



## **ADOLESCENT HEALTH AND DEVELOPMENT**

### **PANEL QUESTIONS – PANEL #2**

### **ADOLESCENTS WITH DISABILITIES**

1. What are the roles that parents play in the sex education of adolescents with disabilities? Is there support, fear, or misunderstanding of their children's needs? What kind of support are the parents given?
2. How is the development of social skills incorporated into sex education for adolescents with disabilities? What steps are taken to improve self-esteem and/or self-efficacy?
3. Can you discuss the way youth with disabilities may lack self-esteem in dating, and how this (or other social situations) may contribute to depression and/or social isolation? What steps can be taken to mitigate this?
4. Sexual education for youth with disabilities generally does not include relationship and dating skills, yet that is what many disabled youth have reported wanting from their sexuality education courses. Should this be included in sexuality education?
5. How might sex educators make relationship and dating skills culturally relevant to the many different populations of disabled youth who may have different cultural norms around dating and relationships than the mainstream, middle class, predominantly white norms?
6. According to the AddHealth data that Dr. Blum showed in class, disabled youth were more likely to report same-sex attraction than other youth. How might this be incorporated into sexuality education curricula with disabled youth?
7. For youth with severe mobility impairments, who may use personal assistants or other caregivers to aid in mobility, should these caregivers play a role in facilitating movement during sexual interaction? (Body placement, use of sex toys and other devices) If so, how and where might these assistants be trained in this area? What if parents are those caregivers? How does one facilitate sexual interaction for those youth without placing undue awkwardness on parent-child boundaries around sexual behavior?
8. Blum's article cited several deficiencies in the provision of comprehensive care to young adults with disabilities-connection to community resources, sexuality education, and planning for transition services. How are adolescents and young adults with disabilities currently receiving sex education? How are they connected with community resources, and what resources/services exist?
9. Blum's chapter and Zola's stories highlight the importance of social inclusion and social skills for adolescents with disabilities. What are some of the advantages and disadvantages of "pulling out" adolescents with disabilities for special services (occupational therapy, tutoring, etc)? Or of going to a separate school or being taught in a separate classroom?

10. Which services, programs, support, or other factors do you think are critical for the healthy development of children and adolescents with disabilities? What helped you get through transitions in adolescence such as puberty, high school graduation, etc.?
11. What are some of the social barriers that young adults with disabilities experience in seeking employment and higher education? What can be done to eliminate these barriers?
12. Since young adults who are intellectually impaired are especially vulnerable to sexual exploitation, shouldn't there be stiffer laws and penalties to protect youths with disabilities from being molested? Who would be eligible to testify, parents, caretakers, the youth? Is this legally feasible? Are there any cases as such?
13. Realizing that young adults with physical conditions still possess reproductive capacity how to we communicate this to parents so they can make the choice to utilize contraceptives?
14. The article suggests that youth need to have a comprehensive education. Wouldn't it be necessary as well to provide parents with the same information so that a possible open discourse may begin between parents and youth in the transition to adult hood? I would think communication should be and important component.
15. What kinds of resources and support are available to parents of children with disabilities? (On the Internet, through community centers)?
16. How have attitudes changed over time regarding sexuality education for children with disabilities? Have you noticed any trends?
17. What are the current policies that most affect children with disabilities?
18. What do you think are the biggest challenges for children with disabilities? In education, sexual education?
19. What legislative or attitudinal changes, if any, do you recommend need to be made to better meet the needs of children with disabilities?
20. How do we develop a society in which socialization of youths with disabilities is practiced when there is a tendency to enroll these youths in specialized schools in which their peers are as disabled or more disabled than they? It would seem we would need to do more than provide wheelchair access to some buildings but more healthcare providers available to assist at regular schools.
21. One study in 1996 (Suris et al), claimed that rates of sexual activity in adolescents with disabilities was the same as adolescents without disabilities. With this thought in mind, sexual health education seems to be an ideal program to sustain. However, another study also claims that adolescents with disabilities are at higher risk for riskier sexual behavior with serious consequences. Should the sex health education program be altered for the children with disabilities so that it places a heavier emphasis upon abstinence and safer sex programs?

