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association for x and y
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Transition to Adulthood for Individuals with X and Y Variations

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Introduction

The focus of this document is on the transition from adolescence to adulthood in children with extra X and Y chromosomes. There is little research in transition for this population, and therefore its recommendations draw from experience and best practices within various disciplines including education, law, psychology, social services. Its guidance is directed to health care providers as well as young people and their families, and educators and social services providers. Health care services transition from pediatric to adult providers is a distinct topic that will be covered separately by another document developed by physicians, nurses and other health care providers.

Transition is the process of attaining adulthood and independence from family. For young people with special health care needs or developmental delays, transition provides additional challenges beyond the typical difficulties of learning to coordinate it all as an adult: finances, health care decisions, post-secondary education, career, relationships. For young people with sex chromosome aneuploidy (SCA), there may be multiple challenges to being able to attain adult functioning as easily as siblings and peers.

This document covers transition considerations in the areas of:

- Financial and health care decision making
- Post-secondary education
- Work and vocational programming
- Government services
- Life skills
- Legal considerations
- Housing
- Healthcare

The challenge in developing this document is that there is a great range of functioning within the SCA population. We know that at least one-third of these young adults have minimal learning or emotional complications. Those with Klinefelter syndrome or a variant may have only hypogonadism or infertility, while those with Trisomy X or XYY have only an extra chromosome with no symptoms. These young people navigate the transition to adulthood with only typical maturation “hiccups”. If they have any health issues, such as requiring hormone replacement, transferring from pediatric to adult primary care providers and specialists may be the only major concern.

But for the majority with additional barriers, such as learning disability, psychiatric difficulties including anxiety or ADHD, or chronic medical conditions, transition becomes a more complicated and most likely a prolonged process. While most individuals with SCA have intelligence in the normal range, there is a small percentage with intellectual disability or severe mental illness who will require life-long support. For many individuals, however, their cognitive and emotional functioning puts them somewhere in the “middle”. That means that the process will take somewhat longer than typical, and that a range of supports may be needed, from post-secondary educational accommodations to government income supports and Medicaid waiver services.

Planning for transition should begin taking place at age 14. For those who have a 504 plan or an Individualized Education Program (IEP), services through the schools are governed by IDEA, the Individuals with Disabilities Act. This act guarantees a “free and appropriate public education” as well as the services required to assist the young person with learning. It may include specialized educational services, accommodations in the classroom, speech therapy, PT and OT, and other medical services necessary for education, and vocational readiness programs. IDEA ends once the student either graduates from high school or at age 21. Once the young person is no longer covered by IDEA, the Americans with Disabilities Act, ADA, governs any special services that are necessary. While services under IDEA are guaranteed and an entitlement for students with disabilities, those governed by ADA require the individual to apply and to meet stringent qualifications to obtain services.

It is difficult for parents of a young teen (or for a pediatrician or teacher) to project the level of functioning of a child who may be in middle or high school. The structure of school as well as support at home often allows the young person to be successful in classroom work and school activities. But once graduated from that structure, young people with poor executive functioning and social skills, in addition to learning disabilities, may struggle, failing out of college, overdrawing their bank accounts, loosing employment, failing to fill prescriptions or follow up with the physician. The wise approach is to make a realistic assessment of the young person’s abilities to accomplish transition successfully while keeping a Plan B on the side should more support be required.

Supports that may be necessary include:

- Guardianship, power of attorney or shared decision-making (See Legal Supports)
- Vocational Rehabilitation training and employment support
- Income support (Supplemental Security Income-SSI or Social Security Disability Income-SSDI)
- Medicaid
- Medicaid waiver developmental disabilities support services or psychiatric services
- SNAP (once known as food stamps)
- Housing assistance (Section 8; other State programs)

This document provides generic information for preserving eligibility for these services. Many services and qualifying criteria are State-specific. The Resource section provides information for learning about those services in the state in which the young person lives.

Financial and Healthcare Decision-Making

An important element of transition to adulthood is that at age eighteen, a young person is considered an adult, and is viewed as someone responsible independently for health care, financial, and all other decisions. The parent no longer has any ability to be involved, absent express permission from the son or daughter. Where there is developmental delay, including immaturity and impulsiveness, or intellectual disability such that the young adult cannot understand financial or medical information, there are provisions that permit parents legally to continue to provide support with decision-making. This section will overview the documents that allow a responsible party, usually the parent, to continue helping the young adult to make financial, health care and legal decisions:

- HIPPA consent
- Health care power-of-attorney or proxy
- Durable power-of-attorney for legal and financial matters
- Shared decision-making
- Guardianship or conservatorship

In the previous section concerning healthcare transition, the impact of HIPPA (Healthcare Information Privacy and Portability Act) on sharing clinical information with parents of children over age 18 was discussed. Absent the young adult's specifically granting written permission to providers to speak with parents, clinicians may not discuss any medical information. Few young people at age eighteen are ready for complete medical independence from their parents. This is particularly true for young adults with SCA who may have complicated dental and medical management issues. Parents will need to ask the young adult to sign **HIPPA forms designating them an authorized party** to share medical information. This is done at the healthcare provider's office after the eighteenth birthday and annually thereafter. The adult can revoke HIPPA consent at any time.

