

A Webinar from AUCD's Sexual Health Special Interest Group

**The Sexual Health Equity for
Individuals with Developmental
Disabilities (SHEIDD) Project:**
Building Community Capacity to
Support the Sexual Health of Youth
Experiencing I/DD

Friday, May 25, 2018

Webinar Overview

- Introductions
- Presentation
- Q & A after presentation
 - You can submit questions throughout the webinar via the 'Chat' box below the slides.
 - The moderator will read the questions after the presentations.
- Survey
 - Please complete our short survey to give us feedback for the next webinar!

Presenters



April Kayser has worked for more than a decade in social services and community health. She currently works for the Multnomah County Health Department as a sexual health educator, teaching sexuality education to middle and high school-age young people and conducting trainings. April is the lead on the County's community capacity building project called Sexual Health Equity for Individuals with Intellectual/Developmental Disabilities (SHEIDD).



Kiersi Coleman is a communication consultant, self-advocate, and program assistant for the UCEDD at OHSU. Kiersi provides content and expertise for the website, and program implementation and evaluation. She leads efforts across communities within and outside of OHSU to improve the lives of people experiencing disabilities, all the while, experiencing cerebral palsy herself.



Lindsay Sauve, MPH, is the Program and Evaluation Manager for the UCEDD. Lindsay leads the evaluation activities of the UCEDD's core grant, as well as develops and manages outcome-based model programs for community members with disabilities, with a focus on health promotion for transition-age youth.

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

Objectives:

- Explore strategies for building community partnerships to promote sexual health education and support for young people experiencing I/DD in their communities.
- Review participatory methods for conducting community needs assessments.
- Identify the guidelines of the SHEIDD Community Needs Assessment
- Share activities, tools, and resources in community-based settings to increase community capacity and provide holistic sexual health education to young people experiencing I/DD

Introductions

- Presenters:
 - April Kayser, Multnomah County Health Department
 - Kiersi Coleman, OHSU UCEDD
 - Lindsay Sauv  , OHSU UCEDD
- Participants:
 - Please share your role/title and state in the chat box

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

The SHEIDD Vision

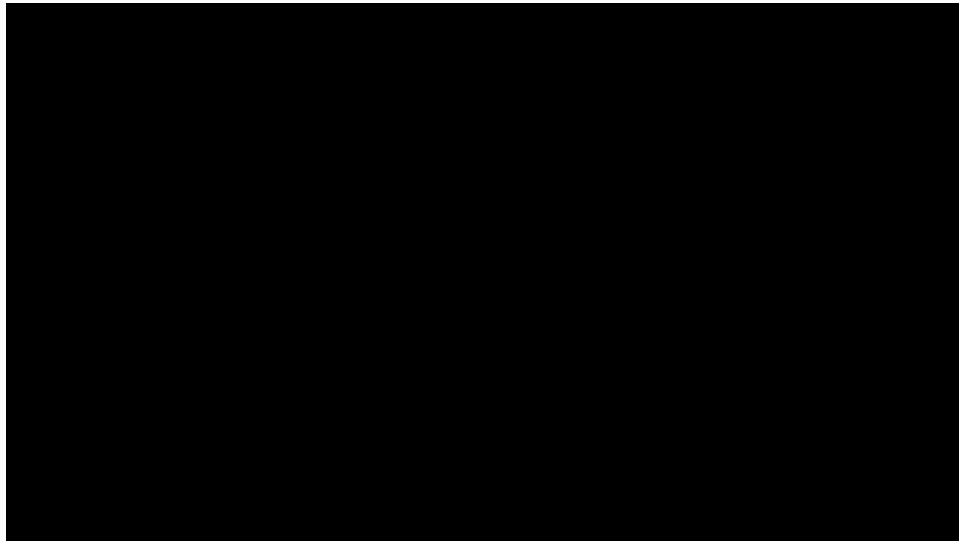
“To promote comprehensive sexuality education and support for young people (ages 14-21) who experience intellectual/developmental disabilities (I/DD) by working together to build the skills of parents/guardians, caregivers, support workers, teachers, health care providers and others to provide sexual health education and support to the young people in their lives.”

This opportunity is made possible by Grant Number TP2AH000046 from the HHS Office of Adolescent Health as part of the Innovative Teen Pregnancy Prevention (iTP3) project. Contents are solely the responsibility of Multnomah County Health Department and do not necessarily represent the official views of the Department of Health and Human Services, the Office of Adolescent Health, or Texas A&M University.



The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

SHEIDD Video



<https://www.youtube.com/watch?v=8ulqagiGFVU&feature=youtu.be>

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

A term we hear a lot in our work is “person-centered.”

What does person-centered mean to you?

Please use the chat function to answer.

