

Puberty and Children with Special Needs

By Melanie G. Snyder

Puberty is a time of unparalleled growth and change for all children – including those with special needs. As a parent, you can best help your child by knowing what to expect and by coaching, supporting and empowering your child through this important part of the journey to independence.

Physical Changes

Children with special needs go through the same hormonal and body changes as any child during puberty, typically between ages 9 and 14. Rapid growth spurts, acne and mood swings come with the territory. Girls develop breasts and get their periods. Boys develop facial hair, their voices change and they begin to experience erections and wet dreams. As your child experiences these changes, share information and offer reassurance that these are normal changes that everyone experiences.

Terri Couwenhoven, M.S., author of a forthcoming book on sexuality education for children with cognitive disabilities (Woodbine House, 2005), highlights the misconception that talking about puberty, feelings and body changes will encourage experimentation and inappropriateness. "More often the inappropriateness stems from ignorance, denial and reduced access to information," she says.

Ensure that your child knows and uses the correct names for all body parts, including genitals. Ask what other terms s/he may have heard and explain that some of these terms offend people. Explain which body parts are private. Then be sure you, your child's caregivers and doctors always ask permission before touching your child, explain why you need to do so, explain what you're doing throughout the process and then, afterward, reinforce what was just done and why.

Help your child become increasingly self-sufficient with grooming and hygiene. Emphasize the importance of keeping clean for both sanitary and social reasons (their growing interest in relationships with others often helps!) Consider allowing your child to choose his or her own soap, shampoo, deodorant and other grooming essentials (added incentive to use them regularly!)

Offer as much privacy to your child as possible during bathing or toileting. Explain the concept of privacy and what things should be done only in private. Set boundaries with your child to maintain privacy for yourself and teach respect for the privacy of others.

Consider the conversations and activities you and your child's caregivers engage in with your child in pub-

lic spaces. If you're conducting private matters in public, it may be difficult for your child to distinguish between "public" and "private." Ask yourself, "Would I want someone doing this with me in this location?" If not, move the activity with your child to a private location and explain why.

Emerging Sexuality/Abuse Prevention

A critical, yet often ignored, aspect of puberty for children with special needs is their emerging sexuality. "For many families this is a difficult time," says Couwenhoven. She encourages parents to be the primary sexuality educator for their child. Books, videos, websites and classes through community agencies can help parents with this role. "Pay attention to how your child learns best, and apply those teaching strategies to puberty education," Couwenhoven advises.

Review sexuality education materials being used at your child's school to determine if the content and teaching approach are appropriate for your child. If not, look for specially adapted materials (see Resources) and work with your child's IEP team to implement them. Being familiar with what is being taught in school will provide you with additional opportunities to reinforce and discuss basic concepts at home.

"As bodies are maturing and feelings are intensifying, the fear of exploitation is magnified," says Couwenhoven. Studies show that children with special needs are at greater risk of sexual exploitation than other children. Dependence on multiple caregivers with regular physical contact may make it difficult for a child with special needs to distinguish between caregiving and exploitation. These circumstances also provide greater opportunities for possible abuse. Sexual exploitation of children with special needs is often perpetrated by someone the child knows.

Couwenhoven recommends that parents explain tactics used by exploiters and define sexual behaviors that are against the law. "Help your child to categorize relationships in their lives and place them in context," she suggests. "Then help them understand sexual expression occurs in the context of a romantic relationship, no place else."

Empower your child to say no to touching that makes him or her feel uncomfortable. Help your child rehearse what to say and do. Agree on several highly trusted people your child should go to for help and to report any violations of the touching rules you've established. Encourage your child to be persistent if they are not believed at first.

Emotional Changes

Your child may feel self-conscious about his or her rapidly changing body and increasingly frustrated at physical or mental limitations. S/he may be easily embarrassed, cry or get angry at the slightest provocation. Patience and sensitivity will go a long way in helping both of you maintain your sanity. Remember: hormones are surging through your child's body constantly, causing much of this emotional rollercoaster.

Talk with your child at every opportunity about what s/he is feeling and why. Explain that sometimes feelings have to do with hormonal changes. Help your child deal appropriately with feelings. Provide an atmosphere of open communication where your child can ask questions and discuss anything without fear of being reprimanded or judged.

Social Changes

Peer relationships become increasingly important during puberty, providing an important training ground for developing social skills. Provide opportunities for your child to spend time with peers, at home, school, church and through extracurricular activities.

Help your child develop the necessary skills to make more independent decisions. Empower your child to express opinions and feelings while also teaching how to understand and respect the feelings and needs of others. Teach active listening skills. Explain body language and

non-verbal cues about how others are feeling, then practice by demonstrating common body language and non-verbal cues and having your child guess what feelings you're portraying.

Teach your child basic social graces like making introductions and starting conversations. Role play social situations with your child. After observing your child in social situations, recognize and reinforce what your child handled well, and offer tips for what s/he might want to do differently next time.

Watching your child trying to fit in with peers and possibly getting hurt as they're learning can be difficult for parents to witness. Helping your child to maintain good self-esteem while their body seems to have turned traitor is difficult. Coping with your child's tears one minute, laughter the next and anger and frustration seconds later can be as much of a rollercoaster for you as it is for your child.

Openly addressing issues like sexuality and exploitation with your child is not easy. But by knowing what to expect and then offering coaching, support and empowerment, you can protect your child while making puberty a time of wonder and growth on the journey to independence. ■

Melanie G. Snyder, mother of two teens, has written for over a dozen parenting magazines, children's magazines Cricket, Calliope and Guideposts for Kids, Harcourt Educational Publishers, SIRS Discoverer, www.EducationNews.org and numerous other publications.

Resources on Puberty and Sexuality in Children with Special Needs

Web resources

American Academy of Pediatrics puberty guide:
www.aap.org/family/puberty.htm

NICHCY—sexuality education—youth with disabilities
www.nichcy.org/pubs/outprint/nd17.pdf

Developmental Disabilities Resource Center on Sexuality (Missouri)—sex education and sexual abuse prevention planning workbook:
www.moddrc.com/Information-Disabilities/TopicPages/S-LetterTopics/SexualityPreparingYourChildwithSpecialNeeds.doc

Disability Solutions - 2 part series on sexuality education:
www.disabilitysolutions.org/pdf/4-5.pdf (part 1) and
www.disabilitysolutions.org/pdf/4-6.pdf (part 2)

Kalparrin Centre (Perth, Australia)—"Transitions: Moving Forward with Your Teenage Child":
www.kalparrin.org.au/transitions/

NICHCY—"Zigawhat!" website for adolescents:
www.nichcy.org/kids/index.htm

Virginia's SOLs for Family Life Education:
www.pen.k12.va.us/VDOE/studentrvcs/familylifeguidelines.pdf

Books

Changes in You for Girls
both by Peggy C. Siegel, M.S. -

Caution: Do Not Open Until Puberty! An Introduction to Sexuality for Young Adults with Disabilities
by Rick Enright, B.A., M.S.W. -

Sexuality: Your Sons and Daughters with Intellectual Disabilities
by Karin Melberg Schwier and Dave Hingsburger, M.Ed.;

I Openers: Parents Ask Questions about Sexuality and Children with Developmental Disabilities
by Dave Hingsburger

SIECUS—annotated bibliography—sexuality and disability:
www.siecus.org/pubs/biblio/bibs0009.html