Health care power-of-attorney or health care proxy is also granted by an adult of age 18 or over. It designates a party to make health care decisions should the adult become incapacitated or too ill to do so. This document may also include an **advanced directive** that instructs the responsible party about heroic measures in end stage illness or end-of-life decisions. Most health care institutions have copies of such forms for completion. Forms are also available online at most State health department websites. The form should be completed in the state where the adult resides. The adult may revoke the designation at any time.

Durable power-of-attorney for legal and financial matters is completed by the adult designating a responsible party, often a parent or a spouse, to take financial and legal actions on his behalf, such as opening or closing bank accounts, filing and paying taxes, applying for and administering government benefits such as Medicaid, or contracting for insurance. A durable power of attorney will continue if the adult becomes incapacitated. It is revocable at any time. The power of attorney needs to conform to State law and will specifically list the areas where the "attorney-in-fact" is designated to act.

Guardianship requires petition to a court in the state where the young adult lives. State law will govern what is required for the application, but it generally requires a statement from at least one physician or psychologist, often from two, documenting that the adult is unable to handle his or her own affairs due to developmental or mental incapacity. In some States, guardianship also encompasses **conservatorship** giving the guardian control over all financial, legal and medical decisions. A number of states have a separate guardianship provision for individuals with developmental disabilities. This designates a "guardian of the person" for health care decision-making but does not extend the guardianship to financial or legal decision making. The adult under developmental disabilities guardianship of the person would need to sign a durable power of attorney granting parents or other responsible party permission to act on his or her behalf on financial or legal matters.

Many parents mistakenly believe that taking guardianship will make them personally liable for any debts or damages caused by their adult child. That is not generally the case. Although a guardian with responsibility for financial affairs is responsible for seeing that all bills are paid, if the young person has no assets to cover an expense, the guardian is not responsible for the debt or the damage.

It is increasingly difficult to convince courts to award guardianship to a parent where the young adult has a developmental disability but is relatively "high functioning" or has an IQ of over 60 or 70. This is the case for most individuals with SCA. For these individuals, a recent concept called **supported decision making (**sometimes, shared decision making) provides a more appropriate means of helping a young adult to assume responsibility for health care, financial and legal affairs.

Supported decision-making recognizes that there are many alternatives, depending on why people think guardianship may be desirable in the first instance. For example, if the issue is financial, there are alternatives including representative payee-ships for SSI payments, authorized representation for Medicaid benefits, joint or limited bank accounts, credit or bank cards with predetermined limits, and powers of attorney. For healthcare, persons with developmental disabilities or delays may execute a healthcare proxy. Formal supported decision making is not available in every state. This website summarizes guardianship and supported decision-making provisions by state:

http://www.supporteddecisionmaking.org/states

Planning for Transition during High School

Students with an Individualized Education Plan (IEP) generally are included in the IEP process at the end of the school year prior to beginning high school. For many individuals, this occurs at about age 14 but may be later for those who are not on the same track educationally as their chronological peers. During this IEP meeting prior to the student's transition to high school, several possibilities should be discussed regarding the individual's potential with respect to future employment and/or continued education after graduation.

For many individuals with an X and/or Y chromosome variation, the potential exists for employment similar to that possible for neurotypical peers but which may begin at a later time than those peers and require additional supports (discussed in Vocational Services). Anecdotal evidence suggests that these individuals will benefit most from having volunteer and/or paid work experience prior to the age of 18 in order to help them best transition to the workplace immediately after high school, after post-secondary education, or later in adulthood. Assessing the interests and aptitudes of a person with an X and/or Y chromosome variation provides a basis for determining potential volunteer or paid work experiences. Functional level and challenges should be also considered in the process and may help eliminate opportunities which would not be suitable. A variety of job options during the high school years should be identified in order to hopefully find one which is appropriate for the individual to prepare for future employment after high school or beyond.