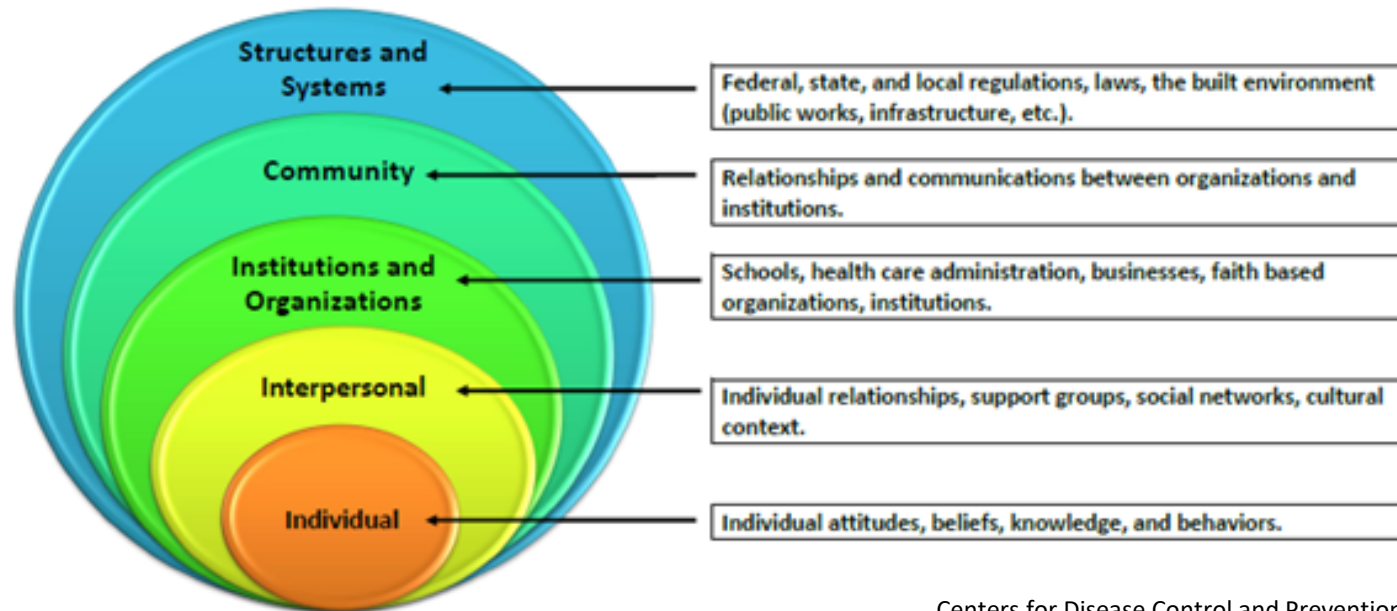
The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

Oregon Training and Consultation (OTAC) summarizes “person-centered” as follows:

- ensuring someone with a disability is at the center of decisions that relate to their own life.
- emphasizing options that are available to a person rather than "fixing" or changing the person.
- understanding what a person wants and needs to live their own, personally defined, good life.