22. For adolescents with disabilities, the severity of the disability typically has a negative correlation with the IQ. As a result, theories have suggested that this gives adolescents with milder disabilities the capacity to grasp mainstream sexual health education. However, other perspectives argue that the psychological and cognitive capabilities of an adolescent with a disability, regardless of the mildness or severity, is still significantly more vulnerable than a normally developing adolescent and thus should not receive the mainstream education. Which viewpoint do you agree or disagree with? Do you also believe that psychological capacity is significantly more unstable for children with disabilities?
23. Dr. Blum mentions in his paper that disability can be “operationalized” in three different ways, that is, to typify the disability so that it can be better defined. He defines the three subcategories as: Functional limitations, compensatory mechanisms, and service utilization. For adolescents with disabilities, do you think that disabilities that fall under all these categories can assay sexual health education effectively? Or do you believe that one category will be more capable than the other?
24. In order to reduce the risk of certain events such as sexual abuse, at what age should sexuality be addressed in children with disabilities? Could you say that their disabilities make them more vulnerable to sexual risks?
25. If are intent is to try to create a shield of normalcy around children with disabilities how does having sex surrogates and special classes affect that shield and what emotional effects does it have on the children.
26. Seeing that children with disabilities are having sex earlier, what accounts for the trend could it be a need to be included and do what they think the other kids are doing, or doing it first to be cool. Would including social skills classes in sex ed classes help to temper the trend and our would these skills help to facilitate sexual relationship adjustment? Does helping facilitate these relationships then now put CWD at high risk for STI and such?
27. CWD have enormous parental input in decisions concerning their health and life but if they are intellectually capable. How involved should parents be in the decision to have sexual education and/or sexual surrogates?
28. Given that many people with disabilities have caretakers who are constantly watching over them, how do people with disabilities manage to maintain some degree of privacy while engaging in sexual activity with their partner? Are there any differences in the extent of privacy given when both partners are disabled as opposed to only one partner having a disability?
29. Given that there are a huge variety of disabilities- chronic illnesses, emotional disabilities, physical disabilities, learning and behavior disabilities, etc.- how do sex educators break down their curriculum to cater to people with specific disabilities? Have there been any pamphlets or booklets published for youth with disabilities which go over the basics of sexual health and risk?
30. According to Robert Blum's paper, Adolescents with Disabilities in Transition into Adulthood, adolescents who are intellectually impaired are more vulnerable to sexual exploitation. Given this information and the knowledge that youth with disabilities

are especially prone to being sexually abused, what is currently being done to stop sexual predators that target disabled people? What information is given to people with disabilities and their families about the danger of sexual abuse?

31. At what level of mental functioning, should a young person who is mentally retarded be considered to be competent enough to make decisions about sex? How do we know such a young person has the competence to consent to sex?
32. Given the physical needs and the consequences that pregnancy can have on health and functioning for young people with some disabilities, should parents of children with such disabilities be more involved in decisions to engage in sexual activity. As an example, is it ethical to waive certain rights to privacy that adolescents without disabilities have? If not, what efforts should be taken to further ensure physical health without limiting sexual choices?
33. What role do sexual surrogates play? Should these surrogates be adults or adolescents?
34. Based on data from Blum's paper, *Adolescents with Disabilities in Transition to Adulthood*, in 2003, why do you think it is that women with disabilities showed no significant difference in unemployment rates compared to women without disabilities in Great Britain by the age of 36?
35. What programs, if any, exist to promote the development of coping behaviors in adolescents with disabilities given that this seems to enhance social adjustment?
36. If young adults with disabilities are no less likely to engage in sexual activity than "normal" young adults, how do pregnancy rates compare between the two groups?
37. Considering the current climate, where it is difficult to maintain real education and open dialogue around adolescent sexuality, was there anyone in a school or institutional setting that was able to provide you or any of your friends with worthwhile information and/or helpful dialogue? If there was helpful dialogue or information, what was it that made it useful?
38. If sexual education is provided for non-disabled adolescents in school, is it not discriminatory to provide comparable education for disabled adolescents?
39. As self-stimulation is condemnable in some religions how would it ever be allowed in sexual education material and teaching?
40. It has been realized that parents are neither comfortable nor adept at providing sexual education for their adolescents. Within this context, how can we assume that parents of adolescents with disabilities will assume the responsibility for a more "focused" sexual education?
41. Can people without disabilities ever teach sexual education to those with disabilities? What about people with different disabilities?

