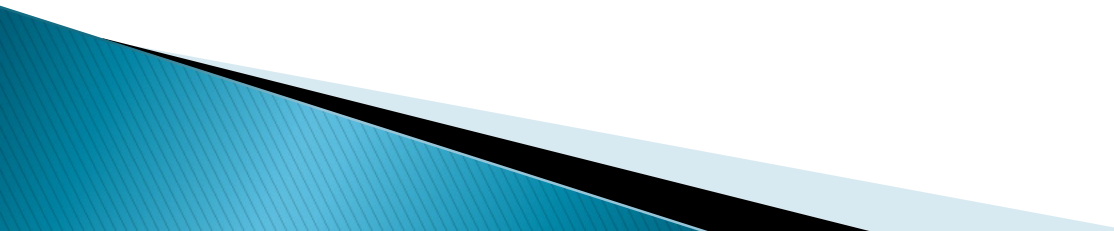


# Transition to Adulthood

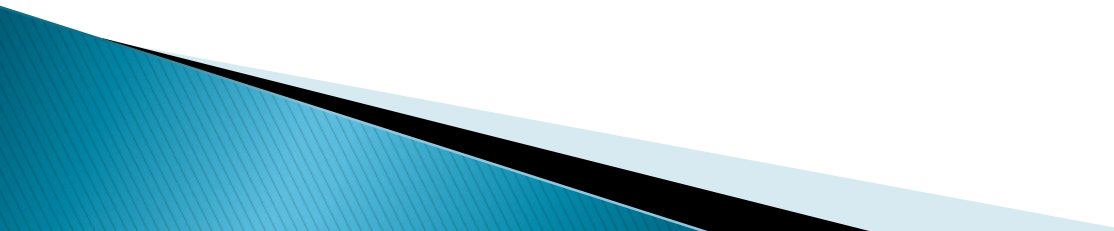
Special Considerations for Adolescents and  
Adults with Extra X and Y Chromosomes

- ▶ This presentation will focus on:
  - Maintaining eligibility–Medicaid and SSI/SSDI income support
  - Programs including SNAP, housing assistance, Independent Living Centers

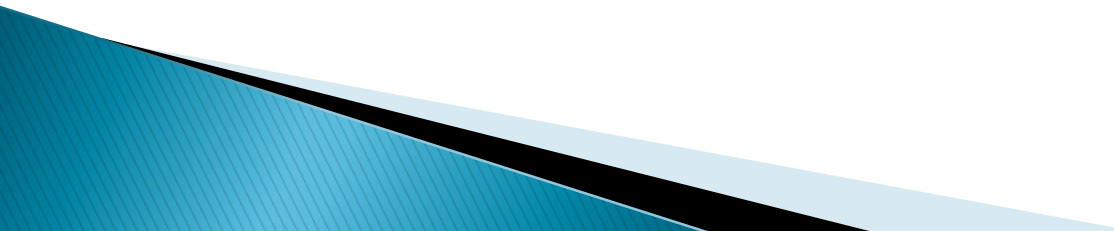
# Special concerns for individuals with extra X and Y chromosomes

- ▶ Tendency to developmental delay, not necessarily developmental disability
  - ▶ Services for persons with more severe disabilities may not be appropriate for those with X and Y chromosome variations
  - ▶ Lack of familiarity with X/Y variations by service providers and government agencies
  - ▶ Families and individuals need to educate those who process their applications
- 


# If you are a parent

- ▶ Learn about legal, financial, medical, educational issues
  - ▶ Institute effective planning for your child's individual circumstances
  - ▶ Know how to educate service agencies about X/Y variations
- 

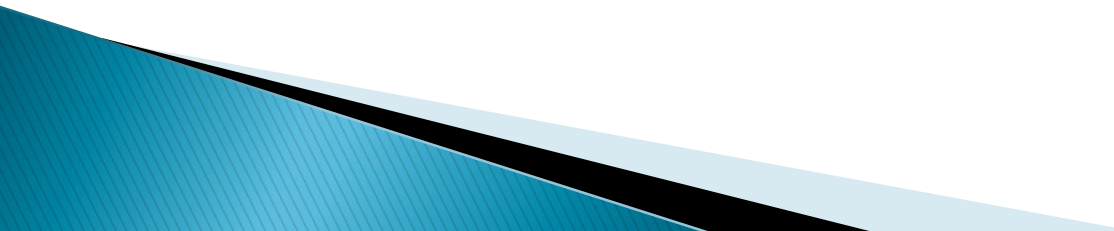
# If you are the adult

- ▶ Assistance with assessing strengths and functioning deficits
    - Trusted family members and friends
    - Therapist
    - Special needs life coach
    - Independent Living Centers
  - Learn how to educate others about your X/Y variation and how it affects your life
- 

