Throughout our lives, we face questions and search for answers that will help us on our journey to a full and meaningful life. This is true for everyone, especially when you or someone you care about experiences a disability or special healthcare need.

*Charting the Life Course* is a tool to assist you in creating a vision for the future. It is designed to help you think about the questions to ask as well as the choices and options to consider as you “plot a course” to a full and meaningful life. It is intended to be a starting point no matter where you are in your life journey.

We hope the life course approach helps you realize that even when your child is very young and as he or she ages and grows into adulthood, their experiences and environment can shape how they will live their life in the future.
Charting the Life Course is a framework that was developed to help individuals with disabilities and families at any age or stage of life think about what they need to know, identify how to find or develop supports, and discover what it takes to live the lives they want to live. Individuals and families may focus on their current situation and stage of life but may also find it helpful to look ahead to start thinking about what they can do or learn now that will help build an inclusive productive life in the future.

The Journey
Throughout our lives, we face questions and search for answers that will assist us on the journey to a meaningful life. While this is true for everyone, it is especially relevant for individuals and families that experience disability and are striving to live full and meaningful lives in their communities. On the journey to a good life, experiences and environments change as an individual grows older and families evolve. Life is constantly changing, and how individuals and families plan and react to change influences the journey.

Core Belief: People with disabilities and their families have the right to live, love, work, play and pursue their life aspirations just as others in their community do.

The Vision
Every child, from a very young age, dreams about what they want to be, where they want to live, if they will get married and have a family, and what their life will look like when they are grown. Parents often encourage their children to dream big, even when it might seem like the dream is out of reach. It should be no different for a child with a disability or special healthcare need. As the child becomes a teenager, it is even more important for the youth and the family to have a vision of what the future might look like. Even as an adult, it is important to continue keeping in mind a vision of the future into later adulthood and senior years. The best gift a parent can give a child is optimism and high expectations, offering encouragement, support and experiences to prepare for the road ahead.

Think about shooting an arrow. You need to have a target at which to aim, or the arrow might go off course and not land where you would like. The goal is for the trajectory of the arrow to go towards the bulls-eye of the target. If the goal is to have real, inclusive lives in the community as adults, then from a young age, the child and the family can begin to aim for that goal and set a path to get there. This is called a life trajectory. If individuals and families want to achieve enviable lives in the community, then they must have a vision of where the trajectory is aimed. What does that enviable life look like? What kinds of things would be part of that life? By having a vision for the future from a young age, it is more likely that the life trajectory will lead the person to the life they dream of.
Charting the Life Course was developed BY families and self-advocates FOR families and self-advocates. The questions in the guide represent the diverse experiences of these individuals and families, and include things they thought about, asked, or wished they had thought about and/or asked in their own life experience with disability or special healthcare needs. The framework is designed to help any citizen with a disability think about their life, not just individuals known by the service system. Even though the framework was developed for people with disabilities, it is designed universally, and could be used by any family making a life plan, whether they have a member with a disability or not.

**Who Should Use the Guide**

**Individuals with Disabilities or Special Healthcare Needs & Their Families:**
*Charting the Life Course* was developed to help individuals with disabilities or special healthcare needs and families at any age or stage of life think about what they need to know, identify how to find or develop supports, and discover what it takes to live the lives they want to live. Individuals and families can focus on their current situation and stage of life but may also find it helpful to look ahead to start thinking about what they can do or learn now that will help build an inclusive, productive life in the future.

**Professionals**
The life course guide will help professionals who serve individuals with disabilities or special healthcare needs and families: 1) to build upon their own understanding of the needs of individuals and families, and 2) by serving as a tool to engage with families individually or in group settings. It is a guide for starting conversations about what individuals need in order to be successful and self-determined throughout their lives and to help them think about how their choices, decisions, and experiences now can help them in the future.

**Community**
The life course guide can be used by anyone who wants to learn more about what individuals with disabilities or special healthcare needs and their families experience and think about as they strive to live full and meaningful lives now and in the future. By considering the questions in this guide, community members may find ways to be more inclusive and accepting of all children and adults in everyday community life.
Family Roles

Family Unit

Family strengths, values, and qualities, as well as what the family unit needs to support and be a successful part of their family member’s life. Supports directed to the family ultimately benefit the individual.

It is important to recognize and acknowledge that individuals, no matter their age, exist within a family system. The role of the family changes and evolves as a child grows and changes, from infancy through early childhood, school age, transition to adulthood, and adult years into aging.

During the earlier years the child is more dependent on the parent or family unit.

During the transition and adult years, the family, while still involved and an important part of the person’s life, takes on different roles as the person assumes a larger role in making their own choices and decisions about how they live their life.

Family Roles can be divided into 2 categories – Caring About and Caring For:

Caring About:

Affection and self-esteem – Parents love their child like no one else does or can. But parents can help make sure that there are always people in their child’s life that care about them and will be there for them, especially when the parent no longer can.

Repository of knowledge – A parent has volumes of information from the time their child is born into adulthood. There are things a parent “just knows”. But who else has this knowledge been shared with? Parents need to start sharing that knowledge, whether verbally, or by writing down information that can someday help another person to assume some of the roles.

Lifetime commitment – A parent will continue to love their child and make sure they are “okay” long after they are able to physically provide day to day care needs.

Caring For:

Provider of day to day care – Parents make sure that their child is safe and well taken care of on a daily basis throughout childhood. This responsibility may continue well into adulthood when a son/daughter has a disability.