42. Should we teach the non-disabled how to be appropriately sexual (in a consensual setting) with the disabled? Should this be included in routine sexual education?
43. Can we clarify the relationship between the increased prevalence of disabilities and ethnic diversity, single-parent & less educated family dynamics, and/or poverty? Is there a causal link here?
44. Is there a clear point in time where most youths develop their disabilities? Pre- or post-natal, or during a certain point in childhood?
45. Is there any insight into why the prevalence of same-sex attraction is higher among youths with disabilities?
46. At what age should sexuality education start for children with disabilities? Earlier than other children, later or at the same time?
47. Should the content of the sexuality education be the same for them irrespective of the type of disabilities, or should it be individualized depending on type impairment or level of disability?
48. Children with disabilities are at a greater risk of being sexually abused. Is this because they have a low self esteem and are thus more vulnerable? If so, are there programs geared towards raising their self esteem?
49. A network among people with similar disabilities has the advantage of helping them to share their problems, but it could also provide room for self-pity and dissemination of negative information about their condition. Is it therefore necessary for such children to avoid these networks and be exposed to whatever conditions their peers are exposed too?
50. What are the logistics involved in reducing the handicap of children with severe physical impairments like cerebral palsy and spina-bifida in developing countries?
51. Given that sex education in public schools is a highly politicized issue; do you think that sex education for adolescents with disabilities can be more comprehensive and effective if it is provided by non-governmental organizations? Are there NGO's that provide such services?
52. How do you think US schools should change to become more supportive and hospitable to children and adolescents with disabilities?
53. What can be done to help young people with disabilities build supportive social networks in their neighborhoods, in their workplaces, and among their peers?
54. Do you think it is best for adolescents with disabilities to get sex education from educators who are themselves coping with a disability, from educators coping with ANY disability, and/or from educators with no disabilities?
55. We have learned how historically there has been a very powerful lobby supporting disability legislation. Has this resulted in adequate or excellent resources related to sex education and adolescents with disabilities, or do policy deficits still remain and if so, what are they?

56. Has society's stereotypes on sex and gender roles changed over the years? How do society's sex-role stereotypes affect adolescents with disabilities?
57. How do gender differences impact how sex education is taught to adolescents with disabilities?
58. Should sex education for adolescents with disabilities differ from sex education for adolescents without disabilities?
59. In class we talked about the greater need for social skills instruction to adolescents with disabilities so that they learn how to locate a partner and maintain a relationship, than instruction on STD prevention or HIV prevention. In your experience, have you found this to be true and if so, can social skills instruction be incorporated into sex education?
60. Stated in class today, the major problem of those with motor impairments and other disabilities is not the sex act, but the inability to locate a partner. Given this statement, should disabled students be placed in classes of other disabled students? Or should they continue to be exposed to non-disabled students in regular classes? What are the benefits of each?
61. For the non-disabled, should education in disability be taught in schools or be socially learned? What are the benefits of education in disability for those who are not disabled? How does one implement such a program in school?
62. Do you think society (ie: schools, teachers, parents) focuses too much on the person's disability and not on other factors such as sexual health, physical games, etc.? Does society focus too much on teaching disabled persons about coping abilities? Should a disabled person's education be any different than a non-disabled person's?
63. How has the advent of the internet (including features such as e-mail and instant messenger) influenced the ability of adolescents with disabilities to learn about sex and form sexual relationships? Does it help them connect with their peers who are in similar situations? Are there any educational websites intended specifically for this purpose? Is such information available to adolescents with disabilities who are unable to use a keyboard or mouse?
64. According to Dr. Blum's Nov. 28th lecture, the general public considers adolescents with disabilities not to be sexual. Is this notion harmful to such adolescents in terms of sexual development? Does it hinder their ability to form sexual relationships? In your opinion, how might this public notion be changed?
65. In your opinion, what is the best forum for adolescents with disabilities to learn about sex: school, home, the internet, support groups, etc.? Whose responsibility is it to teach adolescents with disabilities about sex: parents, teachers, peers? Should sex education (and abstinence-only) campaigns include components for adolescents with disabilities?
66. How does the sexual experiences of adolescents with disabilities in developing countries differ from the experience those in industrialized countries? Are they more or less likely to be sexually experienced? Do they have more or less access to information about sex and

