

Transitions Checklist

FOR INDIVIDUALS WITH CFC SYNDROME
AND THEIR FAMILIES IN THE US



Prepared by CFC International and based on resources from collaboration with organizations in the rare disease community.



CFC International
Cardio-Facio-Cutaneous Syndrome

This is a resource for CFC International's US families and caregivers to reference during your child's transitions. We know this list is not comprehensive, but may be one tool of many that can help you understand what needs should be considered at different life stages. Please note that every state provides a different level of support and resources. If you feel we have left anything out, please feel free to contact us at info@cfcsyndrome.org.

EARLY INTERVENTION

- Work with your county's Early Intervention program to set up an evaluation.
- Develop an Individualized Family Support Plan (IFSP) for authorized support services such as respite, therapies, or personal care supplies.
- Join local or national advocacy groups to educate yourself on what you may need (CFC International, Rasopathy Network, the ARC, Easter Seals, Global Genes, NORD, EveryLIFE).
- Attend IDEA (Individuals with Disabilities Education Act) Training.
- Create a will and talk to someone about estate planning.
- Consider a Special Needs Trust and/or ABLE Account.
- Develop a family emergency plan.

3 TO 5 YEARS

- Develop an IEP based on comprehensive assessment in all areas your child may need support: academic, functional, daily living, social, emotional, behavioral, sensory, communication, mobility, occupational, recreational, and vocational; goals must be measurable; progress must be made; updated annually. Include emergency plans and seizure action plans.
- Visit and evaluate the need for potential early learning centers or public Pre-K programming for children with special needs.

5 YEARS

- Revise the IEP- Reassessment at the transition into elementary school in areas of suspected disability (see above) is required; goals must be measurable; progress must be made; and the IEP must be updated annually. Include emergency plans and seizure action plans.
- For students on a 504 plan, consider the range of services and accommodations that might be needed for your child: Consider a Behavior plan (FBA) if needed.

6 TO 11 YEARS

- Revise the IEP annually. Reassessment is required every 3 years, unless your child has a change in status or an IEP team member requests an earlier assessment (no more than one assessment per need area per year). Include updated emergency plans and seizure action plans. Update 504 plan annually.

12 – 14 YEARS

- Revise the IEP annually; conduct transition assessment every year at transition age. Include emergency plans and seizure action plans. Update 504 annually.
- Learn about diploma options and requirements; discuss these options with your child and the IEP team; understand your child's graduation plan and the timeline for graduation.
- Develop a transition plan as part of your child's IEP. The transition plan complements the IEP, but does not replace it.
Federal Guidelines require a written transition plan that includes the student's needs, strengths, and preferences by the age of 16 (some states require this by age 14). Begin this process by requesting age-appropriate transition assessments in: training, education, employment/vocational skills, and (where appropriate) independent living skills. This will develop measurable postsecondary goals, measurable annual goals, services, activities, instruction, and related services for your child. Your child should be assessed and this transition plan should be updated annually. The student and any relevant outside agencies or services needed must be invited to the IEP when transition planning is discussed. For 504 plans, list reasonable accommodations that might be needed in adulthood.
- Consider a Vocational Assessment.
- Begin looking into vocational and/or recreational opportunities for your child. Programs should focus on social skills, community participation, daily living skills like cooking and financial literacy, decision making, self-advocacy, and self-determination. Make sure they provide transportation when necessary.
- Contact your state's Vocational Rehabilitation department at age 14 to begin services.
- Begin health care transition readiness assessments and training; revise annually.
- Talk with your teen's medical providers about the transition to adult care. Begin researching potential adult providers now.
- Understand the Medicaid waiver and learn about Long Term Care and Home & Community-Based Services (HCBS) options in your state.
- Develop a personalized 'future plan' for your young adults (like an IEP, only for all aspects of their life), following the rules in place in your state.

