

TRANSITION TO WORK, INDEPENDENCE & ADULTHOOD

Strategies for X and Y Chromosome Variations

AXYS 2019 Family Conference, Atlanta GA

Introductions

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It helps to have a plan before graduation

- Vocational/volunteering experience before age 18
- Plan for college/work/life skills for independent living
- Plan to transition medical care to adult providers, and responsibility for health care from parents to the young adult
- This is ideal, but if no plan exists, or the young adult is floundering ...
- You can always create one now

Workshop Outline

- Outline of the components of transition to adulthood
- Maintaining eligibility for possible government benefits
- Accessing government programs
- Transition planning for academic and vocational programs
- Transition to adult medical services
- Q & A
- Follow-up presentation for parents of boys with KS

What are the components of transition?

- Educational (IDEA vs ADA)
- Legal
- Financial
- Vocational
- Health Care
- Social
- Sexual
- Life skills
- Residential
- Online considerations

Impact of X/Y variations is highly variable

- Approximately 30% of individuals with sex chromosome aneuploidy (SCA) need no special assistance to achieve adulthood
- But for the other 70%, accommodations or government assistance are necessary
- My presentation focuses on those who may need programs that address learning disabilities, executive functioning deficits, and social/emotional differences

Realistic expectations may require that the “timeline” for independence be longer

- Immaturity compared with sibs and peers
- Executive functioning may develop later
- Social skills may not be as well developed
- Many suffer overwhelming anxiety when asked to multi-task at work and in school
- RELAX – surveys show that most achieve careers and independence ... but 3, 6, even 10 years after sibs and peers

Importance of record-keeping

- Organize medical and special education records chronologically
- Use a notebook and plastic page holders
- Genetic records, neuropsychological evaluations, AXYS clinic evals
- IEPs and 504 plans
- College/vocational school accommodations and testing
- Workplace evaluations, accommodations, written reviews
- Government support (Voc Rehab, disability determinations, waiver programs)

Don't expect anyone to be familiar with Klinefelter syndrome, Trisomy X, or 47XYY

- Print out and keep handy:
 - Condition brochures available of www.genetic.org
 - Frequently asked questions
 - Medical articles available in the online library
 - “Elevator” talk summarizing how SCA affects your child’s ability to learn, work, and live independently
 - Professionals are even less likely to be familiar with 48 and 49 chromosome variations of these genetic conditions

Legal changes at age 18

- Presumed capable of financial, medical, moral decision-making
- Power of attorney- financial, medical
- Health care proxy
- Guardianship
- Criminal culpability

Online safety and sexual responsibility

- Speak concretely about online safety measures ie what is permissible to post and information that should never be shared
- Discuss what constitutes criminal behavior- downloading child pornography, intimate relations with a minor, sexting, “victimless crimes”
- Miranda rights (the right to remain silent); how to behave if arrested.
- Speak frankly about sexuality, safe sex, avoiding pregnancy
- Breakout Session, Sunday, 1 pm. Potential Legal Issues and Concerns, Sheryl Kelly and Gary Glissman

What if self-support isn't possible?

- For many, being able to self-support is delayed to age 26, 30 or beyond
- Maintain ability to qualify for Supplemental Security Income (SSI) or Medicaid by keeping less than \$2000 in accounts tied to individual's social security number
- Place assets in an ABLE account, a pooled supplemental needs trust or an individual supplemental needs trust
- ABLE accounts <http://www.ablenrc.org/about/what-are-able-accounts>
- Supplemental Needs Trusts <https://www.elderlawanswers.com/what-is-a-supplemental-needs-trust---5274>

SSI/SSDI

- Must meet the Social Security standard of disability: being unable, because of a medical condition, to engage in “substantial gainful activity”
- For 2019, substantial gainful activity is \$1,220 per month
- Klinefelter syndrome, Trisomy X, 47XYY and XXYY are not “listed impairments”, meaning that comorbid or other medical conditions must exist that prevent SGA; render the applicant as disabled as a “listed condition”

Eligibility

- At age 18, an individual can apply independent of parent's income and assets
- Eligibility can be applied for at <https://www.ssa.gov/benefits/disability/>
- Disability determination depends on medical records, neuropsychological evaluations, and vocational records (if any) that are comprehensive and RECENT (within 18 months), clearly stating the conditions prevent self support at this time
- Mild and moderate conditions will not qualify; disabling conditions must be severe; preferably there are two to three conditions preventing SGA
- AXYS multi-specialty clinics can help to provide that documentation

Applying for SSI/SSDI

- Have your documentation complete and well organized prior to starting the application
- Make certain that your son or daughter has assets of less than \$2000
- If working, earnings must be less than SGA
- Inform physicians, psychologists, and educational institutions that you are making the application for benefits
- Complete the application as if you are reporting on your son's or daughter's lowest functioning day of the year

Applying for SSI/SSDI

- Using a Social Security attorney for assistance with the application
- 70 percent of applications are rejected initially. If rejected, appeal; don't start a new application
- Approximately one third of adults with SCA surveyed eligible and receiving benefits
- No need to decide on whether to apply for SSI or SSDI. Social Security administration will choose the appropriate program

SSI/SSDI Benefits

- SSI= \$771 per month (own household) plus eligibility for SNAP (Food Stamps) and Medicaid
- SSI earnings are reduced by \$1 for every \$2 earned
- SSDI amount determined based on work history or parent earnings. Usually \$861 or 50% of parent benefit
- SSDI recipients are eligible for Medicare after receiving benefits for 24 months
- SSDI recipients are eligible to receive benefits as long as they do not earn more than \$1220 per month

Medicaid

- Eligibility varies by state. Income may be up to 130% of Federal poverty level.
- Generally provided automatically when SSI received
- May be work requirements. States may limit Medicaid for youth under 21.
- Required for “waiver” mental health and developmental disability services

Waiver developmental disability services

- Home and community based waiver services (HCBS) may be provided to adults with X/Y variations who meet State's definition of developmental disability
- Many states have waiting lists; apply early
- Life skills training and homemaking assistance
- Extended job development, training and coaching (beyond VocRehab services)
- Limited assistance with housing
- Group homes only for those with severe impairment

Mental Health Services

- Vary by state
- Must meet requirement of “severe and persistent mental illness”
- May include treatment services, job training, limited housing programs
- Generally require Medicaid eligibility or private insurance

Resources

- Parent to Parent (search by state)
- Pacer Center <https://www.pacer.org/students/transition-to-life/>
- National Council for Independent Living <https://www.ncil.org/about/>

Questions?

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