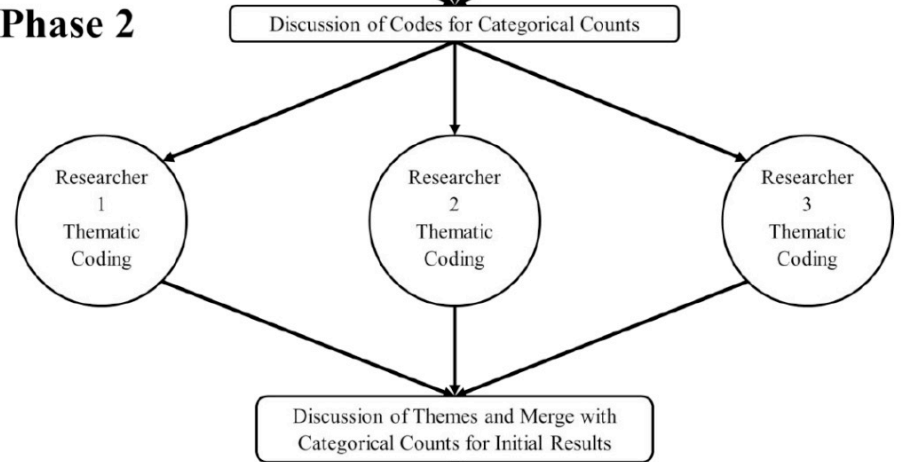
Are there natural Condoms

Why do guys like babs but not necessarily fat?

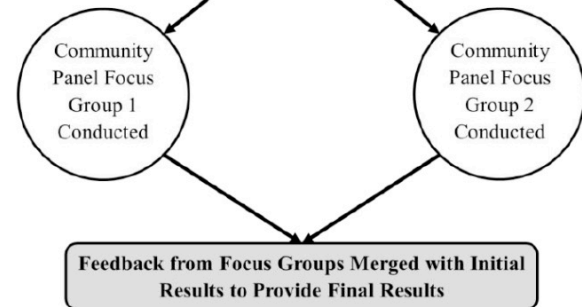
## Phase 1



## Phase 2



## Phase 3



# 3-Part SHARE

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01

## Sexual Health Education

- Anatomy & Physiology
- Health & Hygiene
- STI & Other Diseases
- Safe Sexual Practices

02

## Intimate Relationships and Sexuality Expression

- Finding Potential Partners
- Long-Term & Short-Term Relationships
- Sexuality Expression
- Safety in Relationships

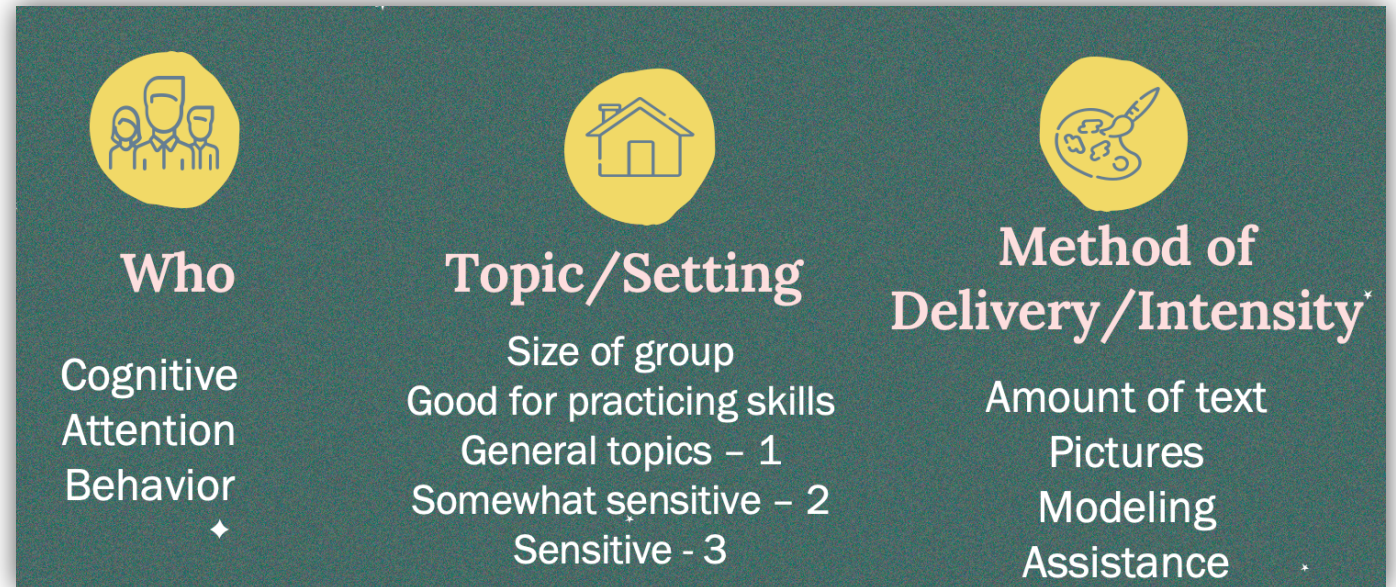
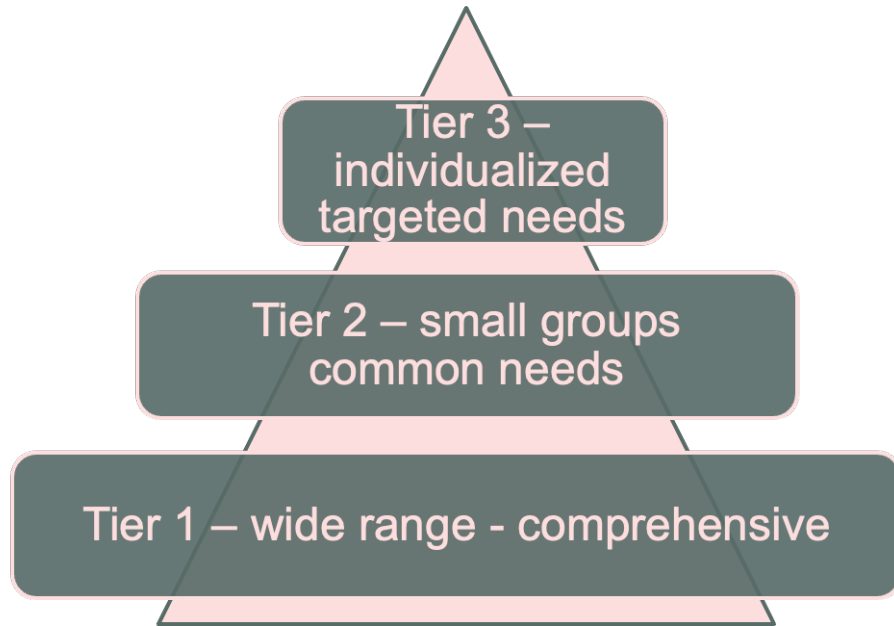
03