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

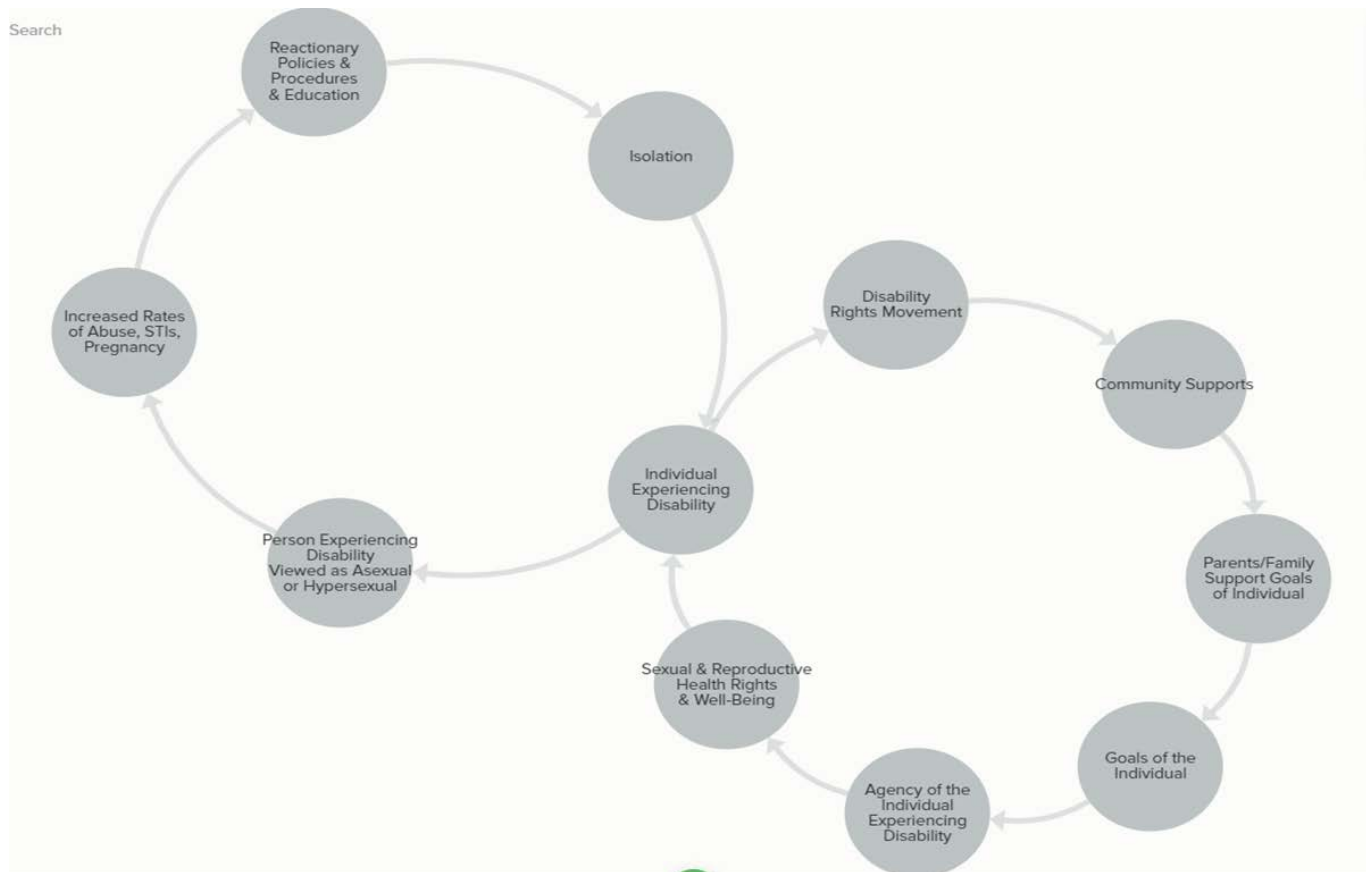
Socioecological Model



Centers for Disease Control and Prevention

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

A Systems Approach



Building Community Partnerships

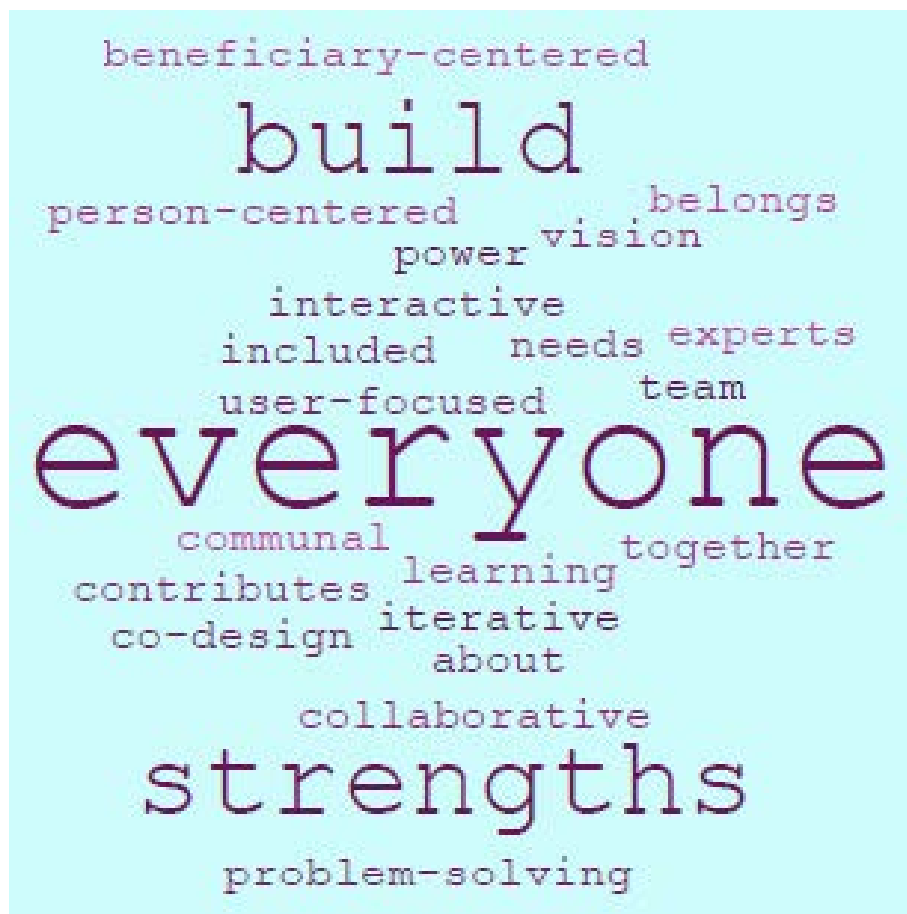
Stakeholders:

- Young People Experiencing I/DD
- Parents/Guardians and Families
- County Developmental Disability Services
- Brokerage Support Services
- Support Service Providers
- Group/Foster Homes
- School Districts and Teachers
- Healthcare providers
- Research Institutions
- Transition Technical Assistance Network
- Advocacy and Community-Based Organizations

SHEIDD Collaboration Strategies

- Participatory Learning Approach
- Human-Centered Design
- Person-Centered Planning Approaches
- Popular Education

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD



SHEIDD Collaboration Strategies

Building Community Partnerships

1. Build Community
2. Designate a Community Advisory Group Coordinator
3. Be Transparent
4. Treat CAG Members as the Experts They Are
5. Be Flexible
6. Find Interactive Ways to Get Feedback
7. Share Power and Resources
8. Celebrate
9. Reflect

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

The CAG Experience



Sexual Health for All



The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD



Results of our
work: What Young
People in Our
Community Want
and Need

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

Community needs assessment: What we did

Questions we asked:

1. Who is the community we serve?
2. What sexual health education and help do young people experiencing I/DD need?
3. What kinds of help do support people need to provide sexual health education and support to young people who experience I/DD?