Material and financial – All parents provide for the material and financial needs of their child during the school years – food, shelter, clothing, etc. However, when a loved one has a disability or special healthcare need, this type of support may go on for much longer, depending on the individual’s ability to earn income.

Facilitator of inclusion, recreation, spirituality, and meaningful activities – Family makes sure that their loved one has opportunities to meet people, make friends, connect with others in the community and have fun interacting with others.

Advocate for support – Parents and family help an individual get supports and services from various sources, including school, agencies, systems, and the community; as well as advocating for inclusion in all aspects of community life.

Families play many roles in a person’s life, especially when that person experiences disability or special healthcare needs. It can be overwhelming when families start to think about who will play those roles if/when they no longer can. Asking someone else to do EVERYTHING that a parent does for their son/daughter is daunting and unrealistic. However, there are likely many people – extended family, friends, and acquaintances – that are willing to do something if asked. Thinking about all the different roles a parent or family member plays and breaking that up into smaller tasks gives others a chance to assume some of those roles, even while the parent or caregiver is still involved. All the things that a parent does for their son/daughter is too much for one person to take on, but many people can each do one small thing.
The *Charting the Life Course* life stages are: prenatal/infancy; early childhood; school age; transition; adulthood; and aging. The Life Course is designed so that families and individuals can focus on a specific stage, while keeping an eye to the future; helping them know what’s coming, what to expect and how to plan for success in the life stages still to come. Throughout childhood and youth, skills and habits can be learned and practiced to realize a vision for a quality of life in adulthood. The questions in *Charting the Life Course*, and in this guide, are designed to help the young person and the family to plan, learn and explore experiences and choices that will lead to an adult life that the person and the family envisions.

The questions in Charting the Life Course are written to reflect a “first person” perspective across the lifespan to represent the viewpoint of the person with a disability and the on-going transformation to an adult who is self-determined, autonomous and independent.

- In infancy and early childhood stages, the person with a disability asks questions about what the family or others around them are doing to support them or helping them learn to do.

- As the child ages, beginning in youth, transitioning to adulthood, and as an adult, the questions are about what they themselves want or the things they should be focusing on.

Figure 1 illustrates how during earlier years the child (any child, whether they have a disability or not) is more dependent on the parent or family unit. During the transition and adult years, the family, while still involved and an important part of the person’s life, takes on different roles as the person assumes a larger role in making their own choices and decisions about how they live their life.

Throughout this document you will see that some questions have a star beside them. These questions are designed to highlight ways to foster self-determination throughout the life course. Self-determination refers to actions that enable a person to be a causal agent in his or her life; to make or cause things to happen (National Training Initiative on Self-Determination, National Gateway to Self-Determination). Simply put, self-determination means making choices, setting goals, assuming responsibility, and driving how one’s own life is lived.

Historically, families and professionals alike don’t start thinking about teaching or instilling self-determination until a person with a disability reaches the age of transition from school to adulthood, or even later. In reality, self-determination is part of the life course journey from the very beginning. Self-determination can be viewed as a quality or characteristic of a person, similar to good manners, or other qualities that parents work to develop in their children. Like other desirable qualities, children can start learning to be self-determined from birth by having opportunities to make choices, learn about new places and things, build community connections, develop skills, and learn responsibility.

Individuals and families, as well as professionals who provide support, need tools that will help them along the way to achieving full and meaningful, self-determined lives. It is hoped that this document is a tool that will help guide you along your journey.
Everything is Connected
Children change as they grow; families also change, grow, and evolve. As families adapt to changes, support needs may also change. Choices and decisions, skills learned or not learned, and gifts and talents all have an impact on the life trajectory. What you do now affects what happens in the future! The life trajectory can also be affected by external factors and forces. Outside influences might push the trajectory in an unintended direction, but through advocacy, connecting and networking, and developing and utilizing supports, the family and the individual can chart a course for the life they envision.

GOAL OF SUPPORTING FAMILIES

Recognizing that individuals exist within a family system, where:

- **The Individual** will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life.
- **Families** will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support the individual to achieve their goal.

Individuals and families are interconnected and as such, the overall goal of supporting families, with all of their complexity, strengths and unique abilities is so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and

inclusion in all facets of community life for their family members.

Quality of Life
Leaving disability out of the discussion, what makes a good quality of life for anyone? Most people would answer with things like having friends and family, relationships, a satisfying job or career, a home of their own, sufficient finances to buy and do the things you want and need, etc. It should be no different just because a person experiences disability. They want the same things in their lives that anyone else does, and there is no reason they cannot achieve the same quality of life that any person expects and strives for.

Quality of Life Core Areas
Within each Life Domain, there are four core quality of life areas every human possesses; that influence who a person is and becomes and how they live their life.

These quality of life core areas are explored in depth for the life domain focus within this guide.

- **Vision & Values**: vision for the future of an enviable life
- **Self-Determination & Responsibility**: control of and responsibility in one’s own life
- **Relationships & Connections**: social circles, personal networks, and links to opportunities
- **Strengths & Gifts**: having valued roles and giving back
The icons in Figure 2 represent the different life categories (going down the side on the following pages) that families and people with disabilities or special healthcare needs experience. Life categories are the different aspects and experiences of life that we all consider as we age and grow, such as daily life, community living, health and wellness. Everyone (whether you have a disability or not) has to figure out: what you are going to do during the day—go to school, volunteer, get a job; where you are going to live; how you are going to stay healthy and safe; and so on.