## Dating & Relationships in the Real World

- Online Dating
- Community Outings
- Putting Knowledge into Practice
- Practical Knowledge

# Tiered Models of Intervention

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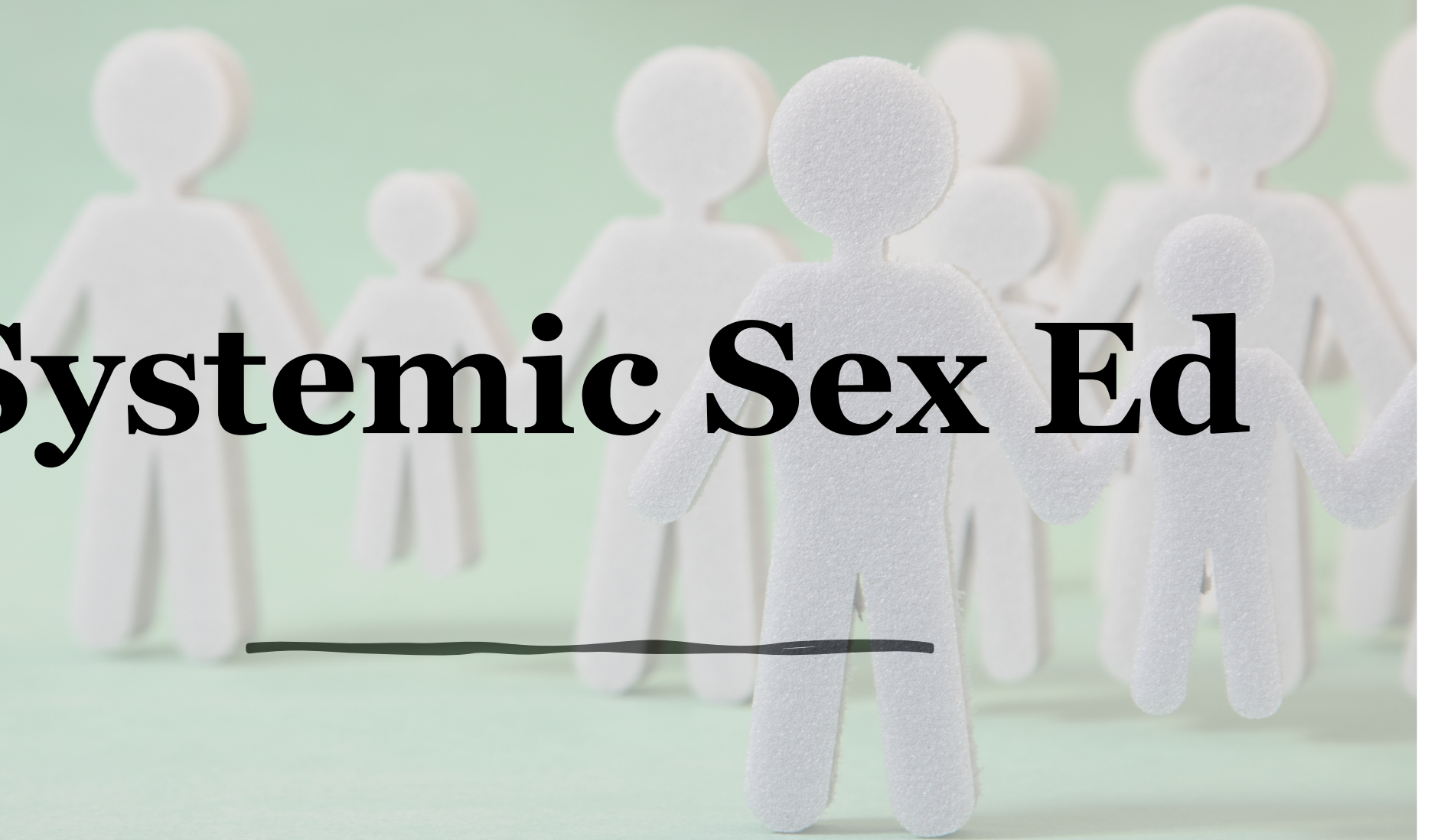
## Things to Note:

