



Charting the LifeCourse

Experiences and Questions Booklet

A Guide for Individuals, Families,
and Professionals

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 health care need.

Charting the LifeCourse 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, options and life experiences 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 this *LifeCourse Experiences and Questions* booklet helps you realize that even when your child is very young, and wherever you are on the journey as he or she ages and grows into adulthood, their life experiences and environment can shape how they will live life in the future.

Charting the LifeCourse: Experiences and Questions Booklet
A Guide for Individuals, Families, and Professionals
Third Edition

© 2015 Missouri Family to Family (MOF2F) at the UMKC Institute for Human Development, University Center for Excellence in Developmental Disabilities. This work is licensed under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-sa/4.0/>.

Lead Authors:

Michelle C. Reynolds, Ph.D
Jane St. John

Editing, Design, and Creative Support:

Rachel K. Hiles, M.P.A.

This publication can be reproduced and distributed in a manner consistent with its intended use. If you have feedback or would like to share how you have used this publication, please direct correspondence to Michelle Reynolds, Ph.D., at (800) 444-0821 or reynoldsmc@umkc.edu.

Suggested Citation:

Missouri Family to Family (2015). Charting the LifeCourse: Experiences and Questions Booklet, a Guide for Individuals, Families, and Professionals. Kansas City, MO: University of Missouri-Kansas City Institute for Human Development, University Center for Excellence in Developmental Disabilities.

Missouri Family to Family is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri-Kansas City Institute for Human Development. It is the state's Family to Family Health Information Center, and is a Parent to Parent USA Alliance Member.

This document was developed in partnership and with support from the Missouri Department of Mental Health, Division of Developmental Disabilities; the Missouri Department of Health and Senior Services, Bureau of Special Health Care Needs; the Missouri Developmental Disabilities Council (PL106-402); and the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs (#H84MC09484).

Grantees undertaking projects under government sponsorship and their evaluators are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official positions of the University of Missouri-Kansas City, or any partners or funding sources.

This document provides information of a general nature and is designed for information and educational purposes only and does not constitute medical or legal advice.

WHAT IS THIS, and who is it for?



Charting the LifeCourse: Experiences and Questions 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 health care needs.

Individuals with Disabilities or Special Healthcare Needs & Their Families

Charting the LifeCourse: Experiences and Questions was developed to help individuals and families:

1. Explore questions and life experiences at all ages and areas of life so they can create and plan a vision for a good life now and in the future.
2. Hold conversations with family, friends, and/or professionals in their support network about life goals and outcomes or what they need to be successful and self-determined now and in the future.

Some people may choose to look only at the sections of this guide that focus on their present circumstance, life stage or a specific life area. Others may prefer to look ahead to future life stages or look at all life areas to help them prepare for and make choices and decisions to obtain future life goals and desired experiences.

Professionals

This guide will help professionals who serve individuals with disabilities or special health care needs and families:

1. Build upon their own understanding of the needs of individuals and families.
2. Start 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 *LifeCourse* 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.

Individuals and families, as well as professionals who provide support, need tools that will help them along the way to achieving full, meaningful, and self-determined lives. We hope this booklet will be a tool that will help guide you along your journey.

WHAT IS IMPORTANT TO KNOW

before getting started?



Charting the LifeCourse is a framework created to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, 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 think about life experiences that will help move them toward an inclusive, productive life in the future.

Even though it was originally created for people with disabilities, this universally-designed framework may be used by any person or family making a life plan, regardless of life circumstances.

FOUNDATION OF THE LIFECOURSE FRAMEWORK

The following are the building blocks of the LifeCourse framework. They are the core principles and values that are important as we begin to think differently about what it means to support individuals with disabilities and their families to have good lives.

Core Belief: All people have the right to live, love, work, play, and pursue their life aspirations.



ALL People

ALL people, regardless of age, ability or family role, are considered in our vision, values, policies and practices for supporting individuals and families.



Life Stages and Trajectory

Individuals and families can focus on a specific life stage, with an awareness of how prior, current and future life stages and experiences impact and influence life trajectory. It is important to have a vision for a good, quality life, and have opportunities, experiences and support to move the life trajectory in a positive direction.



Life Outcomes

Individuals and families plan for present and future life outcomes that take into account all facets of life and have life experiences that build self-determination, social capital, economic sufficiency and community inclusion.