contraception? What sort of support services could be implemented to address the issue of sex and disabilities in developing countries?

67. Are adolescents with chromosomal sex disorders (e.g. Klinefelter's Syndrome) considered to have a disability? Do these adolescents face specific challenges in terms of sexual knowledge, initiation, and activity? What sort of services might be offered to such adolescents to help them cope with the sexual effects of their condition (mental, medical, etc.)?
68. To what extent do "acquired" disabilities (e.g., from trauma, accidents, etc.) account for the total number or percentage of adolescents with disabilities?
69. Is it "acquired" disabilities (e.g., traumatic brain injury) that accounts for the increased risk for disabilities observed among: non-whites, children of parents with lower educational attainment, children of single-parent households, etc.?
70. What should be the appropriate rates of educational attainment and employment for adolescents/adults with disabilities and to what extent is this attainment limited by discrimination?
71. What accounts for the differential rates of educational attainment and marriage rates between males and females with disabilities?
72. Since many young adults with mild to severe disabilities are in school and should be receiving sex education through the curriculum, what accounts for the lack of knowledge and accurate sexual health information that they are receiving?
73. For those children who are not in ordinary public or private schools and who are in schools with other disabled children, what should be the nature of their sexual education? Should it come from teachers within the school, or, alternatively, should a nurse or public health educator be brought in to specifically present sex education to young adults? If a nurse is brought in, are they educated specifically on targeting this disabled audience?
74. Blum (2003) reports that protective factors are important for influencing whether or not young adults with disabilities will develop psychological distress and emotional problems. How can a protective factor such as "seeking social support" be encouraged within schools to promote adolescents with disabilities to learn positive coping styles and build social relationships? Should there be after school groups for kids with disabilities or would this promote further social stigma associated with the handicap?
75. During the transition from school age to adulthood, what type of support is available in the community for sex education as well as job and educational information/placement for specifically low income young adults with disabilities (since family income is documented as one of the most important factors which negatively impacts this transition)?
76. Mental impairment, especially mental retardation puts young adults at great risk for sexual exploitation. What programs are in place in schools or other facilities to target safe sexual practices including contraception and self-advocacy (saying "no" to advances) for young adults with mental disabilities?

77. Youth participatory evaluation projects, which actively engage community members such as adolescents as collaborators and leaders in public health research and practice, hold promises to improve current public health programs and their materials which may be developmentally or culturally inappropriate. Can utilizing learning disabled adolescents' participation in a type of evaluation in which these young people engage in assessing their programs work as well to have a better understanding of sexual behaviors of target population and their negative consequences? How can we understand their needs if those kids may not necessary be capable to perceive their sexual problems and express them?
78. Not so long time ago in Japan, a female teacher who instructed 'Body Song' at special class at elementally school was forced to resign. 'Body Song' had been employed as an empirically effective method to teach kids with learning disability what parts of their bodies should not be touched by others. This method had successfully helped those kids to report it to their parents or teachers when/if they experienced sexual molestations or assaults. In the US, disability lobbying is powerful; however, how to start to change social norms, systems, and policies in countries where disabled population is still a socially ignored population?
79. One out of six of youth in a general population in the US have a chronic condition, and of whom 5 % have functional limitation. How to protect those kids who have social and/or behavioral disability from committing a crime? Is there any law which mandate to provide life-time supervision/supports for those kids? How to balance their human rights and legal obligation of parents?
80. Developing a social skill to allow those who have functional disability to have normal social relationships is a central issue in sex education interventions. What should we plan a sustainability of those interventions to be?