- Assessment is key
- Many different things fall under the umbrella of “sex ed”
- Need to think about knowledge and behaviors
- Healthy relationships are just as important



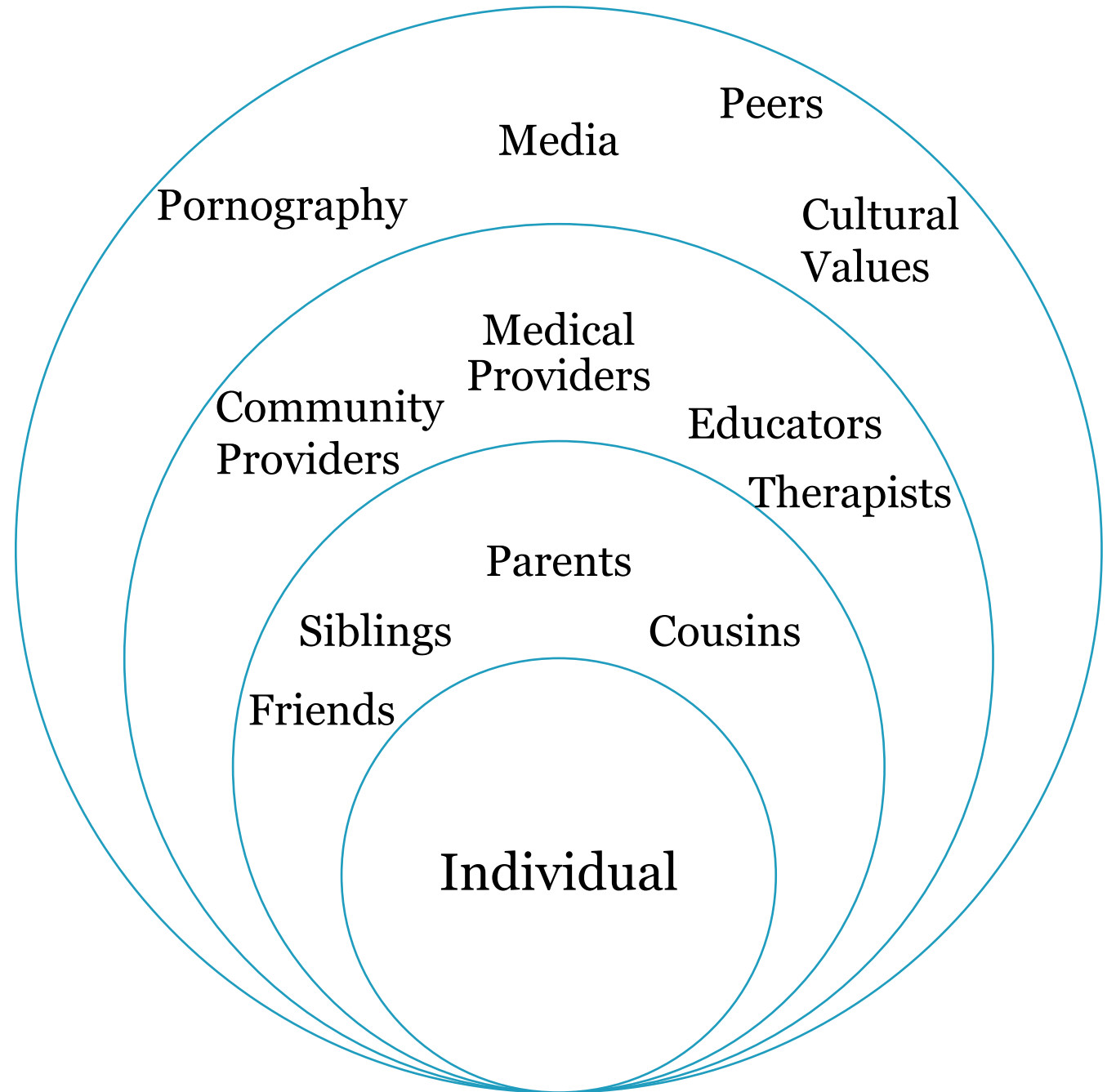
# **Systemic Sex Ed**

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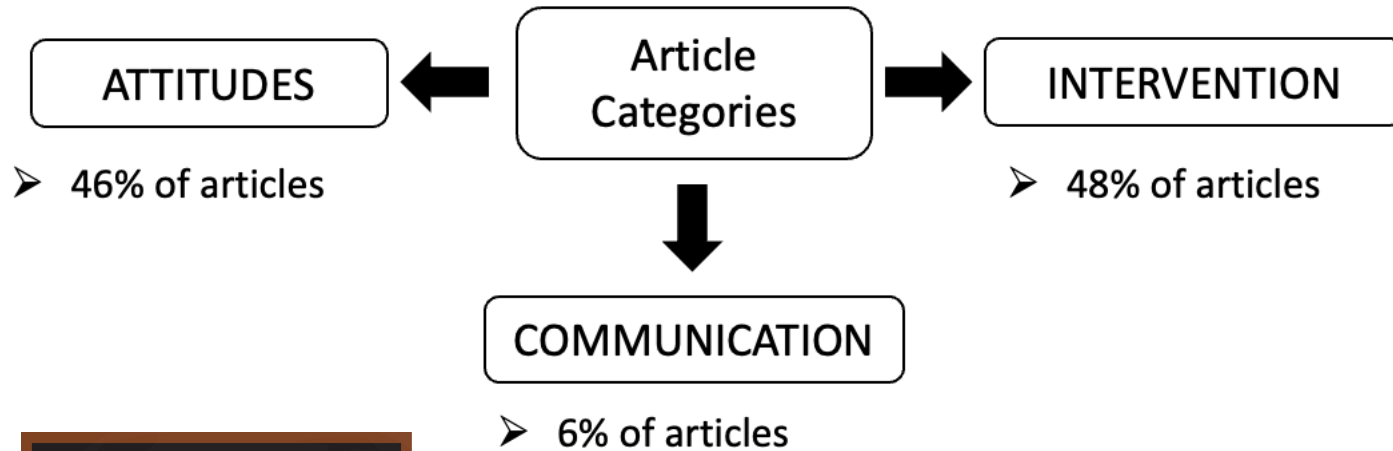


# Thinking Systemically





# Let's Talk About Parents



## ROI Parent Groups

- Parent-initiated
- Supplemented sex ed in school
- Increased comfortability
- You don't have to say and teach everything—you just have to do something

