



TRANSITION TO ADULTHOOD FOR PERSONS WITH COFFIN-LOWRY SYNDROME

Prior to 12 Years Old

- If you have not already, begin the process of obtaining services for your child. (In the United States, Early Intervention services are available (check with your local county to set up an evaluation) or through your local school system depending on the age of your child.
- Join a local advocacy group to help educate yourself on what your family may need (the ARC, Easter Seals, Global Genes, National Organization of Rare Disorders, EveryLIFE are available in the United States). Join the Coffin-Lowry Syndrome Foundation Parent Registry. If you are on Facebook, join the Coffin-Lowry Syndrome Foundation Facebook group@. This is an excellent on-line advocacy group for parents and caregivers of individuals with CLS.
- Create a legal will that specifies your wishes for your loved one with CLS when you are gone. Talk to someone regarding estate planning.
- Consider developing a Special Needs Trust and/or an ABLE Account (for United States) for your loved one with CLS.
- In the United States, some states offer day care for your child up to age 12. Research day care/child care/ sitter options for assistance in caring for your child.

12 – 14 Years

- Begin looking into Vocational and/or Recreational opportunities for your child. For the United States, Federal Guidelines are to have a written transition plan that includes the student's strengths and preferences by the age of 16 (some states specify age 14). The student is invited to the IEP/Transition Planning Meeting. The Transition plan compliments the IEP, not replaces it.
- Consider having a Vocational Assessment conducted for learning skills for potential future employment.



- Complete a Behavior plan (if needed). Begin by having a Functional Behavior Assessment by a board-certified Behavior Analyst for tracking purposes.
- Understand the Medicaid waiver process and learn about services available including Long Term Care options in your county/state (for the United States).
- Write/develop a Personalized Plan for your young adult (similar to an IEP in the United States, only for all aspects of their life – social, housing, recreational, medical needs, guardianship, etc.)

16 Years

- Apply for a Non-driver ID Card (for the United States). This will provide him/her with a convenient form of a government issued ID. It never expires.
- Plan an extensive transition plan in your loved ones' IEP (US). Complete a pre-vocational skills, pre-community living skills, interest survey.
- Consider options for Guardianship. Additional legal and financial areas to consider: 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. You will possibly need legal aid for this process; at a minimum, you will need a guardian ad litem to represent your child. (This is the process in the United States.)
- For Individuals with CLS in the United States, apply for Supplemental Security Income (SSI) for your child. Coffin-Lowry Syndrome is a designated disability specified by the Social Security Administration. SSI will qualify your child for Medicaid (medical insurance) when he/she turns 18. The applicant cannot have more than \$2,000 in assets (excluding primary residence). This benefit may be available to some individuals before the age of 18 depending on the income of the family or they live in an out-of-home residential setting. Contact the Social Security Administration for more details.
- If the adolescent is male, register for the Selective Service (the Draft). This is required by the US 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) for US.
- Take necessary steps to enact guardianship plan.
- Carefully track funding received monthly (SSI for United States).
- If you have not done so, write/develop a personalized plan for your young adult (similar to an IEP, only for all aspects of their life), following the rules in place in your state.
- Apply for local and regional housing lists. Ask if there are any portable vouchers for the disabled population.
- Consider transitioning from a pediatrician to an adult medical provider. This will eventually be needed as they transition to Medicaid services. You will need to locate a physician who accepts adult Medicaid. Research options in your area. Check with your current medical team for suggestions.
- For New Jersey, US residents, apply for Personal Preference Program.

21 Years

- The day after the 21st birthday should look exactly like the day before. Placements and funding should be in place.
- Apply for the Medicaid waiver program in your state in the United States. (Application age varies by state.)
- If your loved one is living with you, consider back up housing options if something were to happen and no longer living in your household would be an option.
- If living with you is not an option for your loved one, seek out alternative accommodations offered in your community through agencies available in your area.



Parent(s) Approaching Age 62 Years

Parents will need to consider the best age for them (the parents) to begin receiving Social Security benefits. Consult with Social Security office as this will need to be recorded as to not affect the child's SSI 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 the social security website). This is for US parents only.