Family System and Cycles

People exist and have give-and-take roles within a family system. Roles adjust as the individual members change and age. Individuals and families need supports that address all facets of life and adjust as the family ages through family cycles and the roles and needs of members change.



Life Domains

People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life. These include daily living, community living, safety and security, healthy lifestyles, social and spirituality, and citizenship and advocacy.



Individual and Family Supports

Supports address all facets of life and adjust as roles and needs of all family members change. Types of support might include discovery and navigation (information, education, skill building); connecting and networking (peer support); and goods and services (daily living and financial supports).



Integrated Delivery of Supports

Individuals and families access an array of integrated supports to achieve the envisioned good life, including those that are publicly or privately funded and based on eligibility; community supports that are available to anyone; relationship-based supports; technology; and that take into account the assets and strengths of the individual and family.



Policy and Systems

Individuals and families are truly involved in policy making so that they influence planning, policy, implementation, evaluation and revision of the practices that affect them. Every program, organization, system and policy maker must always think about a person in the context of family.

To learn more about the LifeCourse framework, visit mofamilytofamily.org.

WHAT DOES IT TAKE

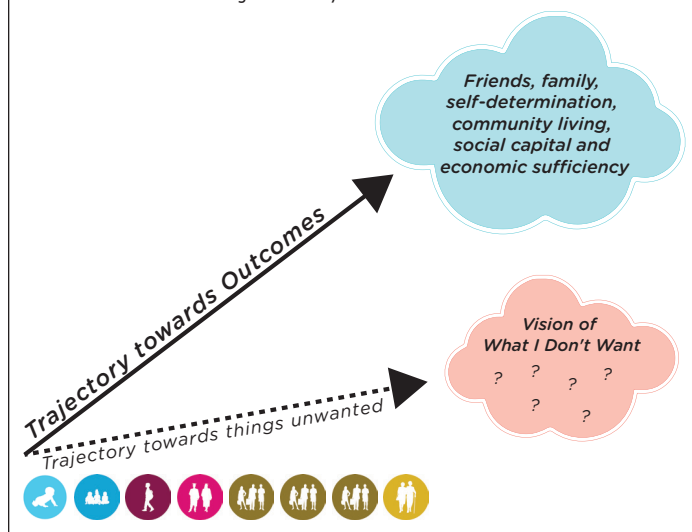
to get to the good life?



From a young age, children dream 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 health care 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 keep a vision of the future in mind into 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 arrow to go towards the bulls-eye of the target. If the goal is to have inclusive, good 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

FIGURE 1. Trajectory toward the Good Life



a vision of where the trajectory is aimed. What does a good life look like –what kind of things would be present? It's also important to think about what they know they DON'T want, so experiences and events don't push the arrow in that direction. By having a vision for the future from a young age, it is more likely the trajectory will lead the person to the good life of which they dream.

QUESTIONS TO ALWAYS THINK ABOUT

Along Your Journey

The following are questions to consider no matter the particular life category or age. These are questions 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.

- What are other people my age doing (for work, fun, etc.) and what adaptations or accommodations are needed so I have similar life experiences?
- Am I learning how to create or maintain community connections and social capital?
- How could assistive technology, adaptations or accommodations assist me in living the life I want?
- Am I learning how to access and integrate a variety of types of support (relationships, community assets, technology) in addition to any paid supports I receive?
- Do you have someone to talk to about your feelings, emotions, and concerns, so that you don't feel alone?
- Do you feel empowered to ask questions or disagree with professionals, and are you helping me know questions to ask and how to assert my wishes/opinions to professionals and supporters? ★
- Are you helping me create a vision for my own life and have the life experiences to get me there? ★
- 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 and helping me learn to do the same? ★

ABOUT THE GUIDE



The questions in *Charting the LifeCourse* 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.
- During transition age and then in adulthood, the questions are about what they themselves want, the things they should be focusing on, and the life experiences they should be having.