The icons on the right represent the different ages/stages of life from pre-natal/birth through aging/end of life (going across the top of the following pages). At the intersection of each life stage and life category is a set of questions for you to ask or think about in order to plot a course toward a meaningful life, now and in the future.

**Figure 2. Life Course Legend**

<table>
<thead>
<tr>
<th>Life Categories</th>
<th>Life Stages</th>
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<tbody>
<tr>
<td><strong>Daily Life</strong></td>
<td><strong>Prenatal/Infancy</strong></td>
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<tr>
<td>What a person does as</td>
<td>Early years, wondering if</td>
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<tr>
<td>part of everyday life—</td>
<td>meeting developmental</td>
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<tr>
<td>school, employment,</td>
<td>milestones</td>
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<td>volunteering,</td>
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<td>communication, routines,</td>
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<td>life skills.</td>
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<tr>
<td><strong>Community Living</strong></td>
<td><strong>Early Childhood</strong></td>
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<td>Where and how someone</td>
<td>Preschool age, getting a</td>
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<td>lives—housing and living</td>
<td>diagnosis</td>
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<td>options, community</td>
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<td>access, transportation,</td>
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<td>home adaptations</td>
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<td>and modifications.</td>
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<td><strong>Social &amp; Spirituality</strong></td>
<td><strong>School Age</strong></td>
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<tr>
<td>Building friendships</td>
<td>Everyday life during school</td>
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<tr>
<td>and relationships,</td>
<td>years</td>
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<tr>
<td>leisure activities,</td>
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<td>personal networks,</td>
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<td>faith community.</td>
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<td><strong>Healthy Living</strong></td>
<td><strong>Transition</strong></td>
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<tr>
<td>Managing and accessing</td>
<td>Transitioning from school to</td>
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<td>health care and staying</td>
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<td>well—medical, mental</td>
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<td>health, behavior,</td>
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<td>developmental, wellness,</td>
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<td>and nutrition.</td>
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<td><strong>Services &amp; Supports</strong></td>
<td><strong>Adulthood</strong></td>
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<tr>
<td>Services and supports</td>
<td>Living life as an adult</td>
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<td>for individuals and</td>
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<td>families—both funded</td>
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<td>(systems) and natural</td>
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<td>supports; personal/family</td>
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<td>financial.</td>
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<td><strong>Safety &amp; Security</strong></td>
<td><strong>Aging</strong></td>
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<tr>
<td>Staying safe and secure—</td>
<td>Aging and preparing for end</td>
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<tr>
<td>emergencies, well-being,</td>
<td>of life (parent/family/</td>
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<td>guardianship options,</td>
<td>individual)</td>
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<td>legal rights and issues.</td>
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<tr>
<td>**Advocacy &amp; Family</td>
<td>⭐ Promotes self-determination</td>
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<tr>
<td>Support**</td>
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<td>Support for families/</td>
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<td>individuals—peer support</td>
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<td>self-advocacy.</td>
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⭐ Promotes self-determination
### Wondering if Meeting Milestones
- Are you worried about how a diagnosis might affect my future? ★
- Do you have a vision or plan in mind for me when I get older that will support my growth and development now? ★
- Have you established a daily routine for me? ★
- How can technology assist you in helping me with daily activities? ★
- Are you playing with me and helping me to find ways to learn about and explore my environment? ★
- Do you recognize and respond to my signs, signals, babbling, gestures, and words? ★

### Getting the Diagnosis: Entering the World
- What are the routines or strategies that will help you and me throughout the day?
- Are there ways you can organize things differently to accommodate me better?
- Are you exploring how technology can assist me with daily activities?
- Are you sending me to preschool? ★
- Who will provide any extra help I might need to attend preschool?
- Do you know where/how to find a child care provider who can accommodate my needs?
- Are you keeping a vision in mind for my future as I learn and grow? ★
- Do you view me as being able to do what other children do, even if I need extra help to do so? ★
- Do you parent me the same way as my siblings/other children? ★
- Do you know where to find tips on parenting?
- Are you giving me opportunities to make choices (between two or three options)? ★
- Are you helping me learn from my mistakes? ★
- If verbal communication is difficult for me, do I have other ways to make my wants, needs, ideas and thoughts known? ★
- Are you helping me start to see myself as separate from you? ★

### Every Day Life During the School Years
- What does my school day look like?
- Am I in the least restrictive environment or neighborhood school? ★
- With whom do I spend the majority of the school day?
- How am I included at school with typical peers? ★
- Am I learning social skills as well as daily living and academic skills in my school experience? ★
- Is there technology to assist me with school activities?
- Are you sending me to the school's “before/after school” program and what supports do I need to participate?
- Do I have an after-school or evening routine?
- Do you ask me what I want to be when I grow up? ★
- Am I learning about lots of different jobs from my family, teachers and others? ★
- Do you make sure I have responsibilities at home (like other family members) such as daily chores? ★
- Am I expected to follow rules like any other child with consequences when I don't?
- Are you giving me the opportunity to make choices and decisions about everyday things (like what I wear, what I eat for a snack)? ★
- Are you helping me with ways to communicate to make my thoughts, ideas, and needs known to others? ★
- Do I know when it's okay or appropriate to talk, who it's okay to talk to, or what to say? ★
### Realizing School is Almost Over