TRANSITION CHECKLIST CONTINUED

AGE 16

- Apply for a driver's license or non-driver ID Card in order to have a form of government ID.
- IEP and transition plan must be revised annually to update annual age-appropriate transition assessments in: training, education, employment/vocation, and - where appropriate - independent living skills. Review and revise your child's course of study to ensure that courses taken have an impact on the student's educational, vocational, and other post-secondary goals. Update IEP services to include travel training and life skills training. Include emergency plans and seizure action plans. Update the 504 plan annually.
- Determine if your child will graduate with a diploma or a certificate of completion.
- Explore work-based learning or volunteer opportunities. Learn about Workability and Employment First laws and opportunities.
- Look into options of guardianship as well as other options for person-centered planning and durable power of attorney. Name a representative and payee for government benefits. Open and maintain a joint bank account, medical power of attorney, and develop advanced healthcare directives.
- Assess if your child understands his/her healthcare needs and how to manage them. Begin helping them keep medical records, and manage medications and appointments if possible.
- If possible, teach your child how to handle emergency vs. non-emergency medical situations, and how to communicate appropriate information to emergency and medical responders.
- Help them recognize healthy and unhealthy behaviors.

AGE 17

- IEP and transition plan (or 504 plan) must be revised. Include emergency plans and seizure action plans.
- Learn about the transfer of parental rights and other legal changes at the age of majority.
- Prepare to assume guardianship/conservatorship. Consider employing legal assistance if needed. Consider the need for guardian ad litem to represent your child.
- Apply for SSI for your child so that he/she may qualify for Medicaid at age 18. Your child may qualify before age 18 based on family income, or if the child lives in a care setting. Individuals on SSI may not exceed \$2,000 in assets (excluding their primary residence).

- Write a personal Letter of Intent outlining your child's abilities, support needs, services, current and future benefits, and your wishes for their future. Determine who will support them legally and/or as natural supports. Revise annually.
- Apply for Adult Services with Federal Agencies (DDS, Rehab, DMH, Vocational Rehabilitation, IHSS, HCBS, Regional Center) 6-12 months before your child's 18th birthday. If your child received services as a minor you may need to reapply as an adult.

AGE 18

- Guardianship is in place.
- SSI funding should be provided monthly.
- Your child may register to vote.
- Males must register for Selective Service (the draft). This is required by the government, but does not mean your child will be drafted. Failure to register can affect eligibility of services.
- IEP and transition plan (or 504 plan) must be revised. Include emergency plans and seizure action plans.
- A "Summary of Performance" must be provided by the school district upon earning a high school diploma or aging out of special education services.
- Visit day and residential programs.
- Apply for Section 8 Housing, if applicable to your child's ability to live independently. Apply for local and regional housing lists. Ask if there are any portable vouchers for the disability population.
- Start transitions from pediatric to adult medical care providers and specialists. Check with your pediatric medical team for referrals.
- Check with your state for state-specific programs.
- Ensure transportation options are in place before school district services end.
- Update your Letter of Intent (see above).

AGES 19- 20

- Update IEP and transition plan (or 504 plan). Include emergency plans and seizure action plans.
- Focus on functional life skills in work, school, community, safety, and travel.
- Enroll or ensure work-based learning or continuing education is occurring.
- Update your Letter of Intent annually (see above).

AGE 21

- All services and funding should be in place.
- Apply for any state waivers if you have not done so.
- Update your Letter of Intent annually (see above).

PARENTS APPROACHING AGE 65

As parents near retirement, it's important to consider the needs of your child with CFC Syndrome when making a decision regarding the best age to begin receiving personal social security benefits. Review the Social Security website to review pros and cons for the parent and the child.

There are a number of webinars that can assist you through this process. Visit www.ssa.gov to determine your benefit and for more information.

AGE 25

Now is the time to determine if your child can remain on your primary insurance when he or she turns 26. 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?

And if so, what documentation/forms are needed to continue the coverage?



WE ARE HERE FOR YOU!

We know that this process can be overwhelming for families. Families with loved ones diagnosed with CFC Syndrome navigate this journey frequently and can be a valuable ally in this journey. That's why we have family liaisons - other parents and caregivers - that have experienced this transition and can answer questions you may have.

Additionally, CFC International hosts a Facebook support group for "Parents and Caregivers of Adults with CFC Syndrome" that can be found at www.facebook.com/parentsofcfcadults. Adult individuals with CFC Syndrome may consider joining our Facebook support group for "Individuals with CFC Syndrome" at www.facebook.com/groups/786897361691187

Contact info@cfcsyndrome.org for more information about any programs we provide.