California Deaf-Blind Services

reSources

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# Taking the Fear Out of Sex Education

*Maurice Belote, Educational Specialist*
*California Deaf-Blind Services*

### *What is sex education?*

Sex education is a comprehensive program that prepares people for satisfying, enriching, and complete lives. It goes far beyond the four subject areas that most adults experienced as children in school: anatomy, physiology, puberty, and reproduction. A comprehensive sex education program has a wider scope, teaching skills such as developing and maintaining friendships, personal and community safety, prevention of abuse and exploitation, physical and emotional intimacy and, most importantly, being in control of your own body. A sex education program provides the information that others need so that they might have the kinds of lives that any of us would wish for ourselves.

### *What's in a name?*

Sex education is called many things. It is sometimes referred to as social/sexual education, which rightly illustrates the ties between social skills training and sexuality. Social skill instruction usually includes the basics: handshaking, establishing appropriate distance, development of appropriate touch, etc. However, for the purposes of this article, the focus is on the sexual half of that program, which generally receives less attention than does the social skills component of such a program. Sex education is also frequently called family life education. This is a term that takes the word sex out of the title which may make the idea more palatable to those who are hesitant to broach the subject. While all of these titles have the same final objectives, for purposes of clarity, this session will refer to the program simply as sex education.

### *Why is this issue so important?*

Not surprisingly, most of us are uncomfortable talking about sexuality, but ignoring social/sexual issues doesn't make them disappear. No one wins when these issues go ignored. Students are left with misconceptions and sketchy knowledge. Families are left to try to teach these skills at home without the benefit of quality, relevant instructional materials. School and community programs are left with students and clients who may ultimately fail because the system failed them, by not providing them with the information they needed in order to become well-rounded, competent members of society. There is a perception that people with disabilities also have sexualities that are disabled, and this is almost always not the case.

Most people, including children and young adults, learn most of what they know about social relationships and sexuality through incidental learning and through the media (film and television). Individuals who are deaf-blind may not have the advantage of some or all of these modes of learning. For individuals with disabilities who may also have had unsatisfactory past experiences or limited experiences, these often subtle social skills must be systematically taught. To complicate matters further, issues of sexuality and human relationships are often demonstrated and learned through very subtle means, which may be especially difficult for individuals with vision and hearing loss. For instance, persons with normal vision and hearing rely heavily on body language, tone of voice, subtle facial expressions, and subtle visual signals when interpreting social situations.

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# Inappropriate Sexual Behaviors

*Mary Maussang, Teacher*
*San Diego Unified School District*

You can imagine my thoughts when I was asked to write about dealing with inappropriate sexual behaviors. Couldn't I write about language development or eating skills? However, after I thought about the topic, I realized that I approach inappropriate sexual behaviors in the same manner as any other inappropriate behavior. We target the behavior we want to change and create a behavior modification program for it. We aim for a fast result due to the uncomfortable nature of the topic.

We must remember that behavior modification programs are individualized. What works for one child may not work with another. Two key elements to any successful behavior modification program are motivation and reinforcement. We need to find rewarding reinforcements that will motivate the student to stop the behavior or to do the behavior at a different time and place. Consistency is mandatory once the behavior program has been established.

Model appropriate touch or demonstrate proper space when a student consistently invades our personal space by standing too close when communicating with us.

Photographs can be taken with appropriate and inappropriate behaviors to give a visual reminder. Videotaping the student takes "modeling" to another level, because they are the model for themselves. Appropriate behaviors can be reviewed by the parents and teachers and then reinforced. Inappropriate behaviors can also be discussed in a more comfortable setting. Repetition is often necessary for progress. The videotape or photos are an easier way to deal with these types of behaviors.

Videotapes and photographs provide visual cues. Using visual cues provides an excellent strategy to develop language. In most cases, the student is doing the behavior because they don't understand what is expected. Receptive and expressive language can be developed when watching the videos. (Remember, receptive language develops before expressive language.) The parent or teacher can pause the tape and discuss what is on the television screen. It is also much easier to communicate with a student when they are not doing the targeted behavior.