The IEP for transition to high school can include both goals related to the student's possible future employment and IEP team members able to provide support relevant to that determination. Incorporating goals for both hard (career-related) and soft (social interactions, promptness, etc.) job skills is optimum for preparing the high school student for potential employment. When appropriate, including state Vocational Rehabilitation (VR) Agency counselors as IEP team members will help not only in determining feasible work-related IEP goals but also in identifying potential places of employment and/or training for employment. Optimally, the IEP should include goals for work opportunities and/or training each year of high school.

Parents/guardians should seek work opportunities privately if their student is homeschooled or is enrolled in a public or private school which does not or will not offer them. Friends, neighbors, and other families with an individual with a disability are good resources for finding work opportunities, as are co-workers and business colleagues. Local and state disability advocacy groups may also be able to assist families in locating appropriate work for their high school students. Individuals at local schools, including teachers, counselors, student organization advisors, etc. are also potential sources of contacts for finding volunteer or paid employment.

For students seeking and with the potential to attend a post-secondary educational institution, appropriate courses, IEP goals (if applicable), etc. should also be determined in conjunction with the relevant school staff (counselors, teachers, IEP team members, etc.) in order to best prepare the student academically, socially, etc. for that future educational setting. Yearly reviews throughout high school will help in assessing whether the student is making adequate progress towards achieving competency for a post-secondary setting.

Post-Secondary Educational Programs

Individuals with an X and/or Y chromosome variation who desire and having the capacity to attend a post-secondary educational program may or may not need academic supports to be successful in that setting.   For those who do, such provisions are available under the Americans with Disabilities Act (ADA), and several different types of educational settings may be suitable. These include attending a college with a specialized program (designated tutors, assistance with daily living, etc.) for individuals with disabilities (many of these programs are quite expensive) or attending an educational institution which includes and supports but is not limited to individuals with disabilities. Colleges providing a specialized educational setting for those with disabilities may offer an array of support, and these institutions should be contacted directly to determine if they may be a good fit for the potential student.

When supports (tutoring, classroom and testing accommodations, etc.) are needed in a traditional post-secondary educational setting, students should contact the Office of Disability Services at their institution to determine what documentation is required to obtain them. Some of these offices will provide the requisite testing and documentation while others require it to be provided by the student. After appropriate accommodations are determined from the documentation, the Office of Disability Services will convey them to each of the student's instructors throughout the duration of the designated program of study. However, it is the student's responsibility to confirm the accommodation with each instructor. This self-advocacy by the student is necessary because parents may not independently communicate with instructors and advisers. The student may, however, sign a FERPA (Family Educational Rights Privacy Act) release to allow the parents to obtain information about their student from the institution of higher education.

Other considerations which should be included when post-secondary education is sought are the level of independent living skills of and financial support needed by the individual with an X and/or Y chromosome variation. For students with limited independent living skills, options other than the traditional residential setting should be considered, especially because of the limited structure offered in the majority of secondary educational institutions. Commuting and online instruction may be preferable to traditional dorm living, at least initially. Taking a gap year (or longer) prior to beginning a program in higher education may be another appropriate option in order to allow the individual more time to mature in needed skills. Financial support for some post-secondary students with an X and/or Y chromosome variation may be available from a number of sources. VR agencies, for example, may be able to provide direct financial assistance to these individuals or direct them to other programs that provide tuition assistance for college and vocational schools. However, family financial and/or other requirements must be met in some instances to qualify for this assistance.

The PACER National Parent Center for Transition and Employment is an excellent source of available college and other post-secondary programs for young adults with learning disabilities. It also offers a wealth of information on transition issues:

Inclusive Postsecondary Opportunities for Students with Intellectual Disabilities - PACER's National Parent Center on Transition and Employment

Vocational Services (training, workplace accommodations, placement and job coaching)

All states have government funded programs for individuals who have disabilities that impact successful employment. Vocational Rehabilitation (VR) agencies help individuals prepare for, obtain, maintain, and regain employment. These services are funded by Federal and State funds. They may have counselors who are involved with the local school districts and attend IEP meetings, but an individual does not have to be in school to access VR services. To find your state VR agency, check https://www.askearn.org/state-vocational-rehabilitation-agencies/.

VR services for an individual with a disability that impacts employment may be requested in a number of ways. If the family member attends school, request VR services to be included in the IEP. If your family member is not in school, request the services yourself directly from the VR agency. Services require an eligibility determination, often based on a neuropsychological evaluation. Make certain that you have a

recent, thorough evaluation for your family member obtained through the school, VR, or privately. Confirm that the updated neuropsychological and medical evaluations include all areas which need to be considered for VR eligibility. VR counselors usually are not familiar with X and Y chromosome variations. A multi-specialty evaluation conducted by a medical center completely versed in SCA, such as one of the ACRC sites, can identify and detail those functional areas that may require specialized training and workplace accommodations. Many VR agencies have priority listings for services. Individuals with two or more areas of disability, a common occurrence in SCA, may have priority for service delivery. Confer with other families of individuals with disabilities who are currently receiving VR services to learn the process and limitations in your state. Remember that accessing services may take time, so start as soon as possible and politely persist in requesting the needed services until they are obtained.