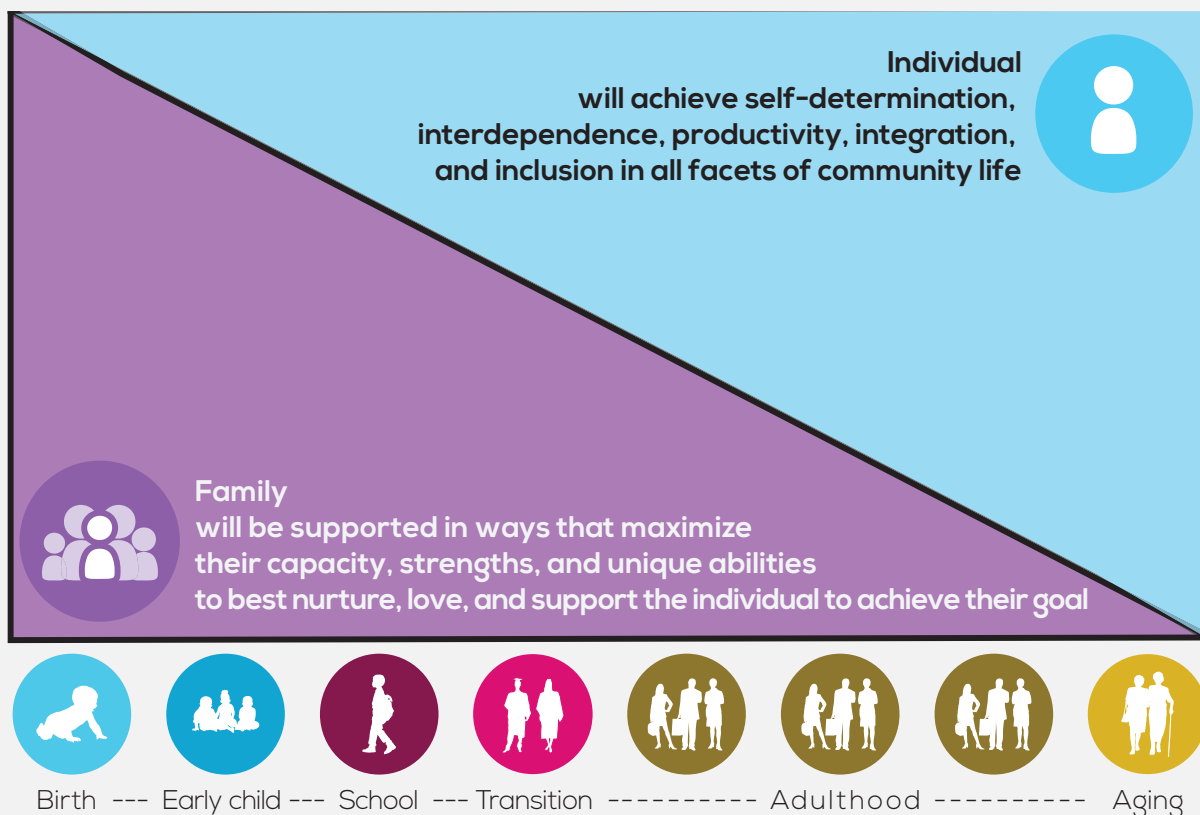
Figure 2 illustrates how during earlier years the child (any child, whether they have a disability or not) is more dependent on the parent or family unit. During the transition and adult years, the family, while still involved and an important part of the person’s life, takes on different roles as the person assumes a larger role in making their own choices and decisions about how they live their life.

SELF-DETERMINATION

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). Self-determination means making choices, setting goals, assuming responsibility, and driving how one’s own life is lived.

Self-determination should be part of the life course journey from the very beginning. Self-determination is 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.

FIGURE 2. Family System across the LifeCourse



NAVIGATING THE GUIDE















LIFE DOMAINS

The icons on the left in Figure 3 represent the different life domains that everyone, including families and people with disabilities or special health care needs, experiences. Life domains are the different aspects and experiences of life that we all consider as we age and grow, such as daily life, community living, healthy living. Everyone (whether they have a disability or not) has to figure out: what they are going to do during the day– go to school, volunteer, get a job; where they are going to live; how they are going to stay healthy and safe; and so on.