Hopefully, this information will guide you to a more successful experience. Remember to have a positive attitude and the belief that your child can progress. ❖

# Puberty Again??

*Jackie Kenley, Parent,*
*California Deaf-Blind Services Staff*

I have been through puberty twice, once with my seventeen year old son and again with my thirteen year old daughter. Now I am experiencing puberty with my eleven year old daughter who is deaf-blind...I am not ready for this!

Fortunately, my daughter's teacher is helping me address this situation by discussing it openly, giving me shopping lists for things that I don't want to buy for her and making me realize that this is going to happen. Also having two other very honest teenagers in the home is a positive although startling influence. These two teenagers will not put up with things that Mom will, such as allowing their sister to appear in the home without a "stitch" on. In Mom's mind, Laura is that sweet little adolescent who is able to run around naked. From the honest teenager's viewpoint, she is starting to mature physically and at that point in one's life when modesty is all important.

Others in Laura's circle of friends and acquaintances have pointed out the obvious physical trend towards adulthood and I have to agree. Although, it is difficult to equate these changes with those of other kids because she seems oblivious to the change.

Laura also seems unaware of what is acceptable in public and what is not. Therefore we have made rules for "private time" for items that are used for stimulation. In other words, it is a rule: to use these things she must be alone in her room. Since much of the world seems private to her because of dual-sensory impairment, we need to help her understand this distinction.

Laura lives at home and I have difficulty imagining her in a residential setting. However, it is our dream and goal that she someday live in a supported living situation. I admit fears of trying to teach her privacy about her body so that she will be safe in these situations.

Our daughter has CHARGE Association and there are many questions as to how her puberty will progress. I understand this is another maze through which I will need much advice from the medical community and I realize that there are questions for which they will have to guess at the answer. We concentrate so much on her other health problems such as heart and ears but this area needs to be addressed.

Again, I am reminded to take one step at a time and to see this as a natural passage in life rather than a problem, and to use all the resources available to search out the unique answers for a unique and wonderful girl as we navigate this passage together. ❖

# Sexuality and the Deaf-Blind Child

*by Heidi A. Sherrie, Adult Deaf-Blind*

When I was asked to do an article on sexuality, I had to give it a great deal of thought as I have touched on some of the aspects regarding this issue as a disabled person throughout my life. What advice can I give to the parents of a deaf-blind child? The most basic thing you can do for your child is to be straightforward, not to pretend that he doesn't know anything about sexuality. Don't assume that a disabled child would be without any sexual feelings or not have the capability to be a sexual human being. Make it an open issue in the household. There will come a time when your child, like any other child, will start to ask you questions about sex, especially in the adolescence years. Then they will have sexual relationships in their adult life.

I do recall as a child, around seven or eight years of age being aware about sexuality. We had an excellent book for children in our home library and it really explained how we came to be. The pictures were simple and colorful in illustrating this concept. I enjoyed the book so much that I would read it again and again. My mother would read it with me at first, then I read it on my own. By the age of nine I had a basic idea of what sexuality is all about. Yes, I was naturally curious about sexuality and I would try to observe rabbits in the act and then watch them have litters. To me it was part of my growing up and I believed that sexuality was a natural part of our lives.

I never knew that child abuse had a name until I was in high school. I had a good upbringing but outside of the home I witnessed some form of abuse and as a child I didn't know what to do. When I was six and was placed in a deaf-blind class there was a young deaf-blind girl who was fifteen, the oldest pupil in the class. She lived near my home and also had a teenage deaf cousin. This cousin and his two friends were bullies and were rough. There were about five of us who rode the two hour commute back and forth to school. The girl's cousin and his friends took this as an opportunity to exploit her. I had to watch her struggle and try to cope with the boys' roughness. Not even the bus driver did anything about it. I didn't talk about it until I was in high school.

The example I just described can happen to your child. Any child having a disability can be at risk to be sexually exploited by anyone who thinks that this child won't squeal on the abuser. When it comes to some deaf-blind children, tactile techniques are used in order to communicate. (Being close to adults or using tactile sign language.) This does give a potential abuser the right to use these techniques as an opportunity to inflict abuse. I don't mean to alarm some parents but these are the possibilities.