VR agencies can provide specialized testing to determine suitable jobs for an individual with an X and/or Y chromosome variation. After this determination, placement with appropriate employers can also be facilitated through VR directly or after obtaining the requisite training/education. Job coaches provided by VR agencies can help an individual to succeed in a job placement and ensure appropriate accommodations are provided to the employee who self-identifies to an employer as an individual with a disability.

Individuals who successfully obtain work after graduation from high school, vocational schools or college, sometimes find that they have difficulty retaining employment. When the cause of difficulty in keeping a job is disability, these individuals are also qualified to use services through VR agencies. The application process is the same whether an applicant is 18 or 40. Recent multi-specialty evaluation of functional medical and psychological deficits is necessary in order to obtain the most appropriate services in a timely manner, without having to sit on a waiting list.

VR agencies can sometimes support college and vocational program tuition, although a family’s income will be counted unless the individual is independent or receives SSI or SSDI income support. Other supports for which a VR agency may pay include transportation, medical services, assistive technology or medical equipment, as long as employment is dependent on these supports.

Preserving Eligibility for Government Services

Government services and income support may be available to children before age 18 if the family has a very low income, or if a very severe disability makes a child eligible for a Medicaid “waiver” to fund medical or additional services such as respite and recreation. In general, however, children with X and Y variations are unlikely to qualify for such waivers. At age 18 or over, however, a young person may qualify for government programs based only on his or her own assets and income, not the parent’s.

Most government programs are “means-tested”, requiring that the applicant have both income and assets in his or her own name below a certain level. For instance, it is common that eligibility for Medicaid requires an income of less than 130 percent of the poverty level and assets (bank accounts, savings bonds, etc.) of less than $2000. Supplemental Security Income (SSI) requires that the applicant earn no more than $1690 per month and have assets of less than $2000. If a child has a bank account of $10,000 given by a grandparent, this amount of funds will exclude him from Medicaid, or SSI. But parents can preserve eligibility for their child or adolescent by placing such assets in a **Supplemental Needs trust** or setting up a trust to be funded once the young person inherits any assets. The trust will shelter the assets and any income that they produce from Medicaid or SSI. Or a young adult with SCA can place assets in an **ABLE account**, a tax free account that will shelter funds of less than $100,000 from being considered countable assets.

It is recommended that families place assets in a trust prior to age fifteen, because some states have instituted "look back" periods for Medicaid. A trust can be set up at any point, but it should be done by an experienced estate attorney familiar with the law governing Supplemental Needs trusts in the state where the young person resides. There are also **"pooled" trusts** available through disability organizations that do not require the legal costs of setting up and administering a separate trust. A parent or other relative can draw up a will that creates a supplement needs trust on their death, and any inheritance to the young person will be placed in that trust. The funds in the Supplemental Needs Trust can be used for expenses such as education, travel, medical care. If the beneficiary is receiving SSI, funds cannot be used for food, housing or clothing, but there are few other restrictions. A trust also allows the trustee to oversee expenditures so that young adults cannot squander the assets with immature spending decision.

In addition to preserving the young person's financial eligibility for services, parents or guardians need to preserve a **well-organized file of all medical records of diagnosis and treatment as well as educational and psychological records**. These records are essential for establishing that a disability occurred before the age of 26 and for providing a continuing record of any disabling symptoms that can establish a need for school and workplace accommodations, for Vocational Rehabilitation, for SSI/SSDI applications, or for Medicaid waiver services for developmental disability or psychiatric illness.

What Government-funded Services may be Necessary?

Many young adults with SCA need no government services. But for those with significant learning disabilities or psychiatric complications, successfully completing college or vocational training and becoming established in a career will take a number of years, during which they will have fairly low incomes and will need assistance with paying tuition, obtaining health care, and paying for food, housing and transportation.

Vocational Rehabilitation is covered separately on Pages 6-7. This is a service available in every state that assists individuals with medical conditions affecting employability to obtain counseling, training, assistance with placement and accommodations and job coaching.

Medical Insurance/Medicaid/Medicare

Young adults may be covered on their parents '**medical insurance** until age 26. For those who age out, or are without insurance, there are options for being covered through employment, through the Affordable Care Act (ACA) or through **Medicaid**. One advantage of the ACA is that it eliminates the exclusion of pre-existing conditions. Adults with low incomes (but whose incomes exceed the Medicaid levels) often receive a substantial subsidy to pay the premium for coverage through the ACA exchanges. Before the ACA, many children and adults with SCA were denied health insurance, were assessed additional premiums, or had any medical condition related to the extra X or Y chromosome(s) excluded from coverage.