LIFE STAGES

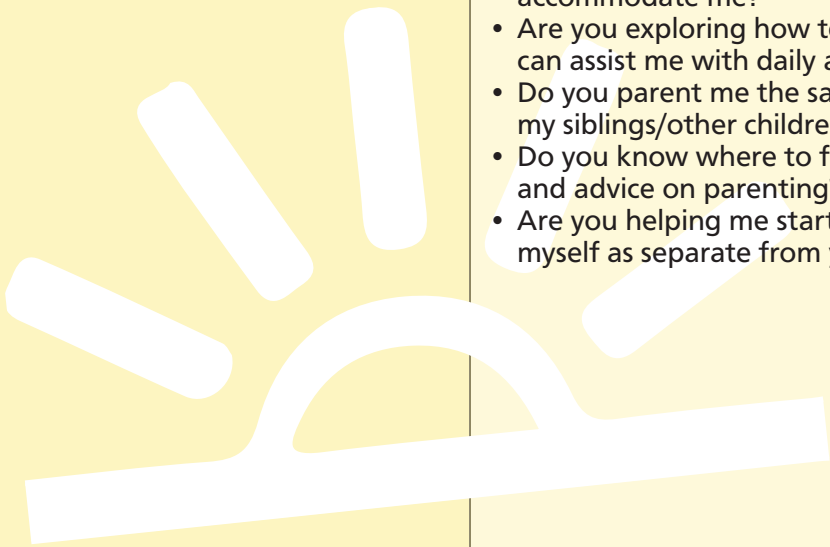
The icons on the right in Figure 3 represent the different ages/stages of life from pre-natal/birth through aging/end of life (going across the top of the following pages). At the intersection of each life stage and life category is a set of questions for you to ask or think about in order to plot a course toward a meaningful life, now and in the future. Individuals and families can choose to look at just one domain, one life stage, or look ahead to think about or have conversations about the future.

FIGURE 3. LifeCourse Legend

LIFE DOMAINS	LIFE STAGES
 <p>Daily Life & Employment What a person does as part of everyday life– school, employment, volunteering, communication, routines, life skills.</p>	 <p>Prenatal/Infancy Early years, wondering if meeting developmental milestones</p>
 <p>Community Living Where and how someone lives– housing and living options, community access, transportation, home adaptation and modification.</p>	 <p>Early Childhood Preschool age, getting a diagnosis</p>
 <p>Safety & Security Staying safe and secure– emergencies, well-being, guardianship options, legal rights and issues.</p>	 <p>School Age Everyday life during school years</p>
 <p>Healthy Living Managing and accessing health care and staying well– medical, mental health, behavior, developmental, wellness, and nutrition.</p>	 <p>Transition Transitions from school to adult life – Realizing school is almost over!</p>
 <p>Social & Spirituality Building friendships and relationships, leisure activities, personal networks, faith community.</p>	 <p>Adulthood Living life as an adult</p>
 <p>Citizenship and Advocacy Building valued roles, making choices, setting goals, assuming responsibility and driving how one’s own life is lived.</p>	 <p>Aging Getting older and preparing for end of life (parent/family/individual)</p> <p>★ Promotes self-determination</p>






 Prenatal & Infancy	 Early Childhood	 School Age
<p>Education</p> <ul style="list-style-type: none"> • Do you recognize and respond to my signs, signals, babbling, gestures, and words? ★ • Are you playing with me and helping me to find ways to learn about and explore my environment? ★ • Are there adaptive devices like switch toys and other assistive technology that can help me explore my environment? <p>Employment</p> <ul style="list-style-type: none"> • Will you need to quit your job to stay home and take care of me? How will we deal with the loss of income? • 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? ★ <p>Individual and Family Life</p> <ul style="list-style-type: none"> • Have you established a daily routine for me? • How can technology assist you with helping me with daily activities? • Are you sharing information with extended family members so they feel comfortable spending time with me? 	<p>Education</p> <ul style="list-style-type: none"> • Are you sending me to preschool or daycare? ★ • Who will provide any extra help I might need to attend preschool? • Do you know where/how to find a childcare provider who can accommodate my needs? • Are you giving me opportunities to make choices (between two or three options)? ★ • Do I have the opportunity to make mistakes and 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? ★ <p>Employment</p> <ul style="list-style-type: none"> • 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 I have chores or responsibilities at home like cleaning my room or picking up my toys? <p>Individual and Family Life</p> <ul style="list-style-type: none"> • What are the routines/strategies that will help you and me throughout the day? • Are there ways you can organize things differently to better accommodate me? • Are you exploring how technology can assist me with daily activities? • Do you parent me the same way as my siblings/other children? ★ • Do you know where to find tips and advice on parenting? • Are you helping me start to see myself as separate from you? ★ 	<p>Education</p> <ul style="list-style-type: none"> • 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 "after school" program and what supports do I need to fully participate? • What supports and services does my school provide or pay for? • Do you know what to do if my school district refuses a request or service? • Will my school district pay for an independent evaluation? • Does my school provide assistive technology to assist/support me? • What if I want to go to a private school– does my home district pay for anything? <p>Employment</p> <ul style="list-style-type: none"> • 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 I have responsibilities at home such as daily chores? ★ <p>Individual and Family Life</p> <ul style="list-style-type: none"> • Do I have an after-school or evening routine? • Am I expected to follow rules like any other child with consequences when I don't? • Are you giving me chances to make choices and decisions about everyday things (like what I wear, what I eat for a snack)? ★ • Are you helping me learn ways to communicate my thoughts, ideas, and needs to others? ★ • Do I know when it's okay or appropriate to talk, who it's okay to talk to, or what to say? ★