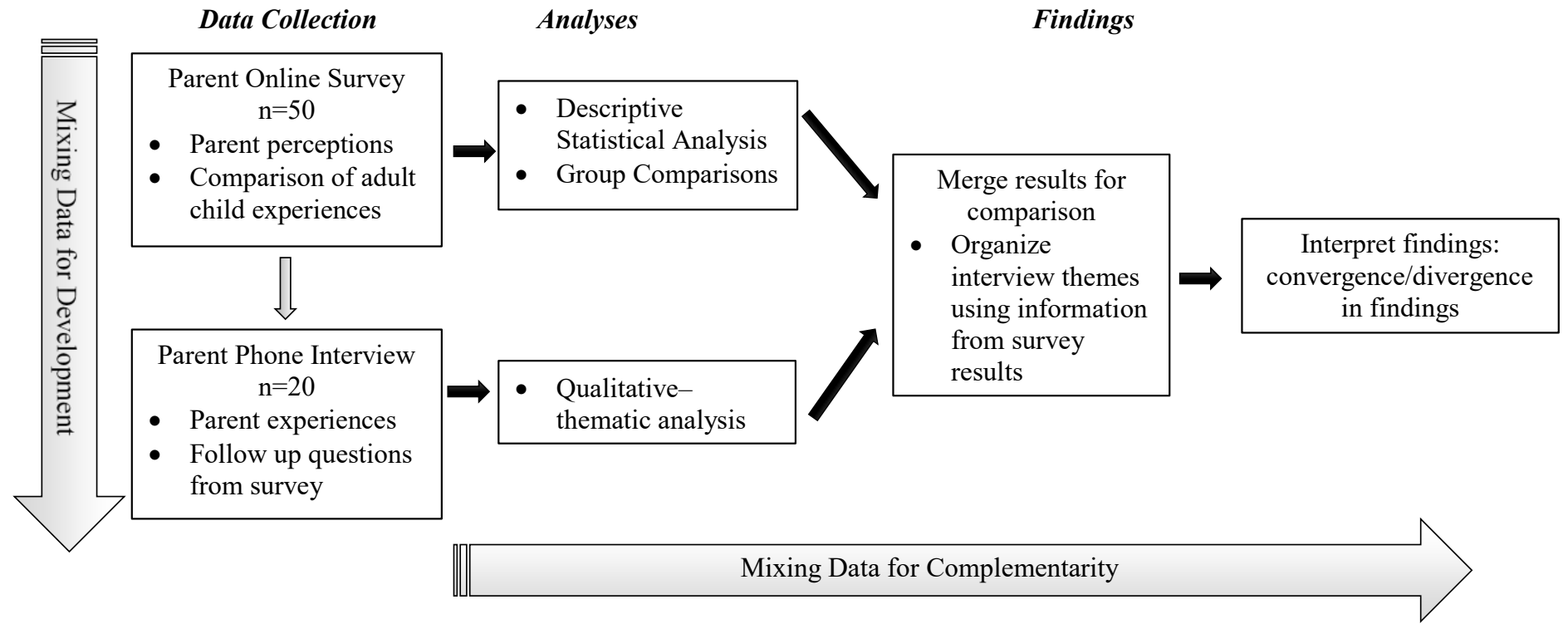


# STUDY 1



# STUDY 2

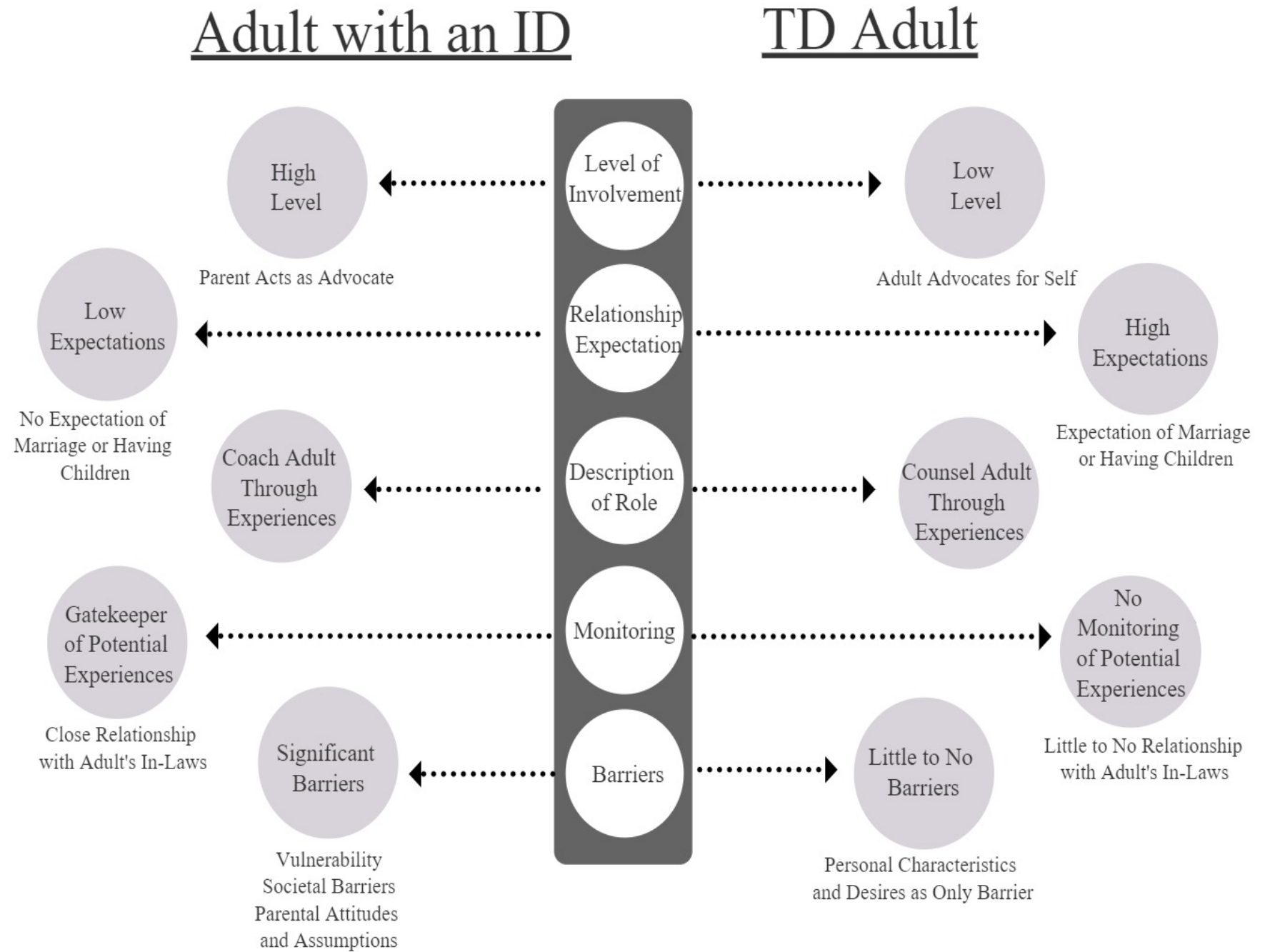
- ❖ 15 interviews
- ❖ Adults with I/DD and Autism
- ❖ Currently in romantic relationships



## Goals:

- Examine experiences with sex ed
- Examine experiences of romantic relationships
- Examine how systemic involvement is different for those with I/DD compared to their siblings and others

# Parents: I/DD vs. TD



# What do Parents and Adults Say?

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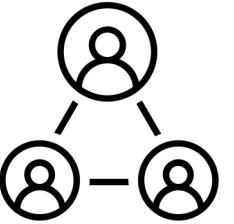




# Notes about Including Systems

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Always be thinking about WHO can get involved and at  
WHAT LEVELS



Recognize that adults with Autism desire romantic relationships, may need help to see that vision through