What can you do to prevent your deaf-blind child from possible abuse? First, make sure that the school or day-care center has strict background checks for employees. They will ask employees to swear that they have not been convicted of a felony. Then a fingerprint check can be used for any matches to a criminal record. This is designed to weed out our employees who may be potential abusers.

Second, teach a child the difference between a good touch or a bad touch. A good touch is hugging, shaking hands and using hands to communicate. A bad touch is touching private parts and feeling under clothes. That would be uncomfortable for the child as he will not know what is happening. As a parent, I know it will be a difficult subject to teach but it is important for the child to know in order to protect himself from abuse.

Third, tell the child that if a person does these things that are uncomfortable, the child can say no and get away from the person. He can tell you or someone he does trust. Emphasize that it is not his fault and that you, as a parent, will not be angry at the child if that happens. The person who does this will be punished.

Like any other adolescent, I went through the same process and I became aware of myself and my own sexuality. I dreamt of having a boyfriend, went through some crushes and dreamt of being the most attractive girl in school. These thoughts were normal. In fact, I never dated in high school but had a good social life going to parties and being with friends. Emphasize using birth control or abstaining from sex if your teen is sexually active and continue to have an open communication on this subject.

I did wonder if I would ever find a man who would accept me for who I am and would love me for my intelligence and personality. It took me two colleges and two men (who weren't right for me) before meeting my future husband at a friend's wedding in Texas. I was about 27 at that time and I married him three years later. If you have concerns about whether your deaf-blind child will ever have a boyfriend or marry the right person, give it some time, as it depends on him or her. The grown up child will be frustrated at times and he or she will need your reassurance that he or she is a terrific person and the important thing is that your child be happy in life. Just be patient and eventually the right partner will be found. ❖

# Sex Education

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*Why isn't sex education taught in most school programs?*

Many special education programs serving students who are deaf-blind and may also have physical and cognitive challeneges do not have systematic, planned instruction in the area of sexuality. Programs that do include sex education generally focus instruction for students who are nearing the end of their public school careers (i.e., ages 17 to 21). For students who are fully included in general education programs, the situation is not always better. The standard sex education units that most students receive in public schools may not always be adapted or modified for persons with significant disabilities. These units also do not always include the specific supplemental information required to meet individual needs (e.g., identification and use of the Circle of Friends process, concrete training in purchasing contraception, etc.). Students who are fully included are sometimes simply excluded from sex education instructional programs because school staff members decide that the information is not relevant to students with disabilities.

There is a fundamental paradox in the absence of sex education programs in school programs. When a person with disabilities loses employment, volunteer work, and/or community living arrangements, the reason cited is often related to the person's lack or perceived lack of social (or social/sexual) skills. Even when the cause is not identified as relating to social/sexual skills, needs in this area are sometimes at the root of the problem.

There seems to be a number of significant barriers to the initiation and year-to-year continuation of sex education programs. While it probably is not necessary or beneficial to dwell too heavily on these issues, identification of these and other barriers will help to facilitate the identification of solutions for overcoming these barriers.

**Barrier: We feel embarrassed talking about sexuality.** Most of us do not feel comfortable discussing issues related to sexuality, especially with our own children or the students we teach. Many adults were raised with the view that these issues are discussed only in more private settings and under more intimate circumstances.

**Barrier: We feel uncomfortable about our own sexuality.** It is only natural that we bring a little of ourselves to everything we teach. Issues of sexuality are very personal and, therefore, any discomfort we feel about the topic will likely be evident to the students we serve. Of course, level of comfort is influenced greatly by the way each of us was raised, including cultural factors, religion, family dynamics, and our own positive and negative history of relationships.

**Barrier: We do not feel competent to teach the subject.** Most of us are not experts on the subject of sexuality, and we may not know where to turn in order to supplement or update our knowledge base. If we depended on teaching what was taught to us, most of us would be significantly hindered in our attempt. For most teachers or agency workers, there is little focus on the subject of sexuality in higher education unless community colleges and universities offer specific courses that we happen to take as part of the general education requirements.