Surveys and focus groups/sharing sessions with **young people experiencing I/DD** and **support people** (members of support networks)

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD



Do you have a disability that started before age 21?

**Share your knowledge
to help us understand more about the
sexual health needs of young people who
experience intellectual/developmental disabilities.**

Multnomah County's Adolescent Sexual Health Equity Program is doing a new study.

You may be able to participate if:

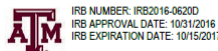
- You are 18-21 years old,
- You experience a disability,
- You live in or near Portland, Oregon.

You would do a survey with a member of our research team that would take about 2 hours. People who participate in the survey will receive a \$40 gift card.

To learn more, please contact April by email or phone:

April Kayser
april.kayser@multco.us
(971) 801-5121

Community
needs
assessment:
How we did it



Community needs assessment: What we learned

Support the Sexual Health of Young People
Experiencing I/DD

1. Provide holistic sexual health education to young people experiencing I/DD.
2. Learn about young peoples' goals.
3. Provide regular skill-building opportunities.
4. Facilitate peer connection.

Community needs assessment: What we learned

Build the Capacity of Support People to Provide Sexual Health Education and Support to Young People Experiencing I/DD

1. Put policies and procedures in place to support the relationships and sexuality of individuals experiencing I/DD.
2. Support collaboration around sexual health education and support.
3. Make inclusive and adaptable education materials and resources available.
4. Provide training opportunities.

Results of our work: Sexuality Education Protocol Tool and Curriculum Review

Community needs assessment recommendation:

Provide holistic sexual health education to young people experiencing I/DD. Recognize young people experiencing I/DD as social and sexual beings by providing them with holistic sexual health education that helps them learn:

- Who they are
- What their rights are
- How to express themselves
- How to build healthy relationships

Curriculum Review: What we did

- Identified the Sexuality Education Protocol (SEP), developed by Pamela Wolfe and Wanda Blanchett
- Brainstormed additional curriculum criteria not included in tool but represent what young people want and need as identified in the needs assessment
- Assigned CAG members to use the SEP tool to evaluate curricula