(**Medicare** becomes effective for persons with disabilities under the age of 65 after 24 months of receiving SSDI (Social Security Disability Income). Please see SSI/SSDI below.)

State requirements for Medicaid eligibility vary widely. Some states have expanded Medicaid to cover low income adults while other states cover only adults with disabilities or those who are parents. Any adult who qualifies for Supplemental Security Income (SSI) is usually automatically also eligible for Medicaid. This website summarizes Medicaid eligibility by state:

https://www.coverage.com/insurance/health/state-by-state-medicaid-guide/

Developmental Disability and Mental Health Medicaid "Waiver" Services

Medicaid also funds community services for adults who qualify for community services through state **developmental disabilities and mental health services**. These are called **Medicaid "waiver services** because they are funded by Medicaid insurance but may not involve "medical" treatment. Many individuals with X and Y chromosome variations do not qualify in their states or even need these services because the criteria for eligibility require substantial developmental delay or a severe and persistent mental illness. A diagnosis of SCA alone will not qualify an adult for these services. Developmental disability services may require that the individual have intellectual disability (IQ of less than 70) or a separate but related diagnosis such as autism spectrum disorder or seizure disorder. Mental health services require severely disabling psychiatric conditions, usually with a history of hospitalization. Parents should check into their state's requirements and make application as early as possible because the intake process can take months, and there are waiting lists for services in many states. Waiver services for individuals with developmental disabilities may include life skills training, community activities, day programs, and housing such as supported apartments or group homes. Waiver services for those with severe psychiatric illness often include day programs and psychiatric rehabilitation, medication management and supported housing.

When applying for any government service or funding it is important to have detailed neuropsychiatric testing done by a professional familiar with SCA, who can document learning, information processing, executive functioning, and communication skills. Attention deficit, anxiety or depression, and diagnoses such as bipolar disorder, or schizophrenia need to be carefully documented by a psychiatrist or psychologist. A physician needs to outline low muscle tone, fatigue, and other medical complications such as hyper-flexible joints, poor balance, or scoliosis affect the individual's ability to self-support. For those with issues such as tremor or seizure disorder, a neurological evaluation should be presented. If the adult received special education services, the evaluation on which services were based as well as the most recent IEP or 504 plan should be presented as part of the application. A **comprehensive multi-specialty evaluation conducted at one of the AXYS Clinic and Research Consortium (ACRC)** sites can provide a summary by a clinician completely familiar with SCA that makes a well-supported argument for income support or waiver services. Such an evaluation is much more likely to educate disability evaluators in government offices about the impact of SCA on employability and medical complications, and need for income support, Medicaid coverage, and other support services. This will place the adult in a higher priority category so that he or she has a greater change of application success.

For a listing of State developmental disabilities offices:

https://www.nasddds.org/state-agencies/#MD

For assistance in finding mental health services, including psychiatric rehabilitation programs, contact the National Alliance on Mental Illness, NAMI: www.nami.org

SSI/SSDI

Income support may be available for individuals with SCA through **Supplemental Security Income (SSI)** or **Social Security Disability Income (SSDI)**. Some states also have temporary income support programs through General Assistance. A majority of individuals with SCA will not qualify for income support but a substantial number do apply successfully at some point in their lives. The important thing to understand is that sex chromosome disorders of any variation are not considered "listed" disabling conditions unless they are associated with symptoms and co-morbid conditions that meet the criteria for disability under the Social Security Administration, which administers both programs. To qualify, the conditions must be so severe that they prevent "substantial gainful activity", or the ability to work and earn at least $1690 per month. Additional information regarding how the Social Security Administration considers genetic conditions that affect multiple body systems at:

https://www.ssa.gov/disability/professionals/bluebook/10.00-MultipleBody-Adult.htm

To qualify for SSI or SSDI, an adult cannot have an earned income in excess of $1690 in 2025. (This is known as "substantial gainful activity." It changes yearly. The updated dollar amount can be found at www.ssa.gov.) For SSI, the individual cannot have assets of more than $2000. SSDI is not means tested. The Social Security Administration will decide which program an individual qualifies for. The website for SSI and SSDI is https://www.ssa.gov/disability/. It is clear and well-written. Families that intend to apply for coverage should be completely familiar with the application process and the regulations on the site. Application for adult benefits should not take place before the applicant's 18th birthday, at which point she will be considered as an independent household and only her own income and assets will be counted.