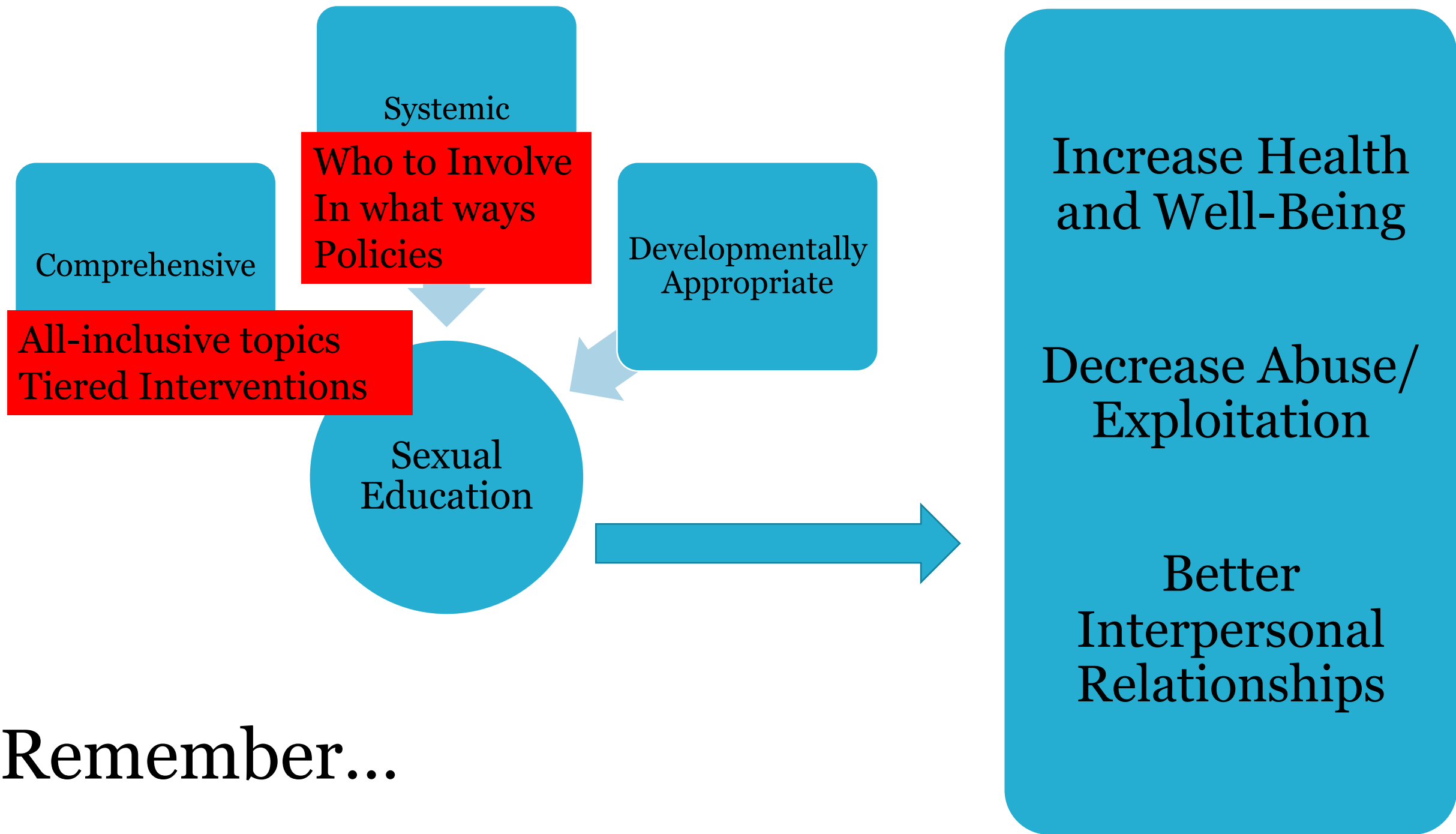
Always be aware of policy restrictions—may take multiple people to help





# **Key Takeaways**

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Remember...



# Thinking Ahead

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- Need to stop viewing sex ed as "scary"—it as an important and necessary component of health and well-being
- A lot of programs/organizations already work really hard on this issue—content is out there, need to increase access and to engage multiple parts of the system to enhance services
- Look in your area and find programs that exist—if there isn't one think about making one—reach out to experts, local providers, and educate yourself