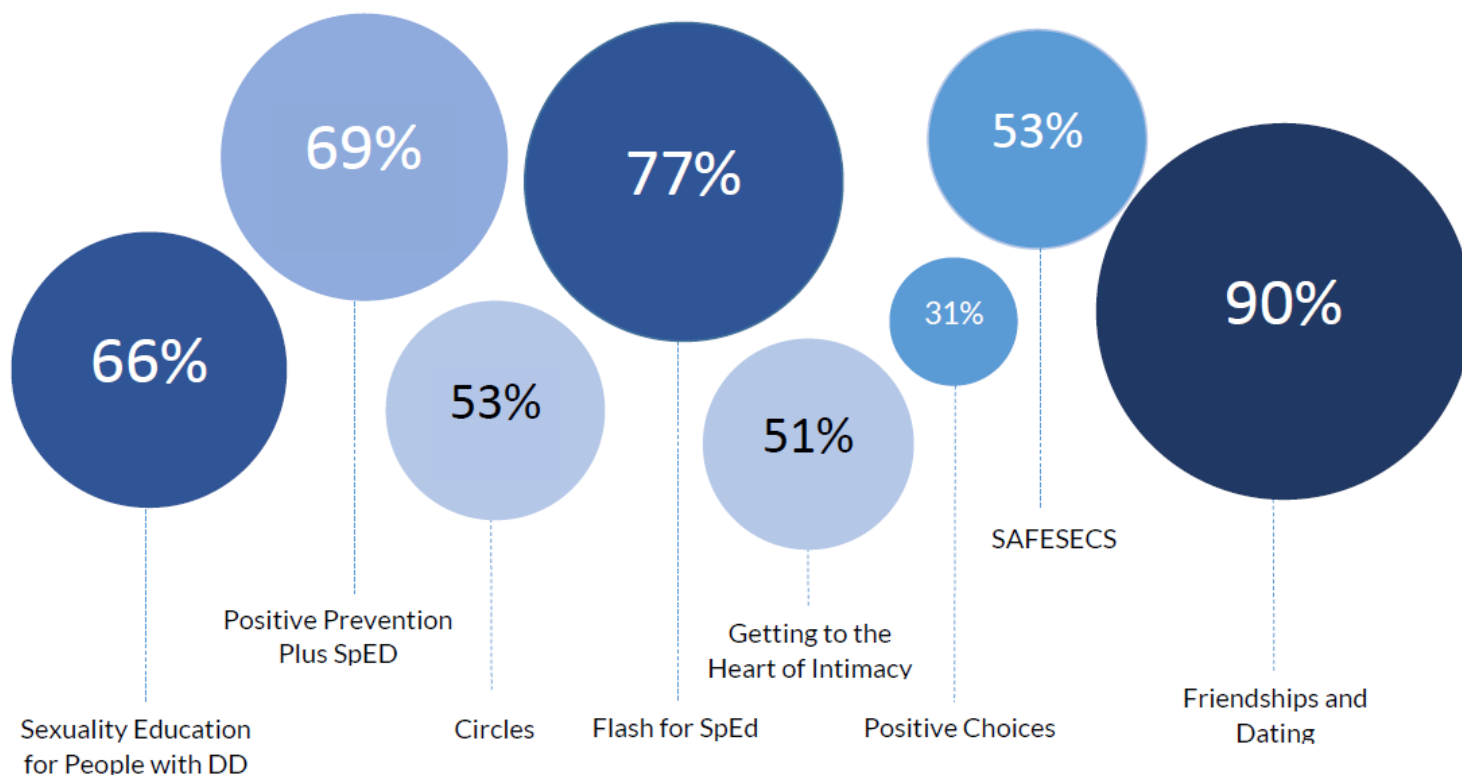
Curriculum review: How we did it

Additions to the SEP tool:

- Was a theoretical framework used to design the program?
- Is the curriculum culturally inclusive?
- Does the curriculum come in other languages?
- Is the curriculum trauma informed?
- Is the curriculum comprehensive / holistic?
- Is the curriculum medically accurate?
- Does the curriculum acknowledge a variety of sexual relationships (i.e. single, married, etc)?
- Is the curriculum relationship rather than pathology oriented?
- Does it include lessons about privacy and right to privacy?

Curriculum review: What we learned

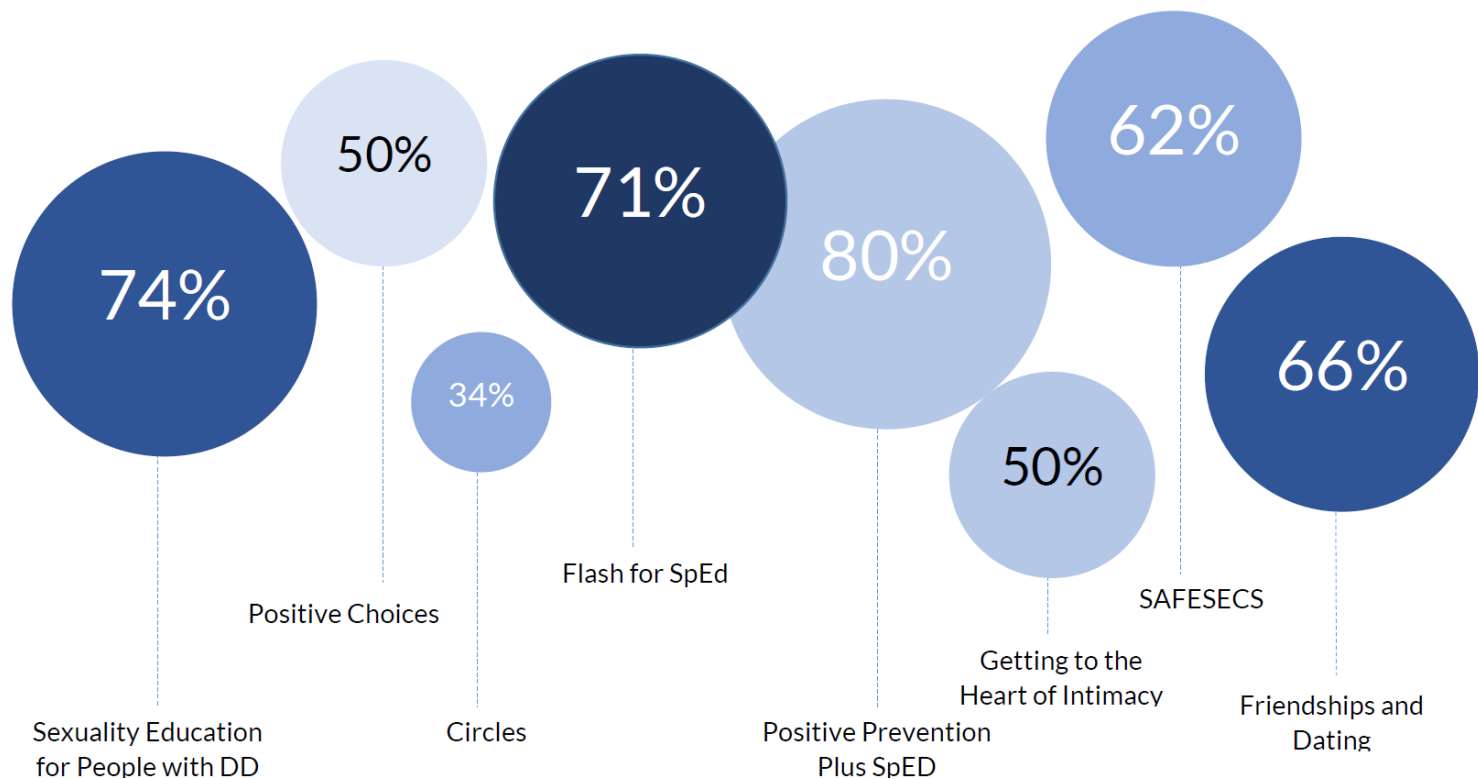
Curriculum overview



The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

Curriculum review: What we learned

Curriculum concepts



The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

Results of our work: Community Education Internship

Community needs assessment recommendation:

Facilitate peer connection. Enhance community inclusion by creating environments where young people have access to accurate, affirming sexual health information and can teach and learn from each other.