Application can be made for SSI or SSDI online or by calling to make an appointment with the Social Security office. Full instructions are available on the website. It is recommended that documents be collected using this guide from the Social Security Administration:

EN-05-10519 - Checklist for Online Adult Disability Application (ssa.gov)

The best chance for success in an application for SSI/SSDI is the comprehensive evaluation conducted by one of the ACRC sites (https://genetic.org/im-adult-looking-answers/clinics/) with summaries provided by healthcare providers fully familiar with SCA and its impact on employability. Disability evaluators for Social Security are often unfamiliar with SCA and may consider these genetic conditions to affect endocrine systems only or to produce only mild disability. For that reason, a multispecialty evaluation that can walk the evaluator through the cognitive, medical and psychological barriers to "substantial gainful activity" is critical.

For individuals who are awarded SSI or SSDI, it is possible to work. Those on SSDI may earn up to $1690 per month in 2025 without losing benefits. Those on SSI will have their benefits reduced by approximately $1 for every $2 earned after the first $65 per month. Individuals on SSI or SSDI will probably be re-evaluated every two to three years to determine that they are still disabled.

SSI will generally qualify a recipient for Medicaid, and often, for food stamps or Supplemental Nutrition Assistance Program (SNAP), as well. SSDI recipients will qualify for Medicare after 24 months of receiving benefits.

SNAP, HEAP, Section 8

Other government assistance programs open to individuals with low incomes, regardless of whether they receive disability benefits, include **SNAP (previously called Food Stamps), Home Energy Assistance Program or HEAP,** and **Section 8 Housing Vouchers.** States and localities have varying qualifications for the programs. There are generally waiting lists of up to ten years for Section 8 housing vouchers.

Centers for Independent Living

Families and individuals can get information on government programs in their area by consulting one of the **Centers for Independent Living** serving their state and region. Independent Living Centers can provide comprehensive assistance with identifying government benefits for persons with disabilities as well as life skills training, advocacy, and recreation programs:

https://acl.gov/programs/centers-independent-living/list-cils-and-spils

Promoting the Development of Life Skills

Adolescents and young adults all need to develop life skills that allow them to function independently of their parents, and assume age-appropriate activities, such as doing their own laundry, learning to use a credit card and saving funds for purchases, or taking public transportation. For typically developing young persons, life skills can be learned through observation of their parents and peers, and through “trial and error”, and learning to choose behavior that “works”. For young people with SCA, learning disabilities and executive functioning deficits may be a barrier to acquiring these skills. At the same time, high school students with SCA usually function too well academically to be assigned to “life skills” classes that are designed for those with intellectual disability.

Parents need to judge how well the young person is progressing with developing skills for independence. Although some will need no extra assistance, in many cases, it will be up to the parent to make certain that these skills are taught and practiced safely, beginning when the young person is still at home.

Parents and young adults will find that most Centers for Independent Living have a life skills curriculum that will augment family skills “instruction”. These centers are publicly funded and provide a variety of transition and other services for persons with disabilities. There are also “independent living” programs available through some community colleges. Private transition and independent living residential programs also exist. They can be quite expensive, with annual tuition and residential costs equivalent to that of a private liberal arts college. And there are supported college programs that combine academics with life skills instruction. Many of these programs were developed for young persons with high functioning autism spectrum disorders. They can be appropriate for the needs of young adults with SCA.

Financial literacy is something lacking in many young people, with or without extra chromosomes. An allowance, if the family budget permits it, tied to doing regular chores will give a child a sense of the value of money and the satisfaction of saving for a special purchase. As teens mature, they can be encouraged to take on small projects and even jobs so that they can open low-cost bank accounts, with a debit card (with no overdraft provision) attached. A debit card is like a credit card with training wheels. Learning to pay for something like a cell phone is something that can be built into the teen's budget. By the time that he leaves high school, he should be familiar with and comfortable with banking, small scale budgeting, and regular bill paying.

Young adults with SCA are often delayed in being able to self-support. They may need extra years to become established in full-time work, so may be dependent on their parents into their twenties and even thirties to help pay for tuition, car payments and insurance, and rent. If an adult child is not able to self-support, even temporarily, parents have several options. These include providing financial assistance, if the family budget permits. Parents are wise to make financial assistance contingent on making progress toward independence, whether that is completing an educational or vocational program, or working part time in paid employment or an internship. If there are disabilities that appear to be making self-support unlikely, and this is supported by medical and neuropsychological reports, parents should help with an application for general assistance, SSI or SSDI.

