



Disability & Healthy Relationships ECHO Summary

Date: 4/9/2026

Topic: Pregnancy & Intellectual/Developmental Disabilities

Presenters: Kye Doran & Alix Herer

Presentation Summary: Kye Doran from OHSU discussed the [Pregnancy Decisions App project](#), aimed at supporting reproductive life planning for women with intellectual and developmental disabilities (IDD). Kye presented general information about sexuality and reproductive life planning for people with IDD, including the importance of education and preparation to avoid unplanned pregnancies, and to create opportunities for healthy pregnancies and parenthood. The Pregnancy Decisions App project includes interviews, a national survey, and app development to provide accessible information on pregnancy, birth control, and parenting. Alix Herer emphasized the role of community-based participatory research and the importance of inclusive, accessible resources.

Community Questions & Responses:

1. What resources are you aware of that may be useful for individuals with IDD who are pregnant or hoping to become pregnant?
 - [Brandeis University information on pregnancy and information on parenting](#)
 - [Planned Parenthood general resources about pregnancy and education for people with disabilities](#)
 - [TETONS](#)
 - [Sexuality for All Abilities](#)
 - [Your Sexual Health Toolkit](#)
 - [Sonoran Center's Birth Control fact sheet](#) and [pregnancy/parenting resources](#)
 - *Health departments and general practitioners, although most are not trained or comfortable working with people with IDD*
 - *Not a lot of support programs in a rural area, many clients who lack supports and access to birth control and then if they become pregnant, they struggle due to lack of support and resources; only one nurse, when there is turnover people can fall through the cracks and have disruptions in essential care.*
2. What supports would be useful for someone with IDD who would like to start family planning? Even if those don't exist, what would those look like?
 - *Barriers: People don't understand that individuals with IDD can and will be sexual and are left out of education, and that leads to pregnancies that are*



unintended, and caregivers not wanting to acknowledge this; providers don't ask about relationship safety and screen for this; widespread lack of education across medical field, systemically.

- *Resources: getting more people involved in education, broad education in the schools, Medicaid/Medicare, transition planning, and across primary care; provide community classes.*
3. How many of the people you work with have access to information about family planning before they are considering that option?
- *Of those that make it to the clinic, they receive the information, but most people don't until after they've already started having children; younger ones – word of mouth (not advertising, not allowed in the schools); referrals, - community health center for a rural health district; abstinence & STIs only allowed, but not permitted to discuss other topics; parents even lack information about STIs, consent, digital safety, birth control options.*
4. What information do you think would be most helpful to provide to someone with IDD who may be considering pregnancy or is pregnant?
- *Resources, reproductive and child development education in accessible language,*
 - *Lived experience matters – moms should train potential moms*
 - *Navigating healthcare, insurance, education systems as a parent is difficult, with or without IDD*
 - *Parenting is also just a difficult learning experience that would be really useful to have support/education groups to prepare*
 - *For medical professionals – disability awareness, not having training or policies about relationship safety, coercion, consent, reproductive life planning, trauma informed care; pattern of providers minimizing issues, talking over patient to guardian/caregivers, misinformation*
 - *Many clients come in from counselors, but parents and caregivers limit access to information, autonomy*
 - *So many online resources and classes are available to self-train and share with clients*
 - *Physical bodies, getting pregnant; encouragement to know that they can do it, have autonomy even*
 - *How to provide resources for different types of disabilities; how to share this information*
5. Are there current organizations that provide this kind of education?
- *NICU information from hospitals*
 - *WIC/health departments*



- *Parenting classes with YMCA or Head Start*
 - *Other UCEDDs: [Virginia Commonwealth LEAP](#), [Vanderbilt](#)*
 - *[The Family Place](#) parenting classes*
 - *[Utah Parent Center](#)*
 - *Planned Parenthood*
 - *[Utah Pride Center](#)*
6. Who could provide this?
- *Peer education opportunities, mentorship, plain language within current trainings*
7. What are the barriers for providing family planning information for people with IDD?
- *Systemic lacking, openness, lack resources, rural area*
8. Are there any stories or experiences you can share that illustrate the need for this type of education?
- *Example of not knowing that “we can take our consent back after we give our consent” – broader education needed*
 - *Barrier that many individuals with disabilities may feel barring them from parenthood, relationships, opportunities to serve/learn/participate*
 - *Research example – medical records did not document whether there was a disability for pregnant mothers. No good way of tracking existence of a disability other than self report*
 - *When there was turnover in the nursing, someone’s birth control lapsed and they had an unintended pregnancy; young adult coming in with parents*