Community Education Internship: What we did

- Incorporated PATH Plan goal into Year 2 work plan: build project and community capacity bringing a person experiencing I/DD on to our education team
- Developed stipendend Community Education Internship position

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

Community Education Intern: How we did it

- CAG sub-committee provided input on position description and internship learning objectives, including:
 - Work with community partners to plan and co-teach sexual health education trainings in different settings
 - Help project coordinator with planning and assisting with Community Advisory Group (CAG) meetings and activities
 - Do outreach activities so more people can learn about the iTP3 SHEIDD project and sexual health equity
- CAG participated in interviews and selected intern
- Partnership between MHCD and UCEDD, who provided onboarding support

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

Community Education Intern!



Results of our work: “Team Work” Training

Community needs assessment recommendations:

Support collaboration around sexual health education and support. Provide teams with tools and strategies to have conversations and make proactive plans around relationship and sexual health education and support.

Provide training opportunities. Supporting the relationship, sexual and reproductive health of individuals experiencing I/DD is complicated. Help support people build the skills they need to put all the pieces in place to assist the young people in their lives.

Results of our work: “Team Work” Training

Provide training opportunities

Skills-based training should include:

- Understanding the relationship, sexual and reproductive rights of individuals experiencing I/DD.
- Applying rights-affirming organizational policies and procedures.
- Exploring and clarifying personal and professional values around relationships, sexuality and disability.
- Strategies to clarify the rights of individuals with I/DD and the responsibilities of support people.
- Learning approaches for teaching sexual health education to individuals experiencing I/DD.
- Strategies to collaborate with teams to provide sexual health education to individuals experiencing I/DD.

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

Team Work Training: Working Together to Support the Sexual Health of Youth Experiencing I/DD: What we did

- Two, day-long trainings
- About 20 participants/training; encouraged to attend as teams:

Special Education
Teacher/School Staff
Service Coordinator
Support Service
Provider
Behavior Professional
Family Member
Healthcare Provider
Family Navigator

Social Worker
Adult Foster Home or Group Home
Operator/Staff
Life Skills Coach
Supported Employment Consultant
Research Assistant
Self-Advocate
Health Education Program/Training Coordinator

“Team Work” Training: What we did

Objectives based on community needs assessment:

1. Understand relationship, sexual and reproductive rights.
2. Build comfort, confidence and skill in providing rights-based, person-centered and holistic sexual health education to young people experiencing I/DD.
3. Practice collaborating with teams to support youth sexual health.

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

“Team Work” Training: What we did

Example from Reproductive Justice Timeline Activity



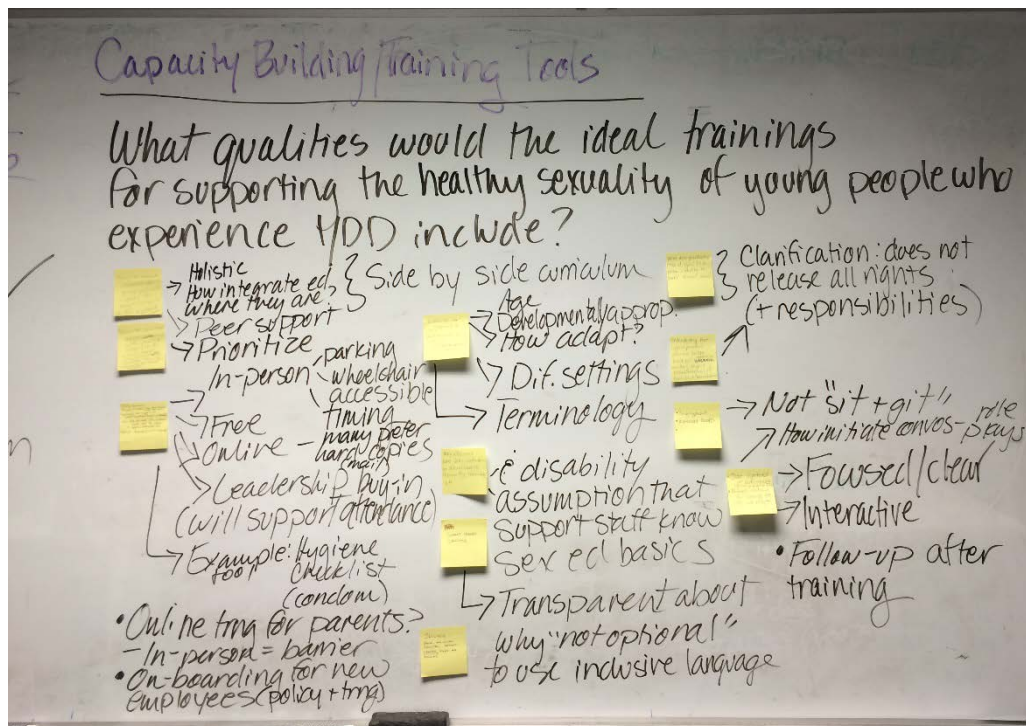
Phoenix and Oklahoma City Indian Health Services use Depo-Provera on Native women with disabilities, despite the fact that it wasn't approved by the FDA. Reason given was for “hygienic purposes” – or to stop the periods of patients with developmental disabilities.