- Have you helped me create a transition plan that is truly individualized and prepares me for adult life after school ends? ★
- Does my transition plan include work or volunteer experience, and practicing how to look for a job, get a job and keep a job? ★
- What daily/independent living skills am I working on as part of my transition plan? ★
- Does my transition plan balance work experience, social skills and academics according to my needs, desires and abilities? ★
- Are you helping me understand that doing my best at school and being responsible will help me get a job that I like someday? ★
- Have you talked to me about post-secondary education? Taken me for college visits? ★
- What are we doing at home to prepare for adult life? Are you teaching me everyday living skills such as preparing meals, doing laundry, etc.? ★
- Do I have responsibilities at home, school, or in the community? ★
- Am I learning about all the different roles people have in life and how they are interrelated? ★
- Are you helping me learn how to apply for a job and start to gain experience in jobs that interest me? ★
- Are you helping me explore assistive technology that would help with learning employment and adult living skills? ★
- Have you talked with me about how I envision my life as an adult and what resources might be needed to help me accomplish that vision? ★
- Has what’s important to me and what’s important for me been addressed in terms of finding a good balance between the two? ★
- What does my perfect day look like? How about my perfect week? ★
- What makes a bad day for me? ★ (What we want to avoid)

### Living Adult Life

- What will I do during the day now that I am an adult? ★
- What are the things I really like to do or want to do? ★
- Can I find a job or volunteer opportunity based on the things I like or want to do? ★
- Is there some type of job or volunteer activity that ties into my passion or interests? ★
- Will I have a full time job, part time job, volunteer, or go to some sort of program? ★
- Where can I learn or improve my employment skills? ★
- Can I turn an interest of mine into a way to earn income or start my own business? ★
- Have we completed a Relationship Map to identify who is in my support network that might be able to find me a job? ★
- Who can help me to get a job or start my own business? ★
- Do I know how to get a job, keep a job or change jobs and build a long-term career? ★
- Do I know how to find ways to continue learning at my job, through volunteering, in the community, or with friends? ★
- What adaptations and supports are available to help me with my daily activities or routine? ★
- Do I know how, or is there someone to assist me with tasks such as meal planning, cooking, or grocery shopping? ★
- Do I know how to find or ask for help when I need it in my daily life? ★
- Is there assistive technology that can help me with my daily activities? ★
- How might my life change if I had money to do the things I want? ★
- Is there a new skill or interest I’d like to develop? ★
- Have we talked about the things that might be in the way of me getting the job I want, and do we have a plan to address those things? ★
- Do you want to try something new where you are currently working? ★
- Have we talked about what’s worked well and what hasn’t worked well for me in previous jobs and discussed what needs to stay the same and what needs to change? ★

### Preparing for End of Life

- What supports do I need to continue living as independently as possible in my own home and community as I age? ★
- Are there community resources for seniors I can utilize, such as Meals on Wheels or housekeeping assistance? ★
- If I’m still living at home with my parents, what will happen when my parents die – where will I live, and with whom? ★
- Can I afford to retire? ★
- What will I do to keep busy if I retire? ★
- How can technology assist me to live as independently as possible? ★
- Is there something new I’d like to learn (hobby, special interest)? ★
- Is there anything important to me about my routine that has to be present or absent? ★
- What does my perfect day/week look like? ★
- What contributes to a bad day for me? (Things we want to avoid) ★