Teens with SCA are just like their peers with respect to household chores. If Mom or Dad is willing to do everything for them, they are unlikely to volunteer. Keep in mind that teens are far more successful in developing **housekeeping, laundry, and food preparation** skills if they are coached in and have lots of hands-on practice with these basic tasks. This is not only important for those going away to college or other training programs, it is critical for maintaining positive family relations if the young adult lives with the family well into his or her twenties. The key is to start early, when the young person is in middle school and junior high. Add additional tasks each year so that by the time of high school graduation, the young adult knows how to cook a basic meal, store food safely, do laundry competently, vacuum, dust and clean a bathroom.

Independence also requires that the young adult be able to travel to school and work independently. Many young adults with SCA learn to drive, but a significant number are unable to pass a driving test or drive safely by age eighteen. (A considerable number also learn to drive in their twenties, once they have gained more maturity and can better manage anxiety. Various agencies for those with disabilities also provide specialized driving education tailored to a person's needs. It is worth looking into these programs.) **Transportation** independence is important for adult life, and should not be discounted. Travel training should be covered in special education classes at school, but this rarely happens. Parents then may need to travel by public transportation with their son or daughter to teach routes and schedules or help them to use apps such as Lyft or Uber, to get to and from shopping, education or work. Some families find that a young person with SCA is comfortable driving short distances locally, although needing to use public transportation for longer commutes.

Young adults with SCA may need guidance in developing **healthy adult relationships**, particularly those involving romance and **sexuality**. It is well documented that adolescents in special education programs are frequently left out of sexuality education or are taught a curriculum that is inappropriate to their learning needs. In addition, few sexuality education programs address the needs of young people whose progress through puberty is atypical, as is often the case for those with Klinefelter syndrome, and occasionally for girls with Trisomy X. Particularly with young adults who are somewhat immature and may have low self-esteem, it is important to help them develop a strong sense of what healthy relationships look and feel like. This is necessary to help teach them to recognize and avoid abusive or exploitative “friendships”. Social skills groups and individual counseling can be used to assist the young person in understanding the give and take of a healthy relationship that benefits both parties. While many young adults with Klinefelter syndrome are infertile, all young adults with SCA need to know exactly how pregnancy occurs, as well as how to avoid pregnancy before a couple is in a relationship and emotionally and financially able to care for an infant.

There are few resources to help parents and other caregivers navigate assisting young people with learning about healthy relationships, particularly those that involve sexuality. Some young adults with SCA do meet the criteria for autism, while many demonstrate “autism” range scores on test domains that measure features such as social anxiety and ability to understand social cues and body language. Among the resources included in this document are books written for parents of young adults with high functioning autism. While not an exact fit for the characteristics of SCA, these books provide some guidance for helping a son or daughter develop healthy relationships.

Internet safety is a concern for all parents. It may be of special concern for children who are somewhat immature for their age, and unable to recognize a relationship that becomes abusive. Parental controls are an option when children are young and not yet able to circumvent them. Once a child can control his own online content, the parents need to tell the child specifically how to recognize and avoid scams and how to avoid being the victim of a sexual predator. Again, there are few resources for helping high functioning young adults with a degree of immaturity develop skills to avoid predators. Parents need to avoid euphemisms when discussing what predators may ask for – meetings in the community, explicit photos, etc. Parents need to make the child comfortable by telling them if they should encounter requests like this online.

It is also important that parents explain very clearly to their adolescent and young adult children that they may be charged criminally if they “sext” another teen, if they download child pornography, or if they exchange sexual comments or attempt to arrange a meeting with another girl or boy who is “underage”. The laws regarding contact with underage or minor children vary by state. But a high school senior who attempts to make online sexual statements to a high school junior can be charged with criminal sexual behavior in some states. Attempting to meet an underage person, even if that person is a police detective impersonating a minor, can result in charges of criminal sexual behavior, even if it is a “victimless” crime. Any sexual “chat” online, or downloading or exchanging pornography, is risky. If the website or chat is under police surveillance, a young person can be identified and arrested. Parents need to make this clear and emphasize and re-emphasize the risk of using the computer for pornography or relationships that veer into sexual topics.

At age eighteen, a young adult will need a **government identification card** for air travel and for other matters, such as banking. For those who do not have a driver’s license, all states also issue government identification cards, usually through the motor vehicle department.

Males over eighteen must register for **Selective Service** even if disability would exempt them from service. This can be done online at https://www.sss.gov/

Young adults should **register to vote** at age eighteen. They may be given opportunities to register while in high school, or when obtaining a driving license.

