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Early & Periodic Screening, Diagnosis & Treatment

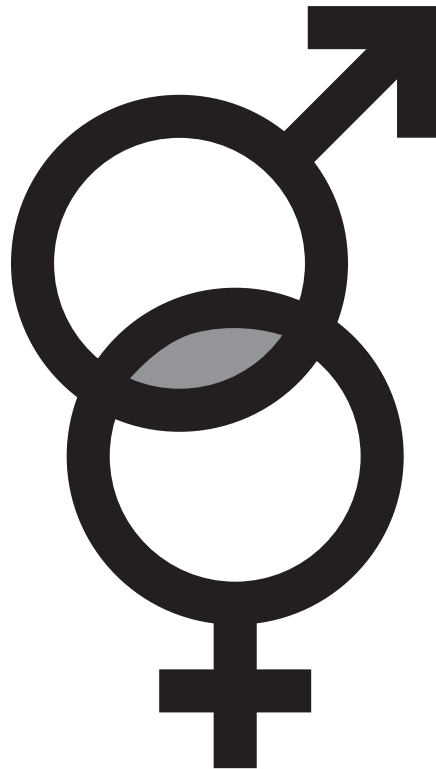
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Evaluation and Management of Gender Nonconforming Children and Adolescents

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During the past few years, there has been unprecedented visibility of transgender people in the mainstream media, helping to increase awareness in the general public as well as in health care systems. While some of the stories such as Caitlyn Jenner's transition have been quite positive, others such as the suicide of 17-year-old Leelah Alcorn illustrate the mental health risks associated with parental rejection and societal marginalization that may be the reality for this population.

It is important for all clinicians working with children and adolescents to understand key terms and concepts related to gender. Gender nonconformity is a variation of expected gender role behavior including preferred clothing, hairstyles, toys, games,



and playmates. For natal males, this often includes an aversion to rough and tumble play and the desire to wear stereotypical female attire. For natal females, gender nonconforming behavior is often characterized by "tomboy" characteristics such as an affinity for sports and toy trucks, and a dislike for dolls and dresses. While gender nonconformity is rooted in society's expectation of gender roles and norms, gender identity develops around the age of three and describes an individual's own internal sense of maleness or femaleness. Children with gender nonconforming behavior may or may not have gender discordance, a mismatch between their gender identity and their assigned sex at birth. Gender discordance that is accompanied

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by distress or affective disturbance is referred to as gender dysphoria. This less pathologizing term, gender dysphoria, replaced “gender identity disorder (GID)” in the fifth edition of the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (see Table 1 on page 3 for DSM-V Gender Dysphoria criteria).

It is important that providers understand the difference between gender nonconformity and gender discordance as they may occur together or separately in individuals. Significantly more youth will display gender nonconforming behaviors without having gender discordance and may be distressed if others perceive them to be the opposite gender. Conversely, many gender discordant youth often display extreme gender nonconforming behavior and are comforted when perceived as the opposite gender. Finally, it is important to note that occasionally, youth may present with gender discordance without displaying gender nonconformity for a number of reasons, usually including a conscious decision to

conform to societal gender role expectations for reasons of safety or self-preservation.

The limited research available on gender nonconforming and gender discordant youth suggests that the majority of these children will eventually assume an adult nonheterosexual sexual identity (gay, lesbian, or bisexual) and a nontransgender (cisgender) gender identity. A small number of prospective studies of gender discordant youth in the Netherlands showed that around 30 percent of the children had a persistent transgender identity by the time they progressed through puberty. Factors that were found to be positively correlated with children whose gender discordance persisted as opposed to desisted included the intensity of discordant feelings in early childhood and a desire to be the other gender coupled with a strong and adamant belief that their true gender did not match their assigned sex at birth.

For those children meeting the DSM-V criteria for gender dysphoria, often the emergence of puberty can be a diagnostic tool. Often during this time adolescents either consolidate their identity into one that aligns with their assigned sex at birth or they experience a worsening of dysphoria related to the development of unwanted secondary sex characteristics. In consistently and persistently gender dysphoric adolescents at Tanner stage 2 or

3, pubertal suppression with the use of GnRH analogues is a completely reversible medical option that can be considered as long as any co-existing psychological, medical, and social problems have been addressed and the legal guardians have given informed consent. Ideally, GnRH analogues would be given under the consultation of a multidisciplinary team including a pediatric endocrinologist to monitor physical development, growth, and bone density. Around the age of 16, adolescents with gender dysphoria who have either previously been treated with GnRH analogues or those who first present at this age, can be considered for cross-sex hormonal therapy with appropriate informed parental consent and patient assent (see Tables 2 and 3 on page 4). This intervention will cause the development of the





secondary sex characteristics of their affirmed gender, including some changes that will be irreversible.

