

SEXUAL HEALTH SPECIAL INTEREST GROUP – UCEDD NETWORK SURVEY

Sexual Health and Disability Efforts



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

RESEARCH, EDUCATION, SERVICE

Survey Overview

To find out about sexual health and disability work by UCEDDs:

- Who's doing what?
- What resources to share?
- What still needed?
- Yes/No and open ended text boxes

Explored:

- Community education
- College courses
- Work groups/consortia
- Clinical services
- Other efforts
- Dissemination
- Technical assistance

Response Rate

- A total of 64 UCEDDs completed the survey
 - $N = 64$
 - 69 individuals responded
- 64/67 UCEDDs = 95.5% of all UCEDDs responded to the survey

Work on Sexual Health and Disability

- Does your center work* on sexual health and disability related topics? ($N = 64$)
 - Yes: 64.1% ($n = 41$)
 - No: 35.9% ($n = 23$)

*Work included: community trainings, educational courses, direct clinical services, technical assistance, etc. Both funded and unfunded efforts.

Community Education

- Does your UCEDD do community education about sexual health and disability? ($N = 64$)
 - Yes: 35.9% ($n = 23$)
 - No: 64.1.% ($n = 41$)

Community Education - Audiences

Community education efforts have been targeted to the following audiences:

- Agencies and staff
- Self-advocates
- LEND fellows
- Medical/nursing students
- Parents and families
- Transition and post-secondary students (TPSIDs)
- Victims/survivors
- Law enforcement

Community Education – Activities/Topics/ Partnerships

- Activities: trainings, classes, seminars, webinars, consortia, state coalitions, lectures, courses, database, videos
- Topics: sexual health, sexual self-advocacy, healthy sexuality, puberty, body parts, sexual abuse, sexual safety, relationships, social skills, assertiveness, boundaries, self care
- Partnerships with health educators from:
DD Administration; Independent Living Centers

Community Education - Curricula

- Mentioned as in use:
 1. [Friendships & Dating Program](#) by the University of Alaska Anchorage, Center for Human Development
 2. [Sexuality Education for People with Developmental Disabilities](#) by Planned Parenthood of Northern New England and Katherine McLaughlin of Sexuality and Developmental Disabilities Workshops
 3. [Leadership for Empowerment and Abuse Prevention](#) by Virginia Commonwealth University, Partnership for People with Disabilities
 4. [Illinois Imagines](#) by the Illinois Coalition Against Sexual Assault
 5. [Intimate Relationships & Sexual Health](#) by Catherine Davies and Melissa Dubie
 6. [A Safety Awareness Program](#) by Rosemary Hughes and colleagues.

Community Education – Curricula *continued*

- Several UCEDDs indicated they are currently working on developing materials and trainings
- Several others mention that things have stopped and started over the years, depending on the activities of key people (champions)
- Key staff person: “We have one staff member that has done some training....although this is not a major focus.”

Other Efforts

- Are there other efforts related to sexual health and disability that your UCEDD is involved, directly or indirectly, in? ($N = 64$)
 - Yes: 34.4% ($n = 22$)
 - No: 65.6% ($n = 42$)

Other Efforts Described

- Other UCEDD efforts described included:
 - Doctoral research
 - Training efforts: direct service providers, OB/GYN staff, college campus
 - Sexual health assessment development
 - Research
 - Journal articles
 - Community forums
 - Participation with state networks and workgroups representing disability
 - Collaboration with community partners

Dissemination of Resources

- Does your UCEDD disseminate resources on sexual health and disability topics? ($N = 64$)
 - Yes: 29.7% ($n = 19$)
 - No: 70.3% ($n = 45$)

Materials Disseminated

- Types of materials distributed:
 - Curricula or interventions
 - Articles
 - Assessments
 - Fact sheets
 - Pregnancy materials
 - Offenders materials
 - Websites or clearinghouse of resources
 - Newsletters

Technical Assistance

- Does your UCEDD offer technical assistance related to sexual health and disability? ($N = 64$)
 - Yes: 21.9% ($n = 14$)
 - No: 78.1% ($n = 50$)

Technical Assistance – Audiences

- People with disabilities
- Families
- Direct staff professionals
- Other UCEDDs
- State & local governments
- Group homes
- Media stories
- Independent living centers
- University's Office of Equal Opportunity (Title IX)

Technical Assistance – Types

- Grant writing
- Institutional Review Board (IRB) submissions
- Policy and practice recommendations
- County office of Sexual Health Equity
- Providing resources and materials

Technical Assistance – Quote

- “We have provided technical assistance to group homes related to this topic; also to our university's office of equal opportunity. They have seen an increase in complaints against individuals with ASD by young women accusing these individuals of "stalking". Technical assistance was provided to the case workers regarding nature of ASD, problems with interpersonal boundaries, and how to more effectively communicate with individuals with ASD.”