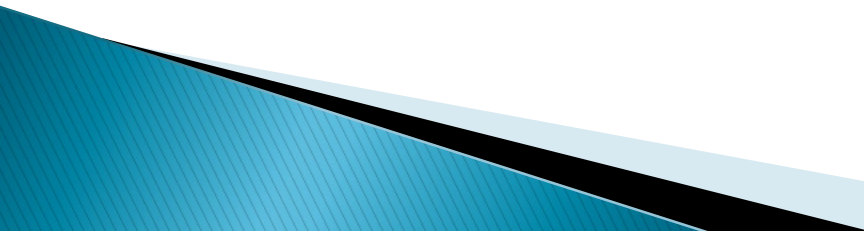
# Preserving the Right to Entitlements

- ▶ Difficult to predict the rate at which young adults with X/Y Chromosome Variations will mature
  - ▶ Complete transition to independence may vary
  - ▶ Hope for the best...but plan for delay and possible limitations
  - ▶ Approximately 1 / 3 of adults with X/Y variations qualify for SSI or SSDI at some point during their lives
- 

# Legal Considerations

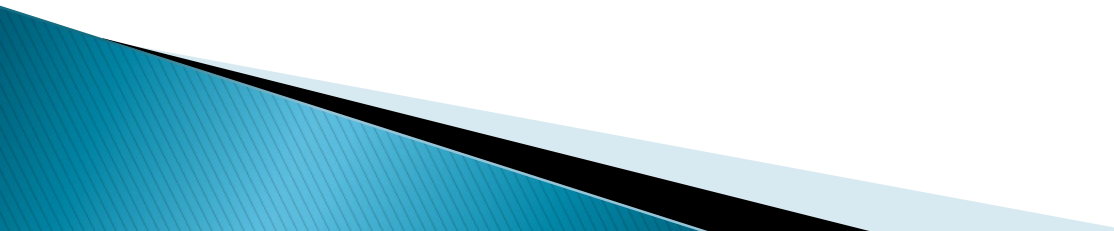
- ▶ Importance of using an ABLE account or a supplemental needs trust (SNT)
  - ▶ Maintain eligibility for SSI and/or Medicaid
  - ▶ Trusts allow some control over funds in cases of immaturity; ABLE accounts self-managed
  - ▶ Necessary changes to family wills, insurance policies, other documents
  - ▶ Importance of establishing a trust by age 15–but it is not too late if an individual is already 18 or older!
- 

# Get expert legal advice

- ▶ ABLE accounts are the easiest and least expensive to set up by the individual
  - ▶ Pooled trusts are less expensive to access than individually created trusts
  - ▶ Wills can be written to automatically establish a trust on death of a parent
  - ▶ These trusts must be written by an attorney expert in SSI and Medicaid requirements. This is not a matter to give your sister-in-law the attorney (unless she is an expert)
- 