### Daily Life/Employment

- Has what’s important to me and what’s important for me been addressed in terms of finding a good balance between the two? ★
- What does my perfect day/week look like? ★
- What contributes to a bad day for me? (Things we want to avoid) ★
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<thead>
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<tbody>
<tr>
<td></td>
<td>• If things change regarding our family income or your ability to work, how will that impact our ability to continue to live in our current home?</td>
<td>• Have you explored adaptations to our home that will better accommodate my needs?</td>
<td>• Have you provided a place in our home that takes into account my sensory or other needs, where I can do homework and other learning activities or go to be more calm and relaxed?</td>
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<td></td>
<td>• Are there accessibility issues in our home that need to be addressed?</td>
<td>• Is our home in a good school district that promotes inclusive education, so I can learn and grow with my siblings and other neighborhood children? ★</td>
<td>• Are you helping me keep my room age appropriate?</td>
</tr>
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<td></td>
<td>• Are there ways you can structure where I live and other surroundings to give me opportunities to do typical activities that young children do? ★</td>
<td>• Am I able to get out and about to explore and learn about my community? ★</td>
<td>• Are there accessibility issues in our home that you need to address so I can begin to do things for myself and be as independent as possible? ★</td>
</tr>
<tr>
<td></td>
<td>• Have you explored adaptations to our home that will better accommodate my needs?</td>
<td>• Do I need assistive technology for myself or our vehicle to be able to get around?</td>
<td>• Am I starting to learn to do things to maintain and upkeep a household? ★</td>
</tr>
<tr>
<td>Safety &amp; Security</td>
<td>• Are you childproofing and otherwise making sure that our home is safe for me?</td>
<td>• Have you made our home childproof or adapted where we live for my safety?</td>
<td>• Do I ride the regular school bus or use special transportation?</td>
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<td></td>
<td>• Are there things in our home that could harm me (for instance lead paint, or sharp edges)?</td>
<td>• Have you talked to police, Emergency Medical Services, or fire department about emergency response for me?</td>
<td>• Is there a neighborhood carpool we could join to take me places and also help me with making new connections? ★</td>
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<td></td>
<td>• Do you have local emergency numbers and poison control information easily accessible in case something happens to me?</td>
<td>• Are local emergency numbers and poison control information easily accessible in case something happens to me?</td>
<td>• Do I feel safe at school and know who to tell if I am being bullied? ★</td>
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<td></td>
<td>• If you go to work or do other things that you can’t take me along, are you leaving me with someone reliable who will keep me safe?</td>
<td>• Are you leaving me with safe, reliable childcare when you need to go out?</td>
<td>• Do you know what to do or who to contact if you are concerned about my safety at school?</td>
</tr>
<tr>
<td></td>
<td>• Have you arranged for someone to care for me (and my siblings) if something happens to you?</td>
<td>• Are you helping me learn who to trust and how to be safe? ★</td>
<td>• What are my family’s rights and my rights regarding education? ★</td>
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<td></td>
<td>• Are you helping me learn about stranger danger, and who I can trust? ★</td>
<td>• Are you helping me learn when and how to call for help? ★</td>
<td>• Do you know about procedural safeguards and what it means for me and for you as my advocate?</td>
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<tr>
<td></td>
<td>• Are you helping me learn not to hurt myself or others?</td>
<td>• Are you helping me learn when and how to call for help? ★</td>
<td>• If I am prone to wandering, have you educated others on how to keep me safe or what to do?</td>
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<tr>
<td></td>
<td>• Are you keeping local emergency providers updated as my needs change?</td>
<td>• Are you helping me learn about stranger danger, and who I can trust? ★</td>
<td>• Are you helping me learn when and how to call for help? ★</td>
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<tr>
<td>Realizing School is Almost Over</td>
<td>Living Adult Life</td>
<td>Preparing for End of Life</td>
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<tr>
<td>• Have you talked with me about where I might want to live in the future (after school ends/when I am an adult)? ★</td>
<td>• Am I still going to live in my parents’ home or move out?</td>
<td>• What home adaptations or other living options are available to help me stay in my home and community as I age?</td>
<td></td>
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<tr>
<td>• Will I continue to live in our family home after graduation?</td>
<td>• What kind of supports do I need to live outside the family home?</td>
<td>• What modifications need to be made to my home to accommodate barriers of aging?</td>
<td></td>
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<tr>
<td>• Have you helped me begin to explore different living options? ★</td>
<td>• What skills do I need to live as independently as I want, and how do I find/get help when I need it? ★</td>
<td>• How can I be supported to age in place?</td>
<td></td>
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<tr>
<td>• Have you helped me figure out what kind of supports I will need to either continue living at home or move into my own place after I graduate? ★</td>
<td>• What kind of setting will I live in? (Who will help me figure out how to own or rent an apartment or house or if I need something provided by the service system?)</td>
<td>• Are there “senior citizen” resources in my community (senior center, transportation, Meals on Wheels, etc.)?</td>
<td></td>
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<tr>
<td>• Am I getting the opportunity to learn and practice skills I will need to live in other settings? ★</td>
<td>• What kind of living options are possible? ★</td>
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<tr>
<td>• If I go to college, will I live in the dorms, at home, or someplace else?</td>
<td>• What are the pros and cons of each option?</td>
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<tr>
<td>• What supports might I need to live away from home while attending college?</td>
<td>• Do I want to live with a roommate or alone? Has anyone asked me if I prefer to choose my own roommate? ★</td>
<td></td>
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<tr>
<td>• Am I learning how to get around in my community (learning to drive, ride the bus, take a cab, etc.)? ★</td>
<td>• Do I need staff, or could a roommate be compensated to provide some of my supports?</td>
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<tr>
<td>• Am I learning about new people and places to widen my world and expectations for my life? ★</td>
<td>• Do I want to be in control of hiring/firing my staff? ★</td>
<td></td>
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<tr>
<td>• Are you helping me to get training and knowledge on safety and security issues? ★</td>
<td>• What kind of accessibility issues should I consider when choosing my home or apartment?</td>
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<tr>
<td>• How are you making sure I am safe in diverse settings? ★</td>
<td>• How am I being supported to have valued roles in my community?</td>
<td></td>
<td></td>
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<tr>
<td>• Do I know when and how to call for help at home or in the community? ★</td>
<td>• How do I get around to places I need or want to go?</td>
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<tr>
<td>• Are you wondering if I will need guardianship when I turn 18?</td>
<td>• Are there things happening to me, such as dementia, adding to concerns for my safety?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Are you exploring alternatives to guardianship so I can retain my right to make my own choices and decisions? ★</td>
<td>• Am I in danger of falling or other hazards?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Do you know about things you can do to help keep me safe without getting guardianship?</td>
<td>• Are there home modifications that will help me stay safe?</td>
<td></td>
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<tr>
<td>• Does my transition plan include learning skills that will help me to “be my own person” and not need a guardian for decision-making support or protection? ★</td>
<td>• Is there assistive technology that will help me stay safe as I age?</td>
<td></td>
<td></td>