Future Technical Assistance

- Would you, or your UCEDD, be willing to provide technical assistance to other UCEDDs looking to increase their capacity related to sexual health and disability? ($n = 38$)
 - Yes: 31.3% ($n = 21$)
 - Not at this time: 47.4% ($n = 17$)

Workgroup or Consortia

- Does your UCEDD have a sexual health and disability workgroup or consortium?
($N = 64$)
 - Yes: 15.6% ($n = 10$)
 - No: 84.4% ($n = 54$)

Workgroups and Consortia Efforts

- Informal workgroups described by several
 - “It’s not a formal working group or consortium.”
 - “we are working to build relationships with community partners...”
- Other described beginning work in this area and being in a needs assessment phase
 - “We have convened a community assessment team to work on a needs assessment...”

Workgroups and Consortia Efforts - Partnerships

Partnerships and workgroup members included:

- UCEDD and LEND staff members
- autism programs
- HIV/AIDS programs
- Community Advisory Councils (CAC)
- state and local government departments
- college and university departments
- state coalitions against domestic violence/
sexual assault

Workgroups and Consortia Efforts - Quotes

- “Currently a Graduate Assistant and LEND trainee are forming a work group to establish a website and publish an article.”
- “We have convened a community assessment team to work on a community needs assessment on HIV/AIDS services and supports for individuals with intellectual and developmental disabilities.”

College Courses

- Does your UCEDD offer college courses about about sexual health and disability topics? ($N = 64$)
 - Yes: 12.5% ($n = 8$)
 - No: 87.5% ($n = 56$)

College Course Efforts

- Students with I/DD in inclusive college programs
- Undergraduate courses
 - e.g. Disability Studies minor with capstone “Senior Seminar in Disability Studies”
- Graduate courses
 - e.g. “Disability, Sexuality, & Health”
- Certificate programs
- Workshops through partnerships

College Course Efforts *continued*

- More workshops and singular trainings offered than actual university coursework e.g. partner once a year with a continuing education department to do a workshop for the certificate on IDD program
- Range: emphasis on how social-political-cultural-historical systems shape approaches to sexuality and disability, *Verses* emphasis on individual vulnerability and support

Direct Clinical Services

- Does your UCEDD offer direct clinical services for sexual health and disability related work? ($N = 64$)
 - Yes: 12.5% ($n = 8$)
 - No: 87.5% ($n = 56$)

Direct Clinical Services - Clinics

UCEDDs associated with clinics:

1. Alaska
2. Iowa
3. Illinois
4. North Carolina
5. Nevada
6. New York (Rose F. Kennedy)
7. Oregon
8. West Virginia

Direct Clinical Services - Described

- Centering families and individuals
- Behavioral collaborations with school district
- Including trauma education
- College coursework for students with I/DD
- Utilizing graduate students in clinical settings
- Assessments on sexual health topics
- Support groups
- “...[pediatric department] provides clinical services and some of the patients may be PWD.”

Clinical Services for Sex Offenders

- Does your UCEDD offer clinical services for people with disabilities who are also sex offenders? ($N = 64$)
 - Yes: 6.3% ($n = 4$)
 - No: 93.8% ($n = 60$)

Offender Services Described

- Counseling services offered:
 - “Some clients... may be sex offenders and part of their counseling would include issues of sexual health.”
- Legal and justice system support:
 - “We work with individuals with challenging sexual behaviors and convicted sex offenders to ensure they receive equal justice under the law and provide supports to both victims, witnesses, and alleged offenders with IDD.”

Offender Services – Quote & Resource

- “Not clinical, but part of Money Follows the Person working on placing offenders in the community. and as part of [state] contract worked with local corrections and disability services this was a very important topic of interest, including one meeting that was about sexual offenders with ID. Also interest in the aging population to understand more relating to nursing home, home care, etc.”
- AEquitas: The Prosecutors’ Resource on Violence Against Women
 - <http://www.aequitasresource.org/>

Areas of Capacity Building

Are you, or someone at your UCEDD, interested in developing capacity in any of the following areas? ($N = 50$)

- Community education: 98.0% ($n = 49$)
- Workgroup or consortium: 60.0% ($n = 30$)
- College courses: 30.0% ($n = 15$)
- Direct clinical services: 30.0% ($n = 15$)
- Other: 22.0% ($n = 11$)
 - research, support within inclusive college programs (TPSIDs), training for medical students, pre-service, continuing education, and policy development for agencies

Support from the Sexual Health SIG

What support could the AUCD Sexual Health SIG provide to build this capacity within your UCEDD?

- Funding
- Emerging research, resources, projects
- Curricula development (promising practices, research and evidence based)
- Multistate collaboration
- Discussion opportunities
- Community needs assessments/gap analysis
- Train the trainer resources

Support from the Sexual Health SIG - Quotes

- “We would love to collaborate with other UCEDDs in a multi-state research project to compare and contrast sexual health education programs and how they are received and the impact they have in the local communities.”
- "We work on disability parenting issues but I've noticed a significant (and interesting!) gap between disability sexuality work and work centered on disabled parenting. There should be more of a bridge and I'd like to be part of building that up if possible. If members of your SIG have ideas, I'd be happy to collaborate."

Support from the Sexual Health SIG – *Quotes continued*

“It would be wonderful if there is a funding opportunity through AUCD that could provide us with some money to dedicate more of our staff time to build capacity in this area. We have been doing a lot in addition to all of our UCEDD work, though a dedicated grant or funding would really help to build capacity.”

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