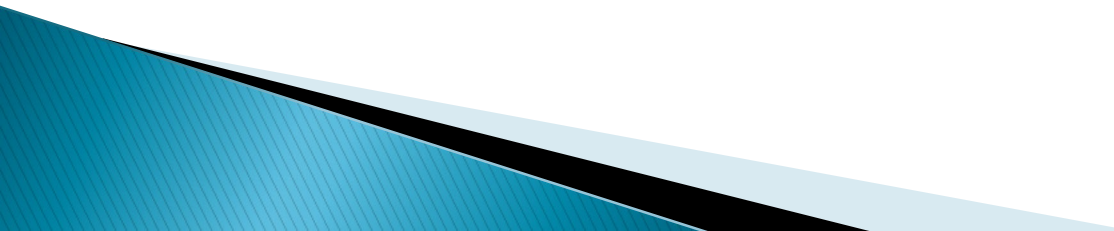


# Medical Recordkeeping

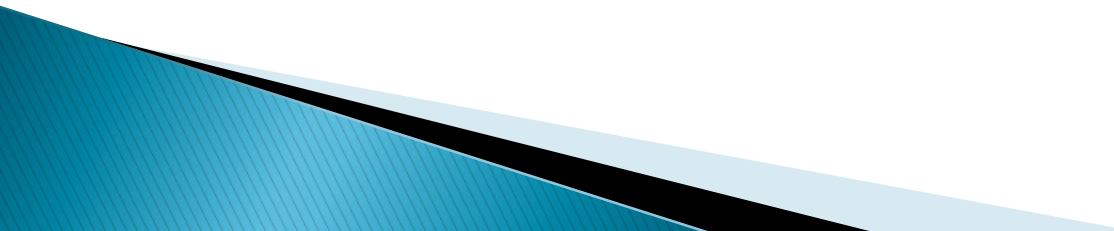
- ▶ Maintain comprehensive medical and educational documentation of genetic diagnosis, learning disability, medical and psychiatric conditions
  - ▶ Organize this in a file or notebook
  - ▶ Records required for accommodations in college or at work, for eligibility for vocational programs, for life skills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

# Independent Living Centers

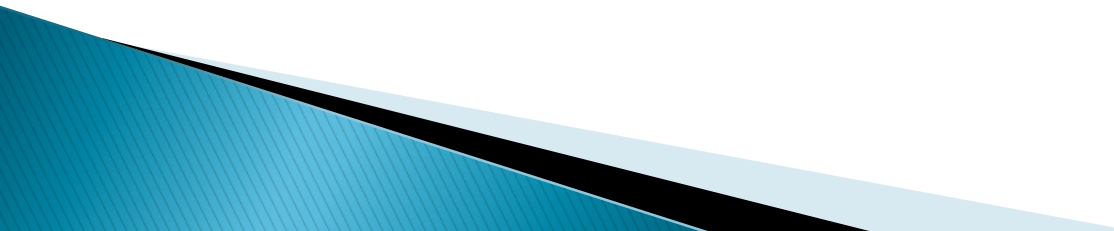
[Http://www.ilru.org/projects/cil-net/cil-center-and-association-directory](http://www.ilru.org/projects/cil-net/cil-center-and-association-directory)

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

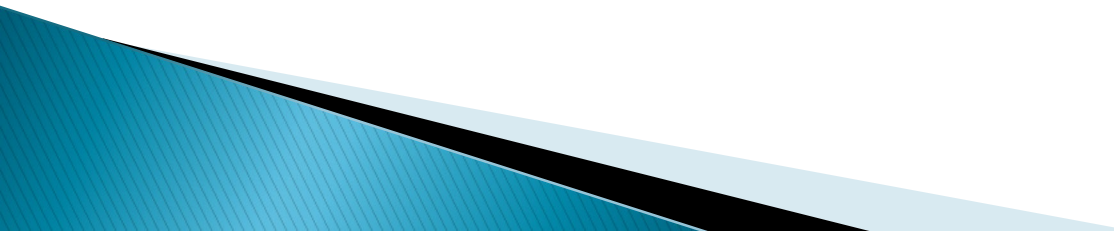
# At Age 18

- ▶ 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
  - ▶ An older worker who becomes disabled may need to apply for SSI and/or SSDI
  - ▶ With SSI determination of disability, most states also make an adult eligible for Medicaid, and often, SNAP assistance
- 

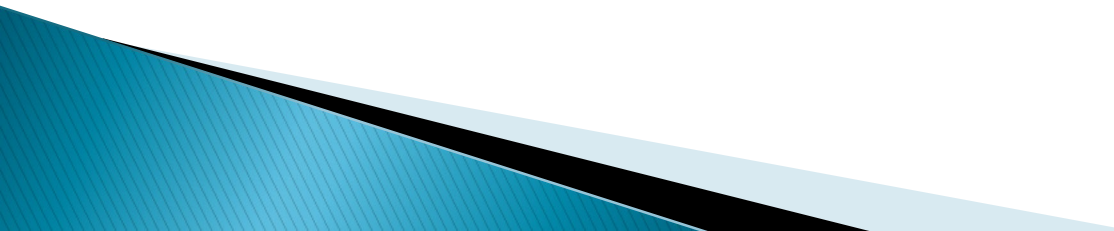
# SSI and SSDI

- ▶ 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 SSI
  - ▶ For adults applying for SSDI, must have been disabled and unable to engage in substantial gainful activity (earning at least \$1620 per month) for at least 12 months. There is no assets limitation
- 