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<tr>
<td>• If I live in my own home or apartment, are there supports in place to help keep me safe?</td>
<td>• What supports do I need to be in place to continue living in my own home/community setting? ★</td>
<td></td>
<td></td>
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<tr>
<td>• Do I understand who I should and shouldn’t let into my home (ie: strangers, repair/utility workers, etc)? ★</td>
<td>• Do I know who to call if I don’t feel safe or need assistance? ★</td>
<td></td>
<td></td>
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<td>• Do I know who to call if I don’t feel safe or need assistance? ★</td>
<td>• Is there assistive technology that can help keep me safe in my home and in the community?</td>
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<tr>
<td>• Is there assistive technology that can help keep me safe in my home and in the community?</td>
<td>• Can I be at home alone or access the community without help? If not, what kind of supports do I need?</td>
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<td>• What should I do if I am being abused by a significant other, support staff or someone with whom I live?</td>
<td>• What kind of setting will I live in? (Who will help me figure out how to own or rent an apartment or house or if I need something provided by the service system?)</td>
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<td>• What kind of living options are possible? ★</td>
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<td>• What are my legal rights and protections as I age?</td>
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<tr>
<td>• Do I have legal documentation of my end of life wishes? ★</td>
<td>• Am I in danger of falling or other hazards?</td>
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<tr>
<td>Services &amp; Supports</td>
<td>Wondering if Meeting Milestones</td>
<td>Getting the Diagnosis: Entering the World</td>
<td>Every Day Life During the School Years</td>
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<td></td>
<td>Will you need to quit your job to stay home and take care of me? How will we deal with the loss of income?</td>
<td>Do you have resources to help pay for my medical or other special care?</td>
<td>What does my school provide or pay for?</td>
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<tr>
<td></td>
<td>Do you need help balancing paying for things I need with meeting our family financial obligations?</td>
<td>Will your health insurance cover my needs?</td>
<td>Do you know what to do if my school district refuses a request or service solely on the basis of money?</td>
</tr>
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<td></td>
<td>If I need testing or assessment, will insurance pay for it, or are there other funding sources?</td>
<td>Do you need help balancing paying for things I need with meeting our family’s financial obligations?</td>
<td>Will my school district pay for an independent evaluation?</td>
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<tr>
<td></td>
<td>What are you doing to get the help I need while waiting for a diagnosis and/or services?</td>
<td>Do you know if I qualify for special healthcare or disability services?</td>
<td>Does my school provide assistive technology to assist/support me?</td>
</tr>
<tr>
<td></td>
<td>• Do you have resources to help pay for my medical or other special care?</td>
<td>Have you considered applying for services, such as Supplemental Security Income (SSI), Medicaid, Special Healthcare Needs, or Division of Developmental Disabilities?</td>
<td>What if I want to go to a private school—does my home district pay for anything?</td>
</tr>
<tr>
<td></td>
<td>• Do you have medical or other special needs?</td>
<td>Do you know the qualifications and income guidelines for the various programs?</td>
<td>Do I receive an “allowance” or have access to money? ★</td>
</tr>
<tr>
<td></td>
<td>• Will you need to quit your job to stay home and take care of me? How will we deal with the loss of income?</td>
<td>• Are you looking for community supports and resources?</td>
<td>• Are you giving me opportunities to decide how to spend money? ★</td>
</tr>
<tr>
<td></td>
<td>• Do you need help balancing paying for things I need with meeting our family financial obligations?</td>
<td>• Are you exploring assistive technology that would benefit me, and do you know how to get it?</td>
<td>• Are you engaging in financial planning for my future?</td>
</tr>
<tr>
<td></td>
<td>• If I need testing or assessment, will insurance pay for it, or are there other funding sources?</td>
<td>• Do you know where to find affordable childcare for me?</td>
<td>• Are you finding or accessing medical and health personnel experienced in caring for children with my diagnosis?</td>
</tr>
<tr>
<td></td>
<td>• What are you doing to get the help I need while waiting for a diagnosis and/or services?</td>
<td>• Are you finding or accessing medical and health personnel experienced in caring for children with my diagnosis?</td>
<td>• What do you need to tell the school nurse about my needs?</td>
</tr>
<tr>
<td>Healthy Living</td>
<td>• Are you keeping me healthy with well-baby visits and taking me to the doctor when I am sick?</td>
<td>• Are you taking me to a pediatrician who understands and meets my needs?</td>
<td>• What if I need to take medications or treatments at school?</td>
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<td></td>
<td>• Do your parental instincts tell you something isn’t going quite right with my health, growth or development?</td>
<td>• Does our pediatrician refer me to specialists when needed?</td>
<td>• Do local emergency providers know our wishes if something happens to me at school?</td>
</tr>
<tr>
<td></td>
<td>• Do you know if I am hitting my developmental milestones on time?</td>
<td>• Do you feel like you have to go along with everything the professionals tell you about me, even if your gut tells you otherwise?</td>
<td>• Are you keeping me up to date with regular childhood checkups and immunizations?</td>
</tr>
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<td></td>
<td>• Do you know what red flags to watch for?</td>
<td>• Do you know what to do if we don’t like or if you disagree with my medical professionals?</td>
<td>• Are you taking me to see specialists for specific issues?</td>
</tr>
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<td></td>
<td>• Are you expressing your concerns about my health or development to my pediatrician?</td>
<td>• Will therapies help me to grow and develop?</td>
<td>• Are you teaching me to greet and interact with doctors and other medical professionals? ★</td>
</tr>
<tr>
<td></td>
<td>• Where are you taking me to find out about my health or development; what kind of testing do I need?</td>
<td>• Am I part of a “medical home”?</td>
<td>• Do I know how to ask for help or tell when I am sick or just don’t feel well? ★</td>
</tr>
<tr>
<td></td>
<td>• Has anyone else mentioned concerns about my health or development to you?</td>
<td>• Have you invited local emergency personnel to our home to meet me and learn about my needs in case of an emergency?</td>
<td>• Are you helping me understand my disability or healthcare needs and how they affect me as I grow and change? ★</td>
</tr>
<tr>
<td></td>
<td>• Are you teaching me about healthy, nutritious food and how my body works? ★</td>
<td>• Are you teaching me about healthy, nutritious food and how my body works? ★</td>
<td>• Do I know what is good (food, sleep, exercise) and bad (drugs, smoking) for my body? ★</td>
</tr>
<tr>
<td></td>
<td>• How are you helping me prepare or and understand puberty?</td>
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</tr>
</tbody>
</table>
### Realizing School is Almost Over
- What support or financial assistance is available for me as I become an adult? Will I be able to earn income?
- Who will pay for my services and supports when I am no longer in school?
- If applying for SSI at age 18, do I need a representative payee?
- Will you help me find scholarships or other funding sources?
- Can Vocational Rehabilitation help prepare me for college or a career?
- Are you helping me to learn to take control of my money and manage my services and supports?
- Would a limited or joint bank account, automatic bill pay or a debit card help me learn money management skills?
- When should you help me start looking for practitioners who focus on adults?
- What do I need to know about the process?
- What health related tasks can I start to help with or do for myself?
- Are you helping me to know the symptoms, triggers, and side effects of my disability or healthcare need and how to get help or interventions?
- Are you helping me learn how to talk about my disability or healthcare needs with others?
- Can some of my therapies be replaced with regular physical activities such as working out in a gym, using a treadmill or elliptical, or doing aerobics?
- Are you helping me prepare for and understand puberty?
- Have you talked to me about birth control/reproductive health?

