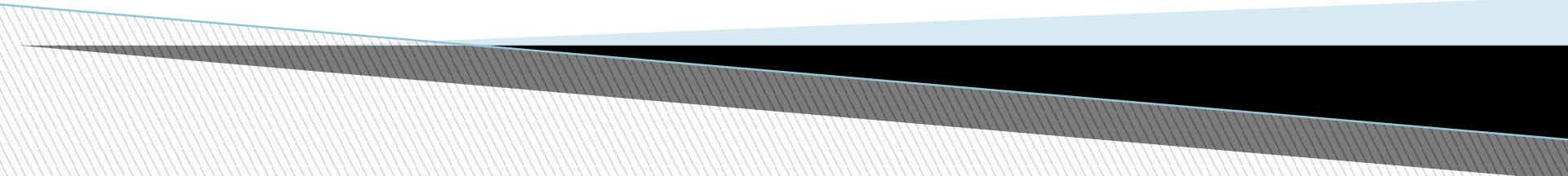


# **Government Benefits**

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](http://www.ilru.org)) for application information.

# **State Vocational Rehabilitation Agencies**

- ▶ 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
- ▶ Advocacy for workplace accommodations

# Independent Living Centers

[Http://www.ilru.org/projects/cil-net/cil-center-and-association-directory](http://www.ilru.org/projects/cil-net/cil-center-and-association-directory)

- ▶ 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  
(Income - \$65)

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

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

# Contact Information

Virginia Isaacs Cover, MSW, MBA  
[ginniecover@gmail.com](mailto:ginniecover@gmail.com)