**Barrier: We have a hard time accepting that our own children or the individuals we serve are or will be sexual beings.** In essence, we feel uncomfortable about the sexuality of the students (children, youths, and young adults) we serve. This is probably partially due to the fact that we don't have a clear image of what the future holds for these individuals. Not every student who comes to us has had the benefit of a systematic Personal Futures Planning process or MAPS process. Therefore, it is not always clear what skills the students will need in order to succeed. Over-protectiveness on the part of families and/or school staff also affects how we view the future of those we serve.

**Barrier: We do not fully understand how other curricular areas relate to sex education.** Many curricular areas that are foundations of most school programs are closely connected to many of the goals of a sex education program. These curricular areas include living skills, community instruction, receptive and expressive communication skills, and social skills. It may not be clear to program instructors how easily some of the skills related to social/sexual education can be (or are being) integrated into students' current educational programs.

**Barrier: We feel uncomfortable about the required graphic and concrete nature of the instruction.** We know that instruction for individuals with significant disabilities (and especially for individuals with vision impairments or who are deaf-blind) must utilize concrete materials and concrete instructional activities. For example, when we want to teach what an apple is, we should not only use a plastic apple or a picture of an apple. We use a real apple that we can smell, touch, taste, chop, cook, etc. This gives accurate information about the real object— size, shape, texture, etc. The use of concrete instructional materials is even more important when the individual has limited

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success with formal communication systems that might allow for greater use of abstract language.

**Barrier: We feel overwhelmed by the breadth of the task.** Students may come to a program at the age of 18 without the prerequisite information and skills needed for a sex education program for a typical 18 year old adult.

Therefore, there may be a great deal of catchup instruction required. In this case, the decision of where to begin instruction might seem overwhelming. When this happens, it is sometimes hard to take the first steps to getting started with the program

### *What might be included in a sex education program ?*

The following represents what might be considered a skeletal outline for a program for all students, including those who are deaf-blind.

*General development:* names and functions of body parts; body changes during puberty; differentiating between babies, children, adolescents, and adults.

*Personal safety and community safety:* differentiating between familiar people and strangers; inappropriate touching of others and by others; public rest room behavior; assertiveness training; abuse prevention.

*Concepts of public and private spaces:* identifying personal private places; differentiating between private places in school and community and private places at home; behaviors appropriate to public and private places.

*Body care, health, and hygiene:* washing and bathing; menstrual care; toileting skills and hand washing; disease prevention; preparation for medical examinations.

*Affectionate expression:* appropriate greetings with acquaintances, friends, teachers, etc.; expressions of friendships; choosing and differentiating between friends and acquaintances.

*Sexual expression:* masturbation; intercourse and birth control; safe alternatives to intercourse; safe vs. unsafe behaviors and sexually transmitted diseases; identification of consensual partners.

Additional course content, depending on specific needs and skills, might include other key areas such as:

- personal values exploration and clarification
- building concepts of self-esteem and positive self-concept
- self-responsibility skills
- problem solving skills
- dating skills
- developing long-term, committed relationships
- pregnancy and family planning
- slang terminology
- alternatives to pregnancy
- child birth
- parenting

### *What components should be considered when designing a program?*

**Relationships built on trust are a critical component to the teacher/student relationship.** Learning is most effective when the student determines that his or her teacher is a trustworthy person who will provide accurate information in a safe and positive environment. It is important when choosing instructors for a sex education program that these issues of trust are acknowledged. The subject matter is at times very personal, and it is imperative that the students feel comfortable with the instructor. Conversely, it is also imperative that the instructors feel comfortable with the students. If there is a communication facilitator or interpreter used by the student, it is important that the student feels comfortable discussing these issues through a facilitator. The student must accept the facilitator as a safe person if they are to be willing to discuss personal matters they may have not yet shared with family and/or friends.

**Families and educators must work as a team to plan instruction and goals.** By working together from the beginning, the team ensures buy-in from all parties involved. This process might begin as one component of the annual family interview or significant other interview. The interview will help the educational staff have a better understanding of family values, as well as the values and standards of the person's local community.

