

Assumptions	Strategies	Outcomes
<p>Adolescents face a range of social-emotional and developmental issues as they transition to adulthood.</p> <p>Adolescents with genetic conditions face additional issues and greater challenges navigating this stage (medical management, health care coordination, self-advocacy, communication/partnership with adult providers , reproductive choices, diet management, insurance related issues)</p> <p>Ideally, children with genetic conditions will gradually become more knowledgeable about their condition and participate more fully in their own care as they progress into adolescence and adulthood.</p> <p>Each child with a genetic condition has individual strengths and weaknesses and will progress in a unique way, according to his or her own timeline, toward greater autonomy and independence.</p> <p>Appropriate support from parents will facilitate successful transfer of health-related responsibilities from parents to children (“doing for” vs. “doing with”)</p> <p>Parents of children with genetic conditions often feel ill-equipped to support their children’s unique challenges as they transition to the adult healthcare system.</p> <p>Parents will be better equipped if they have access to advice /support from parents who have “been there”</p> <p>Parents will be better equipped if they have access to insight from adolescents and/or young adults who have “been there”</p> <p>Support from other parents and young adults can:</p> <ul style="list-style-type: none"> • Decrease parent’s anxiety related to “letting go” • Increase a child’s opportunities to gain independence • Increase parents awareness of the adolescent perspective and experience 	<p>Identify Region 4 parents of children with genetic conditions that are interested in learning more about how to support their children’s transition related to</p> <ul style="list-style-type: none"> • Medical management • Care coordination • Self-advocacy • Communication/partnership with adult providers • Reproductive choices • Diet management • Insurance coverage <p>Facilitate opportunities for interaction among parents of children with genetic conditions to give and receive advice and support and share personal experience around the issue of transition (topical phone calls, online support groups, blogging etc.)</p> <p>As opportunities for interaction among parents are established, invite parents from other Regional Collaboratives to participate.</p> <p>Transcribe tips and answers to frequently asked questions shared during conference calls and blogging and publish on the Region 4 website</p> <p>Provide opportunities for parents to interact with young adults with genetic conditions who can share their personal transition experiences and provide ideas about how parents can best support their child’s independence (topical phone calls, online support groups, blogging, etc)</p> <p>Transcribe insights and experiences shared by young adults during phone calls or online activities and publish on Region 4 Website</p>	<p>Parents will have</p> <ul style="list-style-type: none"> • Increased access to resources to help them support their children’s transition to adulthood • Decreased anxiety about their child’s ability to take on more responsibilities for his/her health care (“letting go”) • Increased competence in their ability to support their children’s’ transition to adulthood • Increased awareness of the needs and experiences of adolescents <p>Adolescents will demonstrate:</p> <ul style="list-style-type: none"> • Increased participation in making health related decisions • Increased self-confidence • Improved diet management • Increased opportunities to communicate with health care providers/improved communication • Increased skills in self-advocacy • Improved adherence to medical protocols • Increased care coordination skills • Increased knowledge of insurance related issues