Thank  
You

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# REFERENCES

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- Bonomi AE, Nichols E, Kammes R, Chugani C, DeGenna N, Jones K, Miller E. Alcohol, mental health disability and violence victimization in college women: exploring connections. In press, *Violence Against Women*.
- Nichols E, Bonomi AE, Kammes R, Miller E. Service seeking experiences of college-aged sexual and intimate partner violence victims with a mental health and/or behavioral disability. In press, *Journal of American College Health*. <https://doi.org/10.1080/074484812018.1440572>
- Bonomi AE, Nichols E, Kammes R, Green T. Sexual violence and intimate partner violence in college women with a disability. *Journal of Women's Health* 2017 [Epub ahead of print]. doi: 10.1089/jwh.2016.6279
- Barnard-Brak, L., Schmidt, M., Chesnut, S., Wei, T., & Richman, D. (2014). Predictors of access to sex education for children with intellectual disabilities in public schools. *Intellectual and Developmental Disabilities, 52*, 85–97. doi: 10.1352/1934-9556-52.2.85
- Brown, M., & McCann, E. (2018). Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities, 74*, 124–138. doi: 10.1016/j.ridd.2018.01.009
- Cheak-Zamora, N. C., Teti, M., & First, J. (2015). 'Transitions are scary for our kids, and they're scary for us': Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities, 28*, 548–560. doi: 10.1111/jar.12150
- Chrastina, J., & Vecerova, H. (2020). Supporting sexuality in adults with intellectual disability-A short review. *Sexuality and Disability, 38*, 285–298. doi: 10.1007/s11195-018-9546-8
- Esbensen, A. J., Bishop, S., Mailick Seltzer, M., Greenberg, J. S., & Lounds Taylor, J. (2010). Comparisons between individuals with autism spectrum disorders and individuals with down syndrome in adulthood. *The American Journal of Intellectual and Developmental Disabilities, 115*(4), 277–290. doi: 10.1352/1944-7558-115.4.277
- Holmes, L. G., Hirnle, M. B., & Strassberg, D. S. (2016). Parental romantic expectations and parent-child sexuality communication in autism spectrum disorders. *Autism, 20*(6), 687–699. doi: 10.1177/1362361315602371
- Marsack, C. N., & Perry, T. E. (2018). Aging in place in every community: Social exclusion experiences of parents of adult children with autism spectrum disorder. *Research on Aging, 40*(6), 535–557. doi: 10.1177/0164027517717044
- Shapiro, J. (2018, January 9). For some with intellectual disabilities, ending abuse starts with sex ed. Special Series: *Abused and betrayed* National Public Radio. <https://www.npr.org/2018/01/09/572929725/for-some-with-intellectual-disabilities-ending-abuse-starts-with-sex-ed>
- Sun, W. H., Miu, H. Y. H., Wong, C. K. H., Tucker, J. D., & Wong, W. C. W. (2018). Assessing participation and effectiveness of a peer-led approach in youth sexual health education: Systematic review and meta-analysis in more developed countries. *The Journal of Sex Research, 55*, 31–44. doi: 10.1080/00224499.2016.1247779
- Treacy, A. C., Taylor, S. S., & Abernathy, T. V. (2018) Sexual Health Education for Individuals with Disabilities: A Call to Action. *American Journal of Sexuality Education, 13*(1), 65–93. doi: 10.1080/15546128.2017.1399492

# REFERENCES CON'T

Abbott, S., & McCloskey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities, 10*(2), 175–181. doi: [10.1177/17446395060263638](https://doi.org/10.1177/17446395060263638)

American Association on Intellectual and Developmental Disabilities. (2019). *Frequently Asked Questions on Intellectual Disability*. Retrieved from <https://aidd.org/intellectual-disability/definition/types-on-intellectual-disability>

Anastasiou, D., & Kauffman, J. M. (2013). The social model of disability: Dichotomy between impairment and disability. *Journal of Medicine and Philosophy, 38*, 441–459. doi: [10.1083/jomph.44026](https://doi.org/10.1083/jomph.44026)

Aras, B., Ovejero, A., & Moretlan, R. (2009). Love and emotional well-being in people with intellectual disabilities. *The Spanish Journal of Psychology, 12*(1), 204–216. doi: [10.1017/S1138741600001639](https://doi.org/10.1017/S1138741600001639)

Azopardi-Lane, C., & Callus, A. (2015). Constructing sexual identities: people with intellectual disability talking about sexuality. *British Journal of Learning Disabilities, 47*(1), 32–37. doi: [10.1111/bld.12083](https://doi.org/10.1111/bld.12083)

Baines, S., Emerson, E., Robertson, J., & Hutton, C. (2018). Sexual activity and sexual health among young adults with and without mild/moderate intellectual disability. *BMC Public Health, 18*, 1–12. doi: [10.1186/s12889-018-5572-9](https://doi.org/10.1186/s12889-018-5572-9)

Ballan, M. (2004). Parents as sexuality educators for their children with developmental disabilities. *SIECUS Report, 32*(2), 29–30.

Bernert, D. J. & Ogleetree, R. J. (2013). Women with intellectual disabilities talk about their perceptions of sex. *Journal of Intellectual Disability Research, 57*, 240–249. doi: [10.1111/j.1365-2788.2011.01529.x](https://doi.org/10.1111/j.1365-2788.2011.01529.x)

Bigby, C. (2008). Known well by no-one: Trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community. *Journal of Intellectual and Developmental Disability, 33*(2), 148–157. doi: [10.1080/13668250801976414](https://doi.org/10.1080/13668250801976414)

Blanchett, W. J., & Wolfe, P. S. (2002). A review of sexuality education curricula: Meeting the sexuality education needs of individuals with moderate and sever intellectual disabilities. *Research & Practice for Persons with Severe Disabilities, 27*(1), 43–57. doi: [10.2511/rrsd.27.1.43](https://doi.org/10.2511/rrsd.27.1.43)