### Living Adult Life
- Can I afford to pay for my own living expenses?
- If not, where can I get assistance or make more money?
- Does my income from employment or other sources exceed the limits for benefits?
- How much money can I afford to spend on social and recreational activities?
- Do I have a special needs trust in place for “extras” that benefits don’t cover?
- Do you know where to go to create my special needs trust?
- Do you also need a living trust or will for yourself?
- Would a limited or joint bank account, automatic bill pay or a debit card help me with managing my own money?
- Who is in my life that knows me well and promotes success in my life?
- If I live in my own home or apartment, are there supports in place to help keep me safe?
- Do I understand who I should and shouldn’t let into my home (ie: strangers, repair/utility workers, etc)?
- Do I know who to call if I don’t feel safe or need assistance?
- Is there assistive technology that can help keep me safe in my home and in the community?
- Can I be at home alone or access the community without help? If not, what kind of supports do I need?
- What should I do if I am being abused by a significant other, support staff or someone with whom I live?

### Preparing for End of Life
- Do I need help with budgeting or paying bills?
- Can I afford to “retire”?
- What kind of benefits do I have or could I qualify for to help support myself?
- Do I have a burial plan or prepaid arrangements in place?
- Who will make my final arrangements (especially if my parents or immediate family are already deceased)?
- Who will handle my final expenses and settle my estate?
- Are there things happening to me, such as dementia, adding to concerns for my safety?
- Am I in danger of falling or other hazards?
- Are there home modifications that will help me stay safe?
- Is there assistive technology that will help me stay safe as I age?
- What supports do I need to be in place to continue living in my own home/community setting?
- What are my legal rights and protections as I age?
- Do I have legal documentation of my end of life wishes?
### Wondering if Meeting Milestones

- Are you taking me out to do typical social things as a family?
- Is there a playgroup that I can join?
- Are you helping me learn to play by spending time playing with me? ★
- Are you finding ways to bond with me, even though you may be feeling stressed?
- Do you know I am happier and more relaxed when you take time for relaxation and renewal for yourself?
- If you enjoy church/worship, are you taking me along so I can become familiar with people and activities there? ★

### Getting the Diagnosis: Entering the World

- Are you helping me to learn and practice my social skills? ★
- Are you helping me be included with other children in social activities, play dates, and parties? ★
- Are you helping me find ways to do what other children in the community are doing for fun and recreation? ★
- Are you getting me involved in play groups, Mom’s day out, parks and recreation or other community activities? ★
- Are you helping me learn and practice how to take turns and play with other children? ★
- Are you taking me to new places and helping me try new things so I can figure out what I like to do? ★
- Are you setting limits on my behavior so I can learn to self regulate and learn to get along with others? ★
- Are you giving me the opportunity to be a part of children’s groups or activities in our faith community? ★

### Every Day Life During the School Years

- Am I learning how to make friends and maintain relationships? ★
- Are there opportunities or strategies at my school to help me make friends? ★
- Are you helping me to get involved and be included in extracurricular activities at school and in the community? ★
- Have you helped me explore clubs or other school activities in which I might be interested? ★
- Are there parks and recreation programs where I can meet and make new friends?
- Are you encouraging me to try different activities so I can figure out what I like to do in my free time? ★
- Are you teaching me about sex, healthy relationships, and boundaries? ★
- Are you helping me explore spirituality and find a welcoming faith community? ★

### Social & Spirituality

- Is there someone you can talk to that will understand your concerns and feelings?
- Are you telling loved ones or friends about your concerns for me and my health/development?
- How do you respond to others’ concerns about me?
- How do you make sure your concerns about me are being acknowledged?
- Do you know other parents who have been in a similar situation or had similar concerns?
- Do you know how to connect with other parents?
- Are you taking time to enjoy being my parent?
- Are you trying to find a balance between your needs, the family’s needs and mine?