Surgical interventions such as male chest reconstruction, metoidioplasty, phalloplasty, and vaginoplasty are completely irreversible and it is recommended that these be deferred until adulthood. Outcome data regarding clinical treatment for gender dysphoria with puberty blockers and cross-sex hormones have consistently shown psychosocial benefit and very little evidence of patient regret.

Health care providers have a critical role in promoting health and resilience for gender variant youth. Parents may bring gender variant children to their provider for a number of reasons including depression, anxiety, bullying, behavior issues, or gender nonconformity. This is an opportunity for providers to advocate for their patient and model the supportive and caring environment that is needed to help these children thrive. This can be done in a variety of ways including but not limited to, creating a welcoming space by asking for and honoring preferred names and pronouns, providing referrals to appropriate specialists if needed (mental health providers or pediatric endocrinologists), supporting parents and family members, consulting with schools and community groups, and promoting self-esteem and coping skills.

Table 1.
DSM-V Criteria for Gender Dysphoria in Children

Criterion A: (A1 must have been present for at least 6 months duration AND at least 5 of the indicators A2-A8 must have been present for at least 6 months duration)

1. A strong desire to be of the other gender or an insistence that one is the other gender.
2. In natal boys, a strong preference for wearing female attire, or in natal girls, a strong preference for wearing only typically masculine clothing and aversion to wearing typically feminine clothing.
3. A strong preference for cross-gender roles in make-believe or fantasy play.
4. A strong preference for the toys, games, or activities stereotypically used or engaged in by the other gender.
5. A strong preference for playmates of the non-assigned gender.
6. In natal boys, a strong rejection of typically masculine toys, games, and activities (including an avoidance of rough and tumble play), or in natal girls, a strong rejection of typically feminine toys, games and activities.
7. A strong dislike of one's sexual anatomy.
8. A strong desire for the primary and/or secondary sex characteristics that match one's experienced gender.

Criterion B: (B1 must also be present)

1. Clinically significant distress or impairment in social, school, or other important areas of functioning.

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Table 2.
Feminizing Therapy

Protocol for induction of female puberty with oral 17- β estradiol, increasing every six months.

- 5 μ g/kg/day
- 10 μ g/kg/day
- 15 μ g/kg/day
- 20 μ g/kg/day
- Adult dose 2-6 mg/day

Antiandrogens: spironolactone

- starting dose 25 mg daily
- maximum dose 200 mg BID

Table 3.
Masculinizing Therapy

Protocol for induction of male puberty with injectable subcutaneous testosterone cypionate, increasing every six months

- 25 mg/m² weekly
- 50 mg/m² weekly
- 75 mg/m² weekly
- 100 mg/m² weekly
- Adult dose
50 mg -200 mg weekly

Table 4.
Resources for Caring for Gender Nonconforming Youth

Professional Organizations

- American Academy of Child & Adolescent Psychiatry (AACAP): www.aacap.org
- Gay and Lesbian Medical Association (GLMA): www.glma.org
- World Professional Association for Transgender Health (WPATH): www.wpath.org

Select Multidisciplinary LGBTQ Clinics serving youth

- UI Department of Pediatric Endocrinology and the UI Department of Child Psychiatry: www.uilgbtqclinic.com
- Ann & Robert H. Lurie Children's Hospital of Chicago: Gender & Sex Development Program: www.luriechildrens.org/en-us/care-services/specialties-services/gender-program/Pages/index.aspx

Medical Resources

- Coleman E, Bockting W, Botzer M, et al. Standards of care for the health of a transsexual, transgender and gender nonconforming people, version 7. *Int J Transgender*. 2011; 13:165-232. Available at: http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351&pk_association_webpage=3926
- Callen Lorde Community Health Center. Transgender health program protocols. 2012. Available at: http://issuu.com/callenlorde/docs/tg_protocols_2014_v.5/3?e=8526609/10794494
- Hembree W, Cohen-Kettenis PT, Delemarre-van de Waal HA, et al. Endocrine treatment of transsexual persons: an Endocrine Society clinical practice guideline. *J Clin Endocrinol Metab*. 2009; 94:3132-54.
- Center of Excellence for Transgender Health, Primary Care Protocols for Transgender Patient Care, 2011. Available at: <http://transhealth.ucsf.edu/trans?page=protocol-00-00>
- Makadon HJ, Mayer KH, Potter J, Goldhammer H. *Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health*, 2nd ed. Philadelphia: American College of Physicians; 2015.

Transitioning from Pediatric to Adult Health Care for Youth with Special Health Care Needs

By Royann Mraz, MD



Nationally, there has been recognition of the need to improve and support the transition of youth to adult health care. A smooth transition is especially important for 15 to 20 percent of youth with special health care needs (YSHCN). Those with chronic complex medical conditions, disabilities, and/or behavioral health disorders are especially vulnerable. They are at risk for gaps in care, which can result in morbidity, hospitalization, and/or long-term complications. Gaps in care can result from lack of health insurance, inadequate planning and support, lack of knowledge, self-empowerment, and self-care skills, and not connecting to adult health providers. Less than 50 percent of YSHCN receive transition services, although those with a medical home are twice as likely to receive services.