In the 90's – Depo-Provera is given to women of color in public health clinics, often without adequate medical information or consent

Western States Center

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

“Team Work” Training: How we did it



Team Work Training: Outcomes/Results

- Positive feedback: most rated the training excellent or very good
- Strong co-facilitation model:
 - Sexuality educator
 - Support service provider
 - Person with lived experience
- A LOT of content for one day.
- Work to do to encourage inclusion of families, cultures and communities.
- Explain the importance of behavior support better.

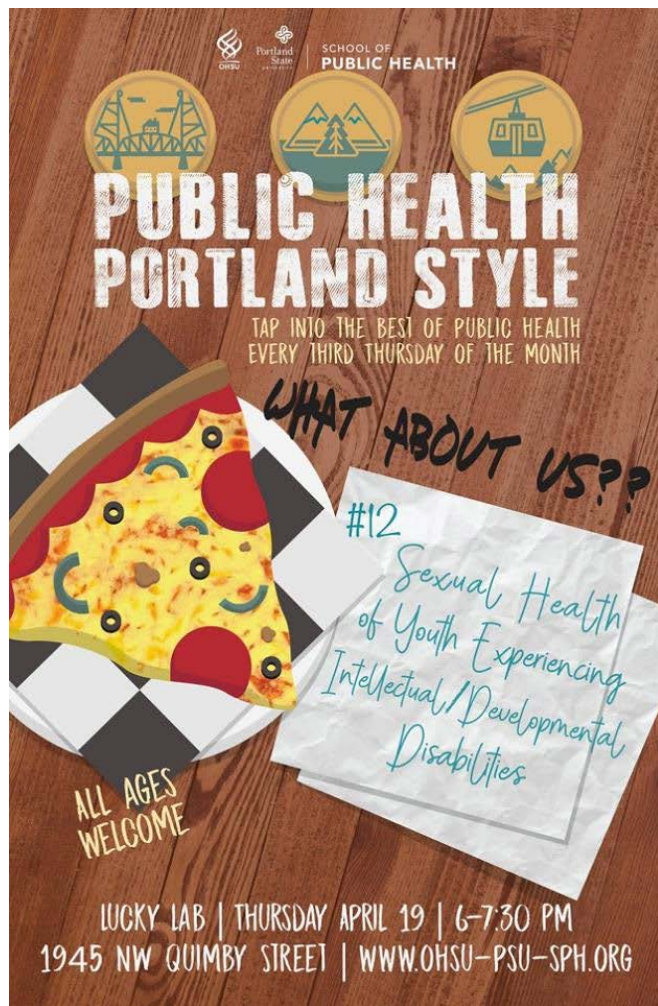
Results of our work: Public Health Portland Style

Community needs assessment recommendations:

Facilitate peer connection. Enhance community inclusion by creating environments where young people have access to accurate, affirming sexual health information and can teach and learn from each other.

Support collaboration around sexual health education and support. Provide teams with tools and strategies to have conversations and make proactive plans around relationship and sexual health education and support.

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD



Public Health Portland Style: What we did

Public Health Portland Style: How we did it

A shining example of community collaboration!

- OHSU UCEDD participation in SHEIDD CAG led to introduction to OHSU organizers
- Presenters included:
 - Shanya Luther, Behavioral Support Specialist and SHEIDD CAG member
 - Nadia Lockheart, SHEIDD Intern
 - April Kayser, SHEIDD staff

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

Public Health Portland Style: Results



Results of our work: Online Resource Hub

Needs assessment recommendation:

Make inclusive and adaptable education materials and resources available. Make sure support people have the resources and teaching tools to provide quality, holistic, affirming sexual health education.