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77–101. doi: [10.1191/1478088706](https://doi.org/10.1191/1478088706)

Brown, M., & McCann, E. (2018). Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities, 74*, 124–138. doi: [10.1016/j.ridd.2018.01.009](https://doi.org/10.1016/j.ridd.2018.01.009)

Brown, R. D., & Pirtle, T. (2008). Beliefs of professional and family caregivers about the sexuality of individuals with intellectual disabilities: Examining beliefs using a Q-methodology approach. *Sex Education, 8*(1), 59–75. doi: [10.1080/14681810701811829](https://doi.org/10.1080/14681810701811829)

Cuskelly, M., & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: Parents, support staff, and a community sample. *Journal of Intellectual & Developmental Disability, 29*(3), 255–264. doi: [10.1080/1366825042000001639](https://doi.org/10.1080/1366825042000001639)

Evans, D. S., McGuire, B. E., Healy, E., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part II: Staff and family carer perspectives. *Journal of Intellectual Disability Research, 53*(7), 913–921. doi: [10.1111/j.1365-2788.2009.01202.x](https://doi.org/10.1111/j.1365-2788.2009.01202.x)

Foley, S. (2012). The UN convention on the rights of persons with disabilities: A paradigm shift in the sexual empowerment of adults with down syndrome or more sound and fury signifying nothing? *Sexuality and Disability, 30*, 381–393. doi: [10.1007/s11195-017-9779-z](https://doi.org/10.1007/s11195-017-9779-z)

Foley, S. (2014). A modest proposal regarding the power of parents to optimize the sexual well-being of their adult sons and daughters with down syndrome. *Sexuality and Disability, 32*, 383–396. doi: [10.1007/s11195-013-9309-5](https://doi.org/10.1007/s11195-013-9309-5)

Foley, S. M., Bourke, K. R., Leonard, J., & Gindler, S. (2014). "I have a good life": The meaning of well-being from the perspective of young adults with down syndrome. *Disability and Rehabilitation, 36*(15), 1290–1298. doi: [10.3109/09638288.2013.854843](https://doi.org/10.3109/09638288.2013.854843)

Fisher, M. H., Baird, J. V., Currey, A. D., & Hodapp, R. M. (2016). Victimization and Schaafsma, D., Kok, G., Stoffelen, J. M. T., Van Doorn, P., & Curfs, L. M. G. (2014). Identifying the important factors associated with teaching sex education to people with intellectual disability: A cross-sectional survey among paid care staff. *Journal of Intellectual & Developmental Disability, 39*(2), 151–166. doi: [10.3109/13668250.2014.899566](https://doi.org/10.3109/13668250.2014.899566)

Sexuality Information and Education Council of the United States (2004). Forty years of knowledge: SIECUS on sexuality and disability. *SIECUS Report: Honoring the Past, Building the Future Celebrating 40 Years of SIECUS, 32*, 2.

Shakespeare, T. (2000). Disabled sexuality: Towards rights and recognition. *Sexuality and Disability, 18*(3), 159–166. doi: [10.1023/A:1026409613684](https://doi.org/10.1023/A:1026409613684)

Sharpe, T. H. (2003). Adult sexuality. *The Family Journal, 11*(4), 420–426. doi: [10.1177/1066480703255386](https://doi.org/10.1177/1066480703255386)

Shitarkhull, R. A., Santelli, J. S., & Hirsch, J. S. (2007). Sex education and sexual socialization: Roles for educators and parents. *Perspectives on Sexual and Reproductive Health, 39*(2), 116–119.

Sinclair, J., Unruh, D., Lindstrom, L., & Scanlon, D. (2015). Barriers to sexuality for individuals with intellectual and developmental disabilities: A literature review. *Education and Training in Autism and Developmental Disabilities, 50*(1), 3–16.

Smith-Acuña, S. (2011). *Systems theory in action: Applications to individual, couples, and family therapy*. Hoboken, NJ: John Wiley & Sons, Inc.

Sobsey, D. (1994). Sexual abuse of individuals with intellectual disability. In A. Craft (Ed.), *Practice issues in sexuality and learning disabilities* (pp. 93–115). London: Routledge.

Turner, G. W., & Crane, B. (2016). Pleasure is paramount: Adults with intellectual disabilities discuss sensuality and intimacy. *Sexualities, 19*(5–6), 677–697. doi: [10.1177/1363460715620573](https://doi.org/10.1177/1363460715620573)

Van Asselt, D., Buchanan, A., & Peterson, S. (2015). Enablers and barriers of social inclusion for young adults with intellectual disability: A multidimensional view. *Journal of Intellectual and Developmental Disability, 40*(1), 31–48. doi: [10.3109/13668250.2014.994170](https://doi.org/10.3109/13668250.2014.994170)

Van Asselt-Soversets, A. E., Embregts, P. J. C. M., & Hendriks, A. H. C. (2015a). Social networks of people with mild intellectual disabilities: Characteristics, satisfaction, wishes and quality of life. *Journal of Intellectual Disability Research, 59*(5), 450–461. doi: [10.1111/jir.12143](https://doi.org/10.1111/jir.12143)