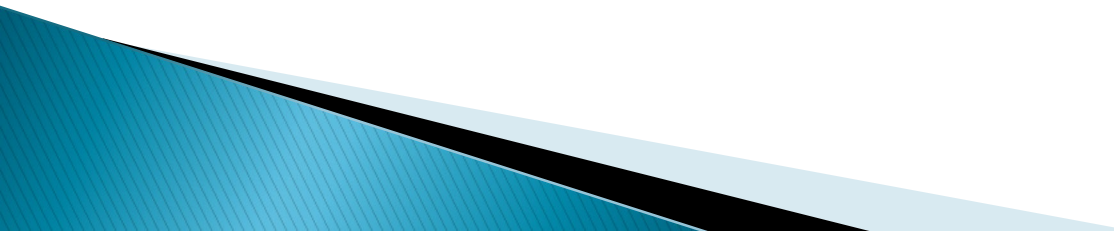
# Application Process

- ▶ 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. Do this questionnaire from perspective of worst performance level
- 

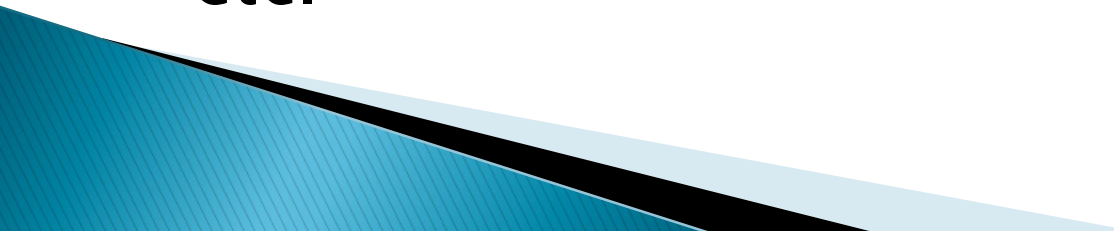
# Application Process

- ▶ In-person or on-the-phone interview with or without the presence of the young adult
  - ▶ Completion by physicians/psychologists of medical documentation that supports inability to earn at least \$1620 per month due to disability
- 

# Disability Determination

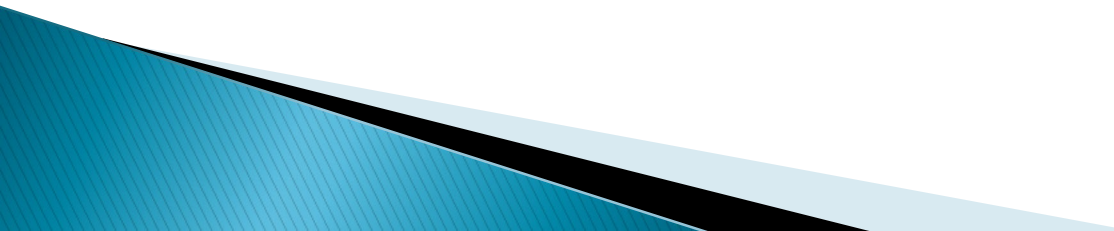
- ▶ Klinefelter Syndrome, Trisomy X, 47,XYY and 48XXYY, etc., are not *listed impairments* that will automatically grant eligibility
  - ▶ Individual determination decides if an individual's impairment due to extra X or Y chromosome(s) is equal to the requirements of a listed impairment
  - ▶ There must be physical, developmental or psychiatric impairment preventing the individual from “substantial gainful activity”
- 

# Examples of co-morbid disabling conditions include:

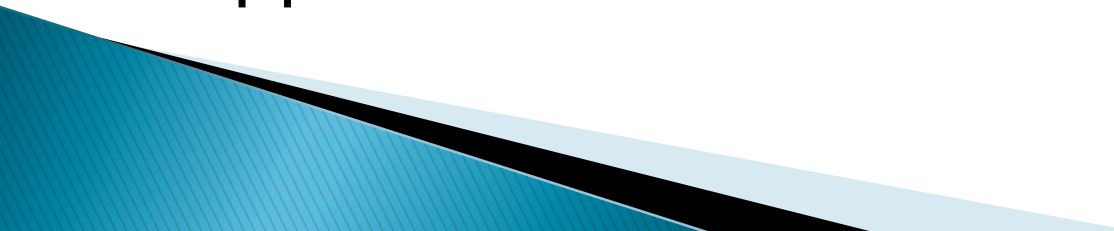
- ▶ Psychiatric: severe depression, anxiety, mood disorders, psychotic disturbances
  - ▶ Developmental: intellectual disability or autism spectrum disorder
  - ▶ Physical: seizure disorder, severe scoliosis, disabling asthma, congenital heart defect, etc.
- 