 Transition	 Adulthood	 Aging
<p>Education</p> <ul style="list-style-type: none"> • Have you helped me create a transition plan that is truly individualized and prepares me for adult life after school ends? ★ • Have you talked to me about post-secondary education? Taken me for college visits? ★ • If I want to go to college, are you helping me find scholarships or other funding sources? ★ <p>Employment</p> <ul style="list-style-type: none"> • Does my transition plan include work or volunteer experience, and practicing how to look for, get, and keep a job? ★ • 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 I like someday? ★ • Am I learning about the different roles people have in life and how they are interrelated? ★ • Are you helping me learn how to apply for a job and gain experience in jobs that interest me? ★ • Are you helping me explore assistive technology that would help with learning employment and adult living skills? • Can Vocational Rehabilitation help me prepare for college or a career? <p>Individual and Family Life</p> <ul style="list-style-type: none"> • What daily/independent living skills am I working on as part of my transition plan? ★ • What are we doing at home to prepare for adult life? Are you teaching me everyday living skills such as preparing meals, doing laundry, or house keeping? ★ • Do I have responsibilities at home, school, or in the community? ★ • What does my ideal day look like? What about my week? • What makes a bad day for me (things I want to avoid)? • Have you talked to me about how I envision my life as an adult and what I need to reach that vision? 	<p>Education</p> <ul style="list-style-type: none"> • Do I find ways to continue learning at my job, through volunteering, in the community, or with friends? ★ • Is there something I've always wanted to learn more about? • Are there skills or interests I would like to explore or develop? <p>Employment</p> <ul style="list-style-type: none"> • What will I do during the day now that I am an adult? • What are the things I really like or want to do? ★ • Can I find a job or volunteer opportunity that matches my passion or interests? • Would I prefer to have a full time job, part time job, volunteer? • Where can I learn or improve my employment skills? ★ • Can I turn an interest of mine into a way to earn income/start my own business? ★ • 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? ★ • How might my life change if I had more money to do things I like? • Does my income from my employment or other sources exceed benefit limits? • Has anyone helped me think about what has or hasn't worked well for me in previous jobs and do I have a plan to address those things? • Have I thought about how to address barriers to getting the job I want? • Would assistive technology help me with college or a career? <p>Individual and Family Life</p> <ul style="list-style-type: none"> • 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? ★ • Is there assistive technology that can help me with daily activities? 	<p>Education</p> <ul style="list-style-type: none"> • Do I want to learn a new skill to keep me busy or earn money in retirement? • Are there senior classes nearby that I am interested in attending? • Is there a hobby or new interest I would like to learn more about? • Do I need information or education about a diagnosis or medications I have received due to my aging? • Am I learning about changes in my body as I age? • Do I need support to learn about end of life planning, benefits, or health care? <p>Employment</p> <ul style="list-style-type: none"> • Can I afford to retire? ★ • What will I do to keep busy if I retire? • Do I have funds or support to replace my income when I retire? <p>Individual and Family Life</p> <ul style="list-style-type: none"> • 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? • How can technology like magnification, assistive listening or other technology assist me to live as independently as possible? • Do I need help with budgeting or paying bills? • Is there anything important to me about my routine that has to be present or absent? • What does my perfect day or week look like? • What contributes to a bad day for me (what needs to be absent)?