**Instruction may require the use of concrete materials and instruction.** This is one of the most difficult aspects of sex education for some students are deaf-blind. It is not always possible to "talk around" a subject, or use abstract descriptions to provide instruction. For some students, instruction must be made very real. Clearly, most educational systems in most cultures do not allow the use of real people to teach issues of sexuality. Therefore, it is necessary to make use of models, replicas, etc., and then establish a correspondence between the models and real life. There are companies that sell lifelike instructional aids that are either suitable for sex education programs, or that can be adapted without too much trouble. For some instructional purposes, the use of a real object is both

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possible and preferable. A real condom that can be explored by the group will make a lot more sense than would a picture and verbal description of a condom. In the case of a teaching unit on condoms, it may also be necessary to take additional steps— such as teaching where and how condoms can be purchased or acquired. A trip to a pharmacy, grocery store, or rest room vending machine to locate condoms would be an appropriate way to take the mystery out of an otherwise very mysterious topic.

**The program must have administrative support for the purchase and adaptation of instructional materials.** Most commercially available family life programs rely heavily on abstract language, visual and auditory learning— modes that may not be available to all learners. Despite this, the materials and activities in these programs can usually be adapted or modified for individuals with disabilities. By including families and administrators in the planning of sex education programs from the beginning, all parties will understand the importance of the topic, value its inclusion in the school program, and support the need for specialized materials and curricula.

**Instruction must be conducted using all appropriate communication modes necessary and using appropriate language levels.** The instructors' challenge is to make sure that each student in the program is fully included in the instruction. This means that instruction will need to utilize the modes of communication used by all students in the program— speech, photographs, symbols, raised line drawings, signed communication, voice output systems, pantomime, etc. The instruction will most likely be as individualized and unique as are the individuals themselves.

**Instructional objectives must focus on generalization of skills.** Instructional activities must be conducted with various materials, in various locations, with various people, and at different times of the day to increase the likelihood that skills will be generalized. For instance, if we teach appropriate rest room behavior and safety, we want to help ensure that the student understands the skills apply in all settings, not just in rest rooms familiar to the individual.

**A comprehensive evaluation system should be utilized to ensure that skills have been attained and generalized.** It is vital for instructors to truly know how thoroughly a skill has been mastered. The students may perform a skill in a particular place with particular people as part of their daily routine. This same skill may not be exhibited in a less familiar environment or under different or exceptional circumstances.

**Instruction should be integrated into all areas of the program.** Generally speaking, sex education is conducted during a time set aside for this purpose. This is understandable— the instructors, students, and materials are all assembled in one place. This does not, however, prevent information and skills from being introduced and/or reinforced throughout the rest of the instructional day. This is especially true of times when students are included in instruction and recreational activities with same-age peers who do not have disabilities. By modeling appropriate (and also inappropriate) behavior, same-age peers help build-in intrinsic motivations for students with disabilities. This is especially true if and when a student is at the age when one of her or his primary objectives is to fit in with the rest of the group.

**Instruction should recognize the value of the teachable moment.** It is much more desirable to teach a skill at a topical moment rather than wait for a contrived setting during a scheduled instructional time. This is especially true for individuals who learn best in natural settings, and this is also when intrinsic motivations are strongest. Teachable moments must be seized, and treasured. Of course, this requires a great deal of flexibility on the part of the instructor— but the benefits cannot be underestimated.

**Individual choices must be respected.** Inclusion into natural environments with same-age peers who do not have disabilities will provide students more information about all the options available from which to draw on when making choices and decisions. While the choices students make may not be the same choices we as instructors would make, it is our role to validate the choice making process and allow for as much personal choice as possible. As in all other areas of instruction, the instructor may not always be able to honor a particular choice. However, in all cases, the choice needs to be acknowledged and an explanation given as to why the choice cannot be honored at that time. We must also find ways to recognize consumer choices— in whatever way these choices are communicated. This requires that instructors know the formal and/or informal communication systems used by students, or that qualified interpreters/facilitators are utilized to ensure full participation by each individual in the group.