Online Resource Hub: What we did

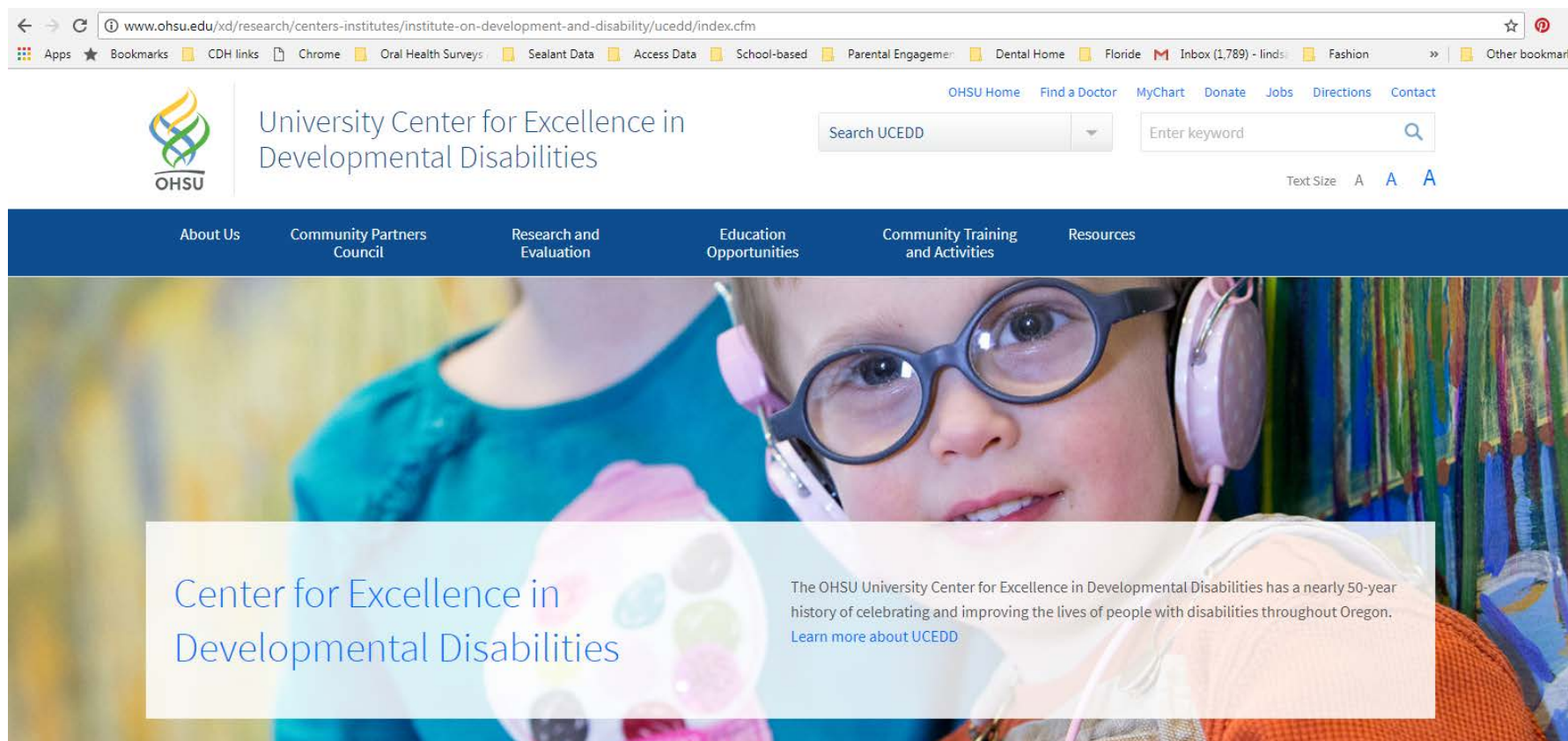
- CAG gave input on criteria that resources should encompass based on needs assessment guidelines
- Developed a rubric to evaluate and vet resources
- Formed a workgroup of CAG members to review and select resources to feature on Resource Hub
- UCEDD will host the Resource Hub for maximum reach

Online Resource Hub: How we did it

- How do resources encourage/include **positive peer connections**?
- How do we ensure resources use **person-centered planning or approach**?
- How will our resources reflect **self-worth**?
- How will we determine the resources **involve a variety of people in sexual health ed**?
- What type of resources **frame sex ed as a basic human right**?

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

Online Resource Hub: Results



The screenshot shows the homepage of the University Center for Excellence in Developmental Disabilities (UCEDD) at OHSU. The browser address bar displays the URL: www.ohsu.edu/xd/research/centers-institutes/institute-on-development-and-disability/ucedd/index.cfm. The page features a navigation menu with links: OHSU Home, Find a Doctor, MyChart, Donate, Jobs, Directions, and Contact. A search bar is labeled "Search UCEDD". The main header includes the OHSU logo and the text "University Center for Excellence in Developmental Disabilities". Below this is a dark blue navigation bar with links: About Us, Community Partners Council, Research and Evaluation, Education Opportunities, Community Training and Activities, and Resources. The main content area features a large image of a young child wearing glasses and headphones, holding a paint palette. Overlaid on this image is a white box containing the text "Center for Excellence in Developmental Disabilities" and a paragraph: "The OHSU University Center for Excellence in Developmental Disabilities has a nearly 50-year history of celebrating and improving the lives of people with disabilities throughout Oregon. [Learn more about UCEDD](#)".

Head, Heart, ACTION!

- **Head:** After this webinar, what is one thing you're thinking?
- **Heart:** After this webinar, what is one thing you're feeling?
- **Action:** After this webinar, what is one thing you're excited about doing to promote and integrate sexual health into your work?

The SHEIDD Project: Building Community Capacity to Support the Sexual Health of Youth experiencing I/DD

Thank you!

- April Kayser
april.kayser@multco.us
- Kiersi Coleman
colmaki@ohsu.edu
- Lindsay Sauvé
sauv@ohsu.edu



Thank you!

Visit the Websites

- AUCD Website: <http://www.aucd.org>
- Sexual Health Website: <https://www.aucd.org/template/page.cfm?id=975>

Questions about the Sexual Health SIG?

- Sexual Health SIG Co-Chairs
 - Julie Atkinson, M.S. : juliea@alaskachd.org
 - Rebekah Moras, Ph.D. : rebekah@alaskachd.org

Questions about the Webinar?

- Anna Costalas: acostalas@aucd.org

Please take a few minutes to complete our survey!