A Checklist for Transitioning to Adulthood

This resource has been created to support families as they begin to work through transitioning their loved one. We know this may not be a complete list, but hopefully a helpful tool to understand what needs to be considered, what you need to prepare for and where to go to get support.

Please also note that every state is different in the level of support and resources they provide. If we have left anything out, please feel free to send it to us at info@ring14usa.org.

Early Intervention

- ☐ If you have not already, begin the process of Early Intervention for your child. Check with your local county to set up evaluation.
- ☐ Join a local advocacy group to help educate yourself on what you may need (the ARC, Easter Seals, Global Genes, NORD, EveryLIFE)
- ☐ IDEA (Individuals with Disabilities Education Act) Training
- ☐ Create a will and talk to someone about estate planning.
- ☐ Consider a Special Needs Trust and/or an ABLE Account

12 - 14 Years

- Begin looking into vocational and/or recreational opportunities for your child. Federal Guidelines are to have a written transition plan that includes the student strengths and preferences by the age of 16, some states are age 14. The student is invited to the IEP/Transition Planning Meeting. The Transition plan compliments the IEP, not replaces it.
- ☐ Consider a Vocational Assessment
- ☐ Behavior plan (FBA) by BCBA for Tracking.
- ☐ Understand the Medicaid waiver and learn about Long Term Care options in your state
- □ Write/develop a personalized plan for your young adult (kind of like an IEP, only for all aspects of their life), following the rules in place in your state

16 Years

- ☐ Apply for a Non-driver ID Card. This will provide him/her with a convenient form of government ID.
- ☐ Plan an extensive transition plan in the IEP Pre-vocational skills, pre-community living skills, interest survey.
- □ Look into options of guardianship as well as other options; durable power of attorney, naming a representative and payee for governmental benefits, opening and maintaining a joint bank account, medical power of attorney, etc.

17 Years

- ☐ Prepare to assume Guardianship/
 Conservatorship
 Will possibly need legal aid for this process. At minimum, guardian ad litem to represent your child.
- □ Apply for SSI for your child
 This is what will qualify your child for Medicaid
 when he/she turns 18. Make sure the applicant does
 not have more than \$2,000 in assets (excluding
 primary residence). This benefit may be available to
 some individuals before the age of 18 if his or her
 family is low income or they live in an out-of-home
 residential setting.
- ☐ If the adolescent is male, register for the Selective Service (the Draft). This is required by the government (but does not mean that the individual would actually be drafted) and failure to register can affect eligibility for services. www.sss.gov/register/who-needs-to-register/
- ☐ Write a Letter of Intent. It is important that you write a letter of intent, which explains your child's abilities, support needs, services, current and future benefits. As well as your wishes for his or her future and who will support them either legally and/or as natural supports.

18 Years

- ☐ Apply for Adult Services with the supporting Federal Agency (DDS, Rehab, DMH)
- ☐ Guardianship in place
- ☐ SSI Funding coming in monthly
- ☐ If you have not done so, write/develop a personalized plan for your young adult (kind of like an IEP, only for all aspects of their life), following the rules in place in your state
- ☐ Apply for Section 8 Housing
- ☐ Apply for local and regional housing lists. Ask if there are any portable vouchers for the disability population. There is likely a 10 year wait, but VERY worth the wait.
- ☐ Start researching possible medical care to transition from pediatrician to adult doctor. Check with your current medical team for suggestions or visit one of the 15q Clinic Network Clinics.
- ☐ If in New Jersey apply for Personal Preference Program

21 Years

- ☐ Day after the 21st birthday should look exactly like the day before. Placements should be already visited, funding in place.
- ☐ Apply for the waiver in your state. (Some states you must be 21 to apply and others you do not.)

Parent(s) Approaching Age 62 Years—

Need to make a decision regarding the best age for parent to begin receiving social security benefits. Consider the pros and cons for the parent and the child. It is very important for the parent to review his/her social security statement (info can be found on social security site). For the child consider:

- As soon as parent begins drawing social security on his/her work history:
- + While parent is alive, the child will receive 50% of the parent's social security payment (up to family limit)

- + When parent dies, the child will receive 75% of the parent's social security payment (up to family limit)
- + The child will receive 50% or 75% based on what the parent would receive at full retirement age (even if parent begins to draw SS prior to full retirement age)
- + Child may switch from SSI to regular SS (disabled child benefit) depending on what the payment is (if SS payment does not exceed SSI monthly benefit, then the child will receive both SSI and SS to take the child to the regular SSI benefit
- As soon as the child begins receiving social security based on the parent's work history the clock begins on Medicare. Two years after the child has been receiving social security (disabled child benefit) the child will be eligible for Medicare.

Child Approaching Age 26

Need to determine whether your child can continue to remain on your primary insurance plan if he/she is currently on it. This varies based on the state, the agency, and the policy. Research the following:

- Can my child remain on my primary insurance after age 26 since he/she has a disability?
- If so, what documentation/forms are needed to continue the coverage?



With gratiture to Angleman Syndrome Foundation for sharing resources.