### Advocacy & Family Support

- What supports are available to help our family?
- Do you know if there are resources devoted to my specific disability?
- Have you found places where you can connect with other families one-on-one or in groups?
- What can you tell family and friends about my diagnosis/special needs?
- What do you tell my siblings about my diagnosis/special needs?
- Who can you talk to when our family and friends don’t understand what you are experiencing or do not understand things about me?
- Do you accept me as a child first, not just a child with a disability? ★
- Do you make sure you are recognized by others as the expert on me and my needs?
- What do you do for yourself and my siblings to help balance my needs?
- Have you thought about connecting with other families that have children my age?
- Are you taking a supporting friend or another parent with you to my IEP meetings?
- Are you helping me learn to be part of school or person-centered planning meetings? ★
- Have you joined the PTA at my school?
- Are you making sure I am getting the extra support I need at school like an aide or personal assistant?
- Are you helping me learn how to talk about my disability or healthcare needs with others? ★
- Are you encouraging and helping me learn how to ask for accommodations for my learning and physical limitations when I need them? ★
## Realizing School is Almost Over

- What opportunities do I have for making new friends at school and in the community?
- How are you helping me build relationships?
- How will I maintain and make new friendships outside of school (especially if most of my friends have gone off to college and I have not)?
- Are you helping me use social media to be included and make or keep in touch with friends?
- Do I have opportunities to do what other young people do for fun?
- What kind of extracurricular activities might I participate in or try (clubs, sports, etc.)?
- Have you asked me if I want to be involved in other activities that are less inclusive, like Special Olympics?
- Am I dating or starting to think about dating?
- Are you teaching me about sex and intimacy?
- Have you talked to me about safe sex/sexual boundaries?
- Am I involved with a youth or young adult group in my faith community?

## Living Adult Life

- What can I do in the community for fun and friendship?
- How will I maintain old friendships and make new ones?
- How can I use social media to make and maintain friendships and relationships?
- Do I have friends with and without disabilities?
- Do I have friends who will share decision-making about what we talk about and do together?
- Do I interact well with others by being a good listener and expressing myself?
- How am I exploring or developing my interests or finding new ones?
- Do I want to get involved in civic engagement or leadership?
- Am I doing the same things as other same-age peers?
- What kinds of relationships do I have in my life?
- Where/how can I find someone to date?
- Will I get married or have a family?
- Will I go on vacation alone or with family or friends?
- Do I have a supportive faith community, and what supports do I need to fully participate?

## Preparing for End of Life

- What opportunities do I have to make/maintain friendships?
- Do I have age appropriate friends (same age friends) that share similar interests?
- What hobbies or interests am I pursuing in my spare time?
- Can I go to a nearby senior center for social activities?
- Do I need extra support to fully participate in my faith community as I am aging?
- Have I made my end of life wishes pertaining to my faith known to others?
The following are questions to consider no matter the particular life category or age. These are questions that you might ask or keep in mind whether you are just starting your journey, or are somewhere along the way. These questions are not intended to be all inclusive or complete, but will help you get started with some general questions to keep in mind as you progress along the life course.

• Are you asking yourself what other people my age are doing (for work, fun, etc.) and asking yourself how that looks for me?

• How are you helping me create or maintain community connections and social capital? ★

• How could technology, adaptations or accommodations assist me in living an inclusive life?

• Are you accessing and teaching me how to access typical community resources in addition to any paid supports I might receive?

• Have you thought about who will be there for me when you die?

• Are you considering my safety and protection without making me overly dependent or taking away my right to be self-determined? ★

• Do you help me to know what to do in an emergency by practicing safety drills, and do we have a disaster plan that takes my needs into account?

• Do you and other family members (i.e. – grandparents) understand that willing or giving property or money to me can have an adverse impact on my ability to access paid services, supports, or benefits, such as Medicaid and Social Security?

• Do you present yourself as an expert regarding me, and are you helping me to learn to be the expert on myself and my needs? ★

• Are you helping others understand that you and I have important expertise about my/our family’s situation?

• Do you have someone to talk to about your feelings, emotions, and concerns, so that you don’t feel so alone?

• Do you feel empowered to ask questions or disagree with professionals, and are you helping me know the questions to ask and how to assert my wishes/opinions to professionals? ★

• How do I know what I don’t know? How do I find out?

• Are you helping me to create a vision for my own life? ★

• How are you encouraging self-determination at all ages, stages, and aspects of my life? ★

• Are you always keeping an eye to the future or the next stages of my life? Are you helping me learn to do the same? ★
Charting the Life Course was created and is offered for your use by the University of Missouri-Kansas City Institute for Human Development (UMKC-IHD), University Center for Excellence in Developmental Disabilities (UCEDD), an applied research and training center for human services. The UMKC-IHD and its faculty and staff work with a variety of university and community constituents to build the capacity of their programs and organizations, conducting work in applied research, interdisciplinary University training, community services and supports, and information dissemination.

The original framework was developed by the Missouri Family-to-Family (MOF2F) Resource Center team over a two-year period through a series of meetings with the Missouri Family to Family Stakeholders group. The MOF2F Stakeholders group includes representatives from over 35 different organizations, with 75% of the members identifying as a family leader. MOF2F staff and the stakeholders group represent the viewpoints of individuals with disabilities or special healthcare needs, parents, family members, professionals in the field, and agencies that serve children, families, and individuals.