 Prenatal & Infancy	 Early Childhood	 School Age
<p>Living Options</p> <ul style="list-style-type: none">• 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? ★ <p>Accommodations and Access</p> <ul style="list-style-type: none">• Are there accessibility issues in our home that need to be addressed?• Are there ways you can structure where I live and other surroundings to give me opportunities to do typical activities that young children do? ★ <p>Transportation</p> <ul style="list-style-type: none">• Do you have access to reliable transportation that accommodates my needs?• Do I need assistive technology for myself or our vehicle so I am able to get out in the community and places I need to go?	<p>Living Options</p> <ul style="list-style-type: none">• 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? ★ <p>Accommodations and Access</p> <ul style="list-style-type: none">• Have you explored adaptations to our home that will better accommodate my needs?• Do you take me to community places and events like others my age (museums, seasonal outings, learning opportunities)? <p>Transportation</p> <ul style="list-style-type: none">• Am I able to get out and about to explore and learn about my community? ★• Do I need assistive technology for myself or our vehicle to be able to get around?	<p>Living Options</p> <ul style="list-style-type: none">• 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?• Are you helping me make my room age appropriate?• Am I starting to learn to do things to maintain and upkeep a household? ★ <p>Accommodations and Access</p> <ul style="list-style-type: none">• Are there accessibility issues you need to address in our home so I can begin to do things for myself and be as independent as possible? ★ <p>Transportation</p> <ul style="list-style-type: none">• Do I ride the regular school bus or use special transportation?• Is there a neighborhood carpool we could join to take me places and help me with making new connections? ★








 Transition	 Adulthood	 Aging
<p>Living Options</p> <ul style="list-style-type: none"> • Have you talked with me about where I might want to live in the future (after school ends/when I am an adult)? ★ • Will I continue to live in our family home after graduation? • Have you helped me begin to explore different living options? ★ • If I go to college after high school, will I live in the dorms, at home, or someplace else? • Am I getting the opportunity to learn and practice skills I will need to live in other settings? ★ • Am I learning about new people and places to widen my world and expectations for my life? ★ <p>Accommodations and Access</p> <ul style="list-style-type: none"> • 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 graduation? ★ • What supports might I need to live away from home while attending college? <p>Transportation</p> <ul style="list-style-type: none"> • Am I learning how to get around in my community (learning to drive, ride the bus, take a cab, etc.)?★ 	<p>Living Options</p> <ul style="list-style-type: none"> • Am I still going to live in my parents’ home or move out? • What kind of supports do I need to live outside the family home? • What skills do I need to live as independently as I like, and how do I find help when I need it? ★ • What kind of setting will I live in? • Who will help me figure out how to own or rent an apartment/ house or if I need something provided by the service system? • What kind of living options are possible? ★ • What are the pros and cons of each option? • Do I want to live with a roommate or alone? Do I know I can choose my own roommate? ★ • Do I need staff, or could a roommate be compensated to provide some of my supports? • Do I want to be in control of choosing/hiring/firing my support staff? ★ • Can I afford to pay for my own living expenses? ★ <p>Accommodations and Access</p> <ul style="list-style-type: none"> • What kind of accessibility issues should I consider when choosing my home or apartment? • How am I being supported to have valued roles in my community? <p>Transportation</p> <ul style="list-style-type: none"> • How do I get around to places I need or want to go? 	<p>Living Options</p> <ul style="list-style-type: none"> • How can I be supported to age in place (stay in my own home)? <p>Accommodations and Access</p> <ul style="list-style-type: none"> • What home adaptations or other living options are available to help me stay in my home and community as I age? • What modifications need to be made to my home to accommodate barriers of aging? <p>Transportation</p> <ul style="list-style-type: none"> • Are there “senior citizen” resources in my community (senior center, transportation, Meals on Wheels, etc.)?