For YSHCN and their families, health care transition is only one of numerous changes at this time. They are also transitioning from high school to postsecondary education/training and/or employment. Legally they can make their own health care and other decisions at 18 years of age (unless they need guardianship). They become more independent, develop relationships, and most live independently. There are often changes in health insurance, dental care, supplemental security income (SSI), and other financial and community supports at 18 years of age. Transition to adulthood can be stressful for YSHCN and their families. Planning and support can impact future health and well-being.

Some of the risk factors for gaps in health care or complications in the post-transition period are having a neurocognitive disorder, low family income, being from a minority group, having poor English fluency, living independently from parents, lack of a medical home, having a behavior disorder, milder disease, and male gender. Protective factors for successful transfer to adult health care are better self-management skills, better medication adherence, attending appointments independently, belief in the importance of follow-up, and a written referral or prior visit to an adult provider. Follow up after transfer and having an involved family can serve as safety nets.

For health care providers, there are a number of barriers to health care transitioning, including lack of time, lack of reimbursement, lack of training of health care providers, lack of adult providers, lack

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of adequate preparation for adult providers to receive young adults with SHCN, lack of communication between pediatric and adult providers, and often fewer care coordination resources for young adults.

The transfer to the adult approach to care involves changes to decision-making, privacy and consent, and access to information. The American Academy of Pediatrics AAP/AAFP recommends that a gradual transitioning to the adult model of care begin at 12 years of age. A transition process over time allows time for preparing youth for self-management and to practice these skills, including decision-making. Nurses, social workers, and care coordinators can help provide the needed education and support for YSHCN and their families.

Each transition, including the timing of transfer, needs to be individualized. It is helpful to assess transition readiness in youth and family in preparation for setting goals. The following are basic readiness questions and teaching points for teens and their families at different ages: (adapted with permission from Kitty O'Hare, MD, Got Transition, and AAP)



12 to 14 years of age

► Youth:

- Can name their chronic conditions
- Knows their allergies
- Lists their medications
- Attends their IEP meeting
- IEP includes a transition plan at age 14
- Does household chores and participates in family life
- Has hobbies and engages in exercise
- Thinks about what they want to be when they "grow up"
- Volunteers and participates in community activities

► Family:

- Started to keep their own health record
- Discussed sexuality
- Begun working on independent living skills with youth

15 to 17 years of age

► Youth:

- Describes how their chronic conditions impact their health
- States what each medication is for
- Takes their medication without supervision
- Has refilled a medication
- Carries their insurance card
- Has scheduled a doctor's appointment on their own
- Updates their own health summary
- Investigates adult doctors for primary and specialty care
- Planning for future school, work, and living options

► Family:

- Investigate secondary education, employment, or vocational opportunities
- Family is thinking about decision-making at age 18 and allowing teen experiences in decision-making

- Apply for funding, case management, and adult services.

18 years of age and up

► Youth/Young Adult:

- Has selected adult doctors for primary and specialty care
- Can refill medications and make appointments
- Has plans for living and working after graduation
- Has foundational skills needed for living and working
- Is linked with funding and support resources

► Family:

- Decision-making is supported by family/guardian (if appropriate)
- Ensures young adult has insurance/SSI benefits in place
- Has supported the young adult in developing a formal plan for adult living and working

There are several very good resources to help health care providers. One resource is The Got Transition Center for Health Care Transition Improvement project, which has defined six core elements for Health Care Transition. The six core elements are:

- 1) Developing a practice **transition policy** available for youth, families, and staff
- 2) **Transition tracking** with a registry for YSHCN
- 3) **Transition preparation** with use of readiness assessment tools and education
- 4) **Transition planning** with development of a medical summary, emergency plan, transition action plan
- 5) **Transfer of care** or transfer to adult approach to care-transition checklist and communication with adult provider
- 6) **Transfer completion** and follow-up



The Got Transition website also provides sample transition policy letters, readiness assessment questionnaires for youth and family, sample letters for transfer of care to another provider, sample medical summary and emergency plans, and links to other resources.

Other resources include the Medical Home Portal, which has information on transition to adult care for providers and youth and contains resources for specific diseases/conditions. The medical record system EPIC contains templates helpful for transitioning on their website. The American College of Physicians is developing disease/condition specific tools to facilitate effective transfer of youth and young adults to adult health care. There also are Maintenance of Certification (MOC) Part 4 Transition Quality Improvement (QI) projects, including one developed by the Illinois AAP. Social media has the potential to help engage youth in the transition process.

Resources:

Clinical Report-Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. *Pediatrics* 2011;128(1):182-200.

Hergenroeder AC, Wiemann CM, Cohen MB. *J of Pediatrics* 2015;167(6):1196-1201.

www.gottransition.org

Additional references and resources are available on the Iowa EPSDT website, www.iowaepsdt.org, under the Resources section.



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