Government Benefits
Special Considerations for Adolescents and Adults with Extra X and Y Chromosomes
What is transition to adulthood?

- The process of acquiring skills and knowledge to take on adult responsibilities
- Change in legal status at age 18 from parental responsibility for medical, educational and financial choices to individual responsibility
- Individuals with X and Y chromosome variations may be delayed in developing the maturity and skills needed for successful transition
Other Changes

- Transition from secondary school system where services are mandated by the IDEA* to adult educational and services system (at ages 18 to 21) where services are governed by ADA*

*IDEA—Individuals with Disabilities Education Act
*ADA—Americans with Disabilities Act
Presentation will focus on:
- Post-secondary education/vocational training
- SSI/SSDI
- Programs including SNAP, Medicaid, Section 8, Independent Living Centers
Special concerns for individuals with extra X and Y chromosomes

- Tendency to developmental delay, not necessarily developmental disability
- Special education system may not recognize need for transition services
- Services for persons with more severe developmental disabilities may not be appropriate for those with X and Y chromosome variations
- Lack of familiarity with X/Y variations by service providers
If you are a parent

- Learn about legal, financial, medical, educational issues
- Institute effective planning for your child’s individual circumstances
- Insure that transition planning is written into your child’s IEP or 504 accommodation plan by age 16 (earlier in many states)
If you are the adult

- You need someone who can help you assess strengths and functioning deficits
- Trusted family members and friends
- Vocational rehabilitation services
- Mental health/learning disabilities centers
- Independent Living Centers
- Special needs life coach
- Therapist
Preserving the Right to Entitlements

- Difficult to predict the rate at which a young adult with X/Y Chromosome Variation will mature
- Difficult to predict how completely the individual will transition to independence
- In X and Y variations there is a wide range of functioning and possible disability
- Hope for the best...but plan for limitations
Legal Considerations

- Importance of a supplemental needs trust
- Maintains eligibility for SSI and/or Medicaid
- Permits trustee control over funds in cases of immaturity
- Necessary changes to family wills, insurance policies, other documents
- Importance of establishing the trust by age 15– but it is not too late if your adult child is already 18 or older!
Medical Recordkeeping

- Maintain comprehensive medical and educational documentation of genetic diagnosis, learning disability, medical and psychiatric conditions
- Organize this in a file or notebook
- Records required for accommodations in college or at work, for eligibility for vocational programs, for life skills or housing support, for application for SSI or SSDI
Vocational Training Options

- The greatest predictor of successful employment after high school is a job or volunteer experience before age 18
- Incorporate vocational training and volunteer experience into your child’s education, even if it means delaying graduation to ages 19–21
- The type of job is not as important as the experience of working/acquisition of workplace behavior
Vocational Training and Placement Benefits

- Even if an individual is college-bound, he or she may still be eligible for training, placement and job coaching services through school.

- Be aware that you may access vocational rehabilitation services at any point in the future. Check with your Independent Living Center (www.ilru.org) for application information.
All states have a network of centers providing vocational testing and assessment, vocational training, including college, some medical and therapeutic services, job development—help with finding and applying for employment, job coaching, and advocacy for workplace accommodations.
Independent Living Centers


- Centers provide:
- Information and referral services
- Benefits advice
- Assistance with applications for SSI/SSDI, Medicaid, food stamps, housing vouchers
- Life skills training (money management, transportation, self-advocacy)
At Age 18

- Need to consider whether application for SSI or SSDI is appropriate
- Program may help to provide income support while the young person acquires the skills and education to become independent
- With SSI determination of disability, most states also make an adult eligible for Medicaid, and often, food stamps assistance
SSI and SSDI

- For adults 18 and over, eligibility is based on individual’s, not family’s, earnings and assets
- Individual may have no more than $2000 in assets in own name
- For adults applying for SSDI, must have been disabled and unable to engage in substantial gainful activity (earning at least $1170 per month) for at least 12 months
Substantial Gainful Activity

- Definition: earnings over $1170 per month as of January, 2017, in *competitive employment*

- College students are not excluded just because they are students; they may be eligible if, in the opinion of their physicians and special education personnel, they cannot earn $1170 per month, due to their disability
In addition, the adult may have assets in his or her own name of no more than $2000 for SSI.

There is no means testing for SSDI, for those with a work history or obtaining benefits based on a parent’s work history.

*Excludes a modest car for work or school.

Check with [www.ssa.gov](http://www.ssa.gov) for specific asset allowances.
Application Process

- Covered in detail at [www.ssa.gov](http://www.ssa.gov)
- Starts with a phone call to the 800 number to open a case and set up an interview
- Completion of electronic on-line detailed disability questionnaire
- In-person or on-the-phone interview with or without the presence of the young adult
- Completion by physicians/psychologists of medical documentation
Disability Determination

- Klinefelter Syndrome, Trisomy X, 47,XYY and 48XXYY, etc., are not listed impairments that will automatically grant eligibility.
- Individual determination decides if an individual’s impairment with extra X or Y chromosomes is equal to the requirements of a listed impairment.
- There must be physical, developmental or psychiatric impairment that is preventing the individual from “substantial gainful activity”.
Examples of co-morbid disabling conditions include:

- Psychiatric: depression, anxiety, mood disorders, psychotic disturbances
- Developmental: intellectual disability or autism spectrum disorder
- Physical: seizure disorder, severe scoliosis, disabling asthma, congenital heart defect, etc.
Application Timeline

- 4 to 6 months for determination of disability

- 55% of applications rejected on first round; use of an advocate or specialized attorney to help prepare the application can increase chance of eligibility

- If rejected, file an appeal within 90 days, and use an attorney or an advocate to prepare the appeal
What are the benefits?

- Monthly income for SSI ranges from about $460 per month to as much as $807 per mth.
- SSDI calculates benefits differently.
- Income incentive, once eligible for SSI is:
  
  SSI payment is reduced by
  
  \[(\text{Income} - $65) \div 2\]

  Each dollar earned reduces SSI by approximately 50 cents.
SSDI Based on Parent’s or Individual’s Earnings Record

- When parents receive Social Security retirement or disability benefits, or when a parent dies
- Any child who has a disabling condition acquired before the age of 22 may be eligible for SSDI
- Same application process as SSI
- Benefits are based on parent’s or older individual’s earnings record
SSI and SSDI Redetermination

- For young persons with delayed earning potential, annual reviews
- or at least every three years
- Work incentive programs permit earnings Medicaid buy-in continues after income supports lapse
- Immediate reinstatement on SSI if the adult is laid off or fired
Medical Coverage

- Medical coverage which is secondary to private medical insurance
- Funding for Medicaid waiver services for persons with developmental and psychiatric disabilities
- Eligibility determined by state
- Generally limited to those with persistent and severe disability
Developmental disabilities

- Intellectual disability (generally, IQ of less than 70 and/or adaptive behavior scale of less than 70)
- Neurological and seizure disorders
- Autism spectrum disorders
- Services funded through Medicaid Waiver Programs will pay for vocational programs, life skills training, and sometimes, housing programs
Mental health programs

- Must have substantial disability from severe disorders such as bipolar disorder, major depression, schizophrenia
- The standard is “severe and persistent”
- Waiver programs will pay for medication management, psychiatric rehabilitation, vocational training and placement, and sometimes, supervised housing
Additional Benefits

- SNAP (Food Stamps)
- Housing assistance (Section 8)
- General assistance

- These are all locally determined and currently at risk if Federal funds are involved.
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