**Instruction must recognize the balance between allowing students to make choices and validating choice making while, at the same time, giving boundaries based on current scientific and medical knowledge.** This is one of the most difficult aspects to instruction in sex education for individuals who may have developmental disabilities and/or limited formal communication skills. As teachers and family members, we strive to give

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students factual information, and then guide them in identifying the boundaries of their own behaviors based on individual experiences, attitudes, values, etc. In the 1990s, however, there are sexual practices that put people at risk of contracting life threatening diseases. The program team must come to agreement on what behaviors will be labeled OK and what behaviors must be labeled as dangerous and "out of the question". These qualifiers must be based on specific individual situations, and by assessing the individual's ability to take precautions, make informed decisions, etc. Of course, the instruction must provide *alternative* behaviors for the practices that might be ruled "out of the question".

**Boys and girls (or young men and women) should not be separated during instruction.** Separation suggests to children and young adults that the "other side" has secrets or mysteries that cannot be divulged. It will make for more natural future interactions if both sexes become accustomed—from the beginning—to discussing issues and raising questions related to sexuality together as a unified group.

**Instruction should be provided by a team of at least two persons, preferably by a man and woman working side by side.** In terms of professional liability, instruction by two or more people ensures that there is another person present to remember exactly what was taught and discussed. Concern over issues of liability may be an unfortunate reality but one that should not be overlooked. In addition, it also makes good sense to teach in pairs. Team teaching exposes students to different viewpoints and experiences. As much as we strive to keep our own opinions out of the instruction, a topic that is as laden with issues of personal values and beliefs as is sex education is sure to be heavily influenced by what we as instructors bring to the program. When men and women teach sex education together, they will hopefully model positive communication, cooperation between the sexes, and build on and compliment the other's skills.

**Instructors can be honest with themselves about their own inadequacies with the subject matter.** We are not all experts in the field of sexuality. We all fall somewhere on the continuum, between being very knowledgeable all the way to requiring remedial instruction. One instructor may feel very comfortable with anatomy but not comfortable with talking about feelings and emotions. Another instructor might not be strong in naming the body parts, but may have a gift of leading discussions and/or activities related to values clarification. While it is most desirable that instructors identify personal areas of need and seek out professional growth activities in these areas, it is also fair to acknowledge and take advantage of individual strengths and talents.

**Instruction in school, living, or work settings should take into account agency policy statements.** These policies, covering issues of sexuality and sexual expression, may already exist or may be under development. It would be unfair for instructors to teach something that would result in an individual being reprimanded for doing what they were taught was acceptable to do. For this reason, it is only fair to students that we assist to inform them of what current policies exist for their home and work settings. In addition, students should know that policies that apply in one location may not apply in others, and that some settings do not fall under policies at all. In the case of the latter, students must make decisions and choices based on their own values, principles, and their understanding of the law.

**A sense of humor is a must.** Sex education is a difficult subject, and one that makes almost all instructors at least a little tense. Activities may not always proceed as planned and hoped, and surprises are inevitable. Maintaining a flexible attitude and the ability to laugh at yourself will help take off some of the rough edges.

The following instructional materials may be useful in developing instructional activities and/or augmenting and adapting existing sex education curricula.

- Life-size anatomically-correct teaching figures
  Teach-a-Bodies Instructional Dolls
  P.O. Box 101444
  Ft. Worth, TX 76185
  (817) 923-2380
- 17" anatomically-correct teaching figures
  Victoria House Dolls
  P.O. Box 663
  Forestville, CA 95436
  (707) 887-1516
- Rubber models of female and male genitalia
  Jackson Pelvic Models
  33 Richdale Ave.
  Cambridge, MA 02140
  (617) 864-9063
- Models of fetus at various stages of development
  Nasco West
  1524 Princeton Ave.
  Modesto, CA 95352
  (209) 543-1234
- Life-sized female and male instructional charts
  Planned Parenthood of Minnesota
  Resource Center
  1200 Lagoon Ave., Dept. 300
  Minneapolis, MN 55408
  (612) 823-6568 ❖

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