Young adults need to understand **civil and criminal responsibility** before they reach the adult age of eighteen. They should know what a contract is and what the responsibility is for signing one. They also need to understand criminal responsibility (possible internet crimes are discussed in a previous paragraph) and how to react if they are questioned by law enforcement. Young adults with disabilities are vulnerable in interactions with law enforcement because they may be resistant or disrespectful due to fear. They may also be easily coerced into a false confession. Every parent should teach a young person with SCA to be polite if stopped by law enforcement, and to provide only identification if asked for information. If law enforcement wants to question them, they need to understand that they have "Miranda" rights to request an attorney and otherwise to remain silent until represented by an attorney. This can prevent a false or incriminating confession. Parents need to know that SCA is almost never a defense to a criminal act, and that special treatment due to SCA is unlikely. Should there be a situation involving possible criminal charges, it is best to obtain an attorney to represent the young adult as quickly as possible.

Housing is usually at home or at school initially after high school. Many young adults with SCA can live independently in apartments if they have adequate funds. A significant number, however, do not have the financial, housekeeping, and other life skills necessary to live away from their parents as teens or in their early twenties.

Over the past twenty years, a significant number of **residential life skills programs** have been developed to support high functioning young adults with learning disabilities or autism spectrum disorders in dormitory and apartment settings. Some are associated with colleges and vocational programs. They are usually self-pay and often quite expensive (usually equivalent to private liberal arts college fees) but they may be an option for some families.

If limited finances are likely, and the young person has developmental disabilities that will prevent self-support, there are opportunities to apply for government housing help in paying for housing. The most common program is **Section 8** housing assistance. There are also many Federal and state programs that set aside housing units for adults with disabilities and low incomes. Most programs have waiting lists. An early waiting list application for programs that a young adult may need in the future can result in housing when it is needed in the future. Regional Centers for Independent Living, described on Page 11, can help families identify affordable housing and housing dedicated to those with disabilities.

Supported housing programs are offered by developmental disabilities and mental health non-profit programs. They may include small group homes with part-time or full-time staffing support, or apartment programs with staff members who visit a few times weekly to help residents with housekeeping, finances, and health care. These programs are usually reserved for those who meet the criteria for Medicaid waiver services and have a need for intensive supervision. Many will also have income support through SSI or SSDI. Most individuals with SCA do not have disabilities significant enough to qualify for these programs, but for those with intellectual disability or severe psychiatric disorder, the programs offer sufficient supervision to allow them to live apart from their families.

Healthcare Transition Considerations

Overview of health care transition concerns

- Ability to consent (need for assistance with decision-making)
- Health literacy
- Medical complications
- Assessment of transition readiness
- “Coaching” young adult and family in increasing responsibility for health care self-management
- Health care summary for transfer to adult physicians
- Comprehensive evaluation (neuropsychological testing plus relevant medical information to support college and vocational accommodations, application for government benefits such as SSI/SSDI, Medicaid, and developmental disability or mental health wrap-around or waiver services

Clinical health care transition needs are beyond the scope of this consensus document. The clinical needs of young adults with 47,XXY; 47,XXX; 47,XYY; and 48,XXYY, are complex and vary greatly by both karyotype and individual needs. There are measures that parents can take to insure that transition to adult healthcare status goes as smoothly as possible.

Begin discussing transition to another primary care provider while your son or daughter is in high school. If the primary care physician is a family practitioner, your child can stay with the practice. Many pediatricians will see a young adult until age 21, or even age 26. But if he or she will need to move to an adult provider, request that the pediatrician create a summary of the medical history and current treatment plan, particularly related to SCA.

Most young adults, regardless of special needs or learning disabilities, require decision-making support from their parents, at least initially. This is easiest to establish with a health care proxy document or by signing a HIPAA authorization to share information.

There are online questionnaires that can assist a family with understanding their teen’s degree of health literacy and transition readiness. A very useful website for families is:
Got Transition® - Six Core Elements of Health Care Transition™

This website, gottransition.org, has online quizzes for your family to assess your child’s need for support and information in taking on elements of his or her own healthcare. It also guides you through the process, which may take four to six or more years. Some young adults with SCA, particularly those affected by intellectual disability or significant psychiatric conditions, are never able to safely assume individual responsibility for all appointments, medications, and follow-up. Give your child responsibility for the following health care tasks beginning in high school, supervising him or her, until ready to do this independently. If your child can successfully master these tasks before age 21, he or she will be more likely to be successful in self-managing healthcare as an adult:

- Refilling prescriptions and picking them up at the pharmacy
- If there are multiple prescriptions, help the child to fill a weekly medication box and set an app on a phone as a daily reminder
- Phoning or going online to make doctor visits, X-ray and other appointments
- Before a medical visit, help your child to develop a list of issues to discuss with the provider
- If oral instructions are difficult for a child to understand or remember, ask the provider to give the child a written visit note and help your child organize the notes in a folder