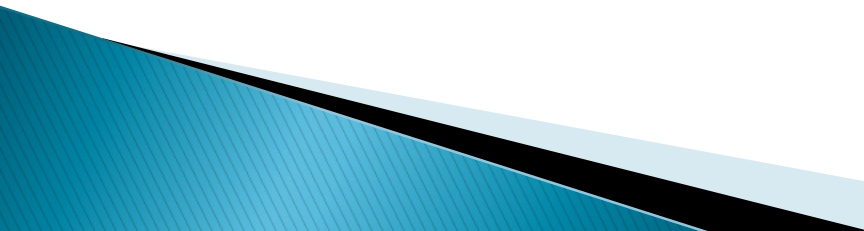
# Disability Profile

- ▶ A successful application requires a complete picture of the number and severity of symptoms
  - ▶ The additive effect of the clinical picture can produce an inability to work and consistently earn \$1620 per month
  - ▶ It is helpful if clinicians can describe the X/Y chromosome variation and tie it to inability of the person to self-support at this time
- 

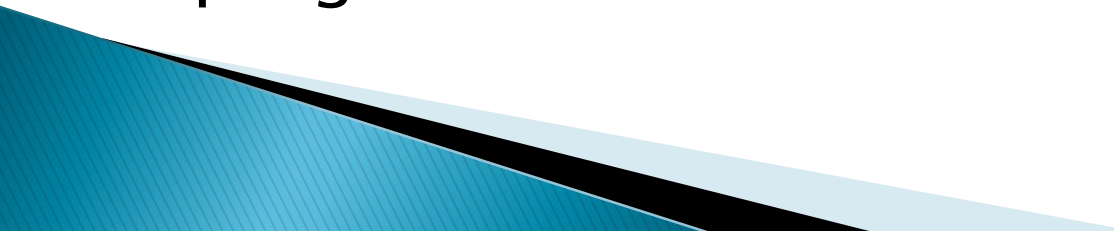
# Application Timeline

- ▶ 7 to 9 months for determination of disability
  - ▶ 55% of applications rejected on first round; use of an advocate or specialized attorney to help prepare the application or appeal may increase chances of success
  - ▶ If rejected, file an appeal within 90 days, and use an attorney or an advocate to prepare the appeal
- 

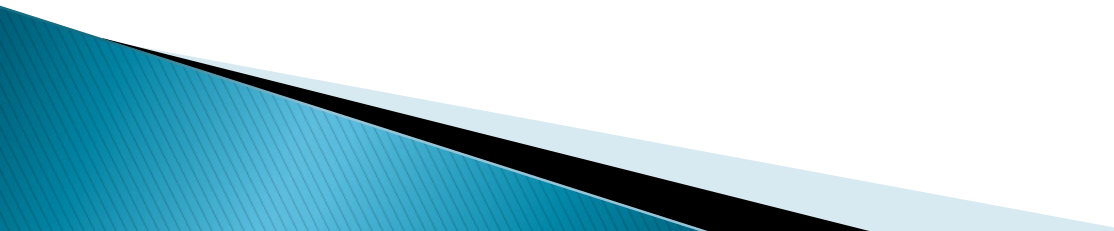
# Medical Benefits of SSI/SSDI

- ▶ With receipt of SSI, recipient usually qualifies for Medicaid. It is always secondary to any private insurance that the individual has
  - ▶ After 24 months receiving SSDI, a recipient qualifies for Medicare
  - ▶ If an individual loses SSI or SSDI because of earned income, many states will permit the individual to stay on Medicaid
  - ▶ Ticket to Work may allow SSI or SSDI to stay on Medicare
- 


# Developmental disabilities

- ▶ Services vary significantly by state
  - ▶ 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

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

# Additional Benefits

- ▶ SNAP (Food Stamps)– based on income at or below 130% of Federal poverty level– \$14,580 for a single adult
  - ▶ Housing assistance (Section 8 vouchers) or affordable income-determined housing– usually there are waiting lists (3–10 years)
  - ▶ General assistance
  - ▶ These are all locally determined
- 

# Contact Information

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