SAFETY & SECURITY

 Prenatal & Infancy	 Early Childhood	 School Age
<p>Personal Safety</p> <ul style="list-style-type: none"> • Are you childproofing and otherwise making sure that our home is safe for me? • Are there things in our home that could harm me (for instance lead paint, or sharp edges)? • If you go to work or other places I can't go, are you leaving me with someone reliable who will keep me safe? • Are you aware of how to spot abuse or neglect by other caregivers and how to report it? <p>Public Safety (disaster, fire, police)</p> <ul style="list-style-type: none"> • Do you have local emergency numbers and poison control information easily accessible in case something happens to me? • 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? <p>Legal and Financial (rights, advocacy, planning)</p> <ul style="list-style-type: none"> • Have you arranged for someone to care for me (and my siblings) if something happens to you? • Am I eligible for life insurance? • Do I need a Special Needs Trust? • What is the plan to pay for therapies or services above what my health insurance covers? 	<p>Personal Safety</p> <ul style="list-style-type: none"> • Have you made our home childproof or adapted where we live for my safety? • Are you considering assistive technology that can help keep track of me if I am prone to wandering? • Are you leaving me with safe, reliable childcare when you need to go out? • Are you helping me learn how to say no or tell someone if I feel uncomfortable or am being abused? • Are you helping me learn who to trust and how to be safe? ★ <p>Public Safety (disaster, fire, police)</p> <ul style="list-style-type: none"> • Have you talked to police, Emergency Medical Services, or fire department about emergency response for me? • Are local emergency numbers and poison control information easily accessible in case something happens to me? • 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? <p>Legal and Financial (rights, advocacy, planning)</p> <ul style="list-style-type: none"> • Are you engaging in financial planning for our family's and my future? • Have you established legal means for someone to care for me in your absence or if you can no longer care for me? • How will my caregiver pay for things if you are no longer here to provide my direct support? • Do you have a basic understanding of public benefits I might qualify for, such as Supplemental Security Income (SSI), Social Security Disability Income (SSDI), Medicaid, Food Stamps, or other state and local eligibility-based sources? • Do you know how to find and have the means to hire an attorney qualified to create my special needs trust? 	<p>Personal Safety</p> <ul style="list-style-type: none"> • Do I feel safe and know who to tell if I am being bullied or victimized? ★ • Do you know what to do or who to contact if you are concerned about my safety at school? • If I am prone to wandering, have you educated others on how to keep me safe or what to do? • Have you considered technology that can help find me if I am prone to wandering? • Are you helping me learn about stranger danger, and who I can trust? ★ • Are you helping me learn when and how to call for help? ★ • Are you helping me learn not to hurt myself or others? • Do I receive an "allowance" or have access to money? ★ • Are you giving me chances to decide how to spend money? ★ • Do we have a "password" to protect against stranger danger? <p>Public Safety (disaster, fire, police)</p> <ul style="list-style-type: none"> • Are you keeping local emergency responders up-to-date as my needs change? • 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? <p>Legal and Financial (rights, advocacy, planning)</p> <ul style="list-style-type: none"> • What are my and my family's rights regarding education? ★ • Do you know about procedural safeguards and what it means for me and for you as my advocate? • Do we have a funding plan in place for my special needs trust? • Do you know you do not have to put money into the trust right away? • Do you also need a living trust or will for yourself? • Have you communicated the importance of not putting my name on any beneficiary designations to extended family members?






 Transition	 Adulthood	 Aging
<p>Personal Safety</p> <ul style="list-style-type: none"> • Are you helping me get training and knowledge on safety and security issues? ★ • Do I know how to stay safe when I am out with friends or in new places? • Do I know who to call or tell if I am being bullied or victimized? • Would a limited or joint bank account, automatic bill pay, or debit card help me learn money management skills? ★ <p>Public Safety (disaster, fire, police)</p> <ul style="list-style-type: none"> • Do I know when and how to call for help at home or in the community? ★ • Am I learning what to do in an emergency by practicing safety drills, and do we have a disaster plan that takes my needs into account? • Are you helping me learn how to appropriately interact with law enforcement, and are you helping public safety entities learn how to best interact with me? <p>Legal and Financial (rights, advocacy, planning)</p> <ul style="list-style-type: none"> • How you will know if I need a guardian when I turn 18 or if there are other ways to help me stay safe? • Are you exploring alternatives to guardianship (i.e.: power of attorney or supported decision making), so I can keep my right to make my own choices and decisions? ★ • Does my transition plan include learning skills to “be my own person” and not need a guardian for decision-making support or protection? ★ • Are you considering my safety and protection without making me overly dependent or taking away my right to be self-determined? ★ • Do I understand how my special needs trust can supplement my quality of life in the future? • Do I understand the concepts of money management, and how can you help me learn to manage my finances? • Are we considering options if public benefits were no longer available to help provide my support? 	<p>Personal Safety</p> <ul style="list-style-type: none"> • 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 should not let into my home (i.e.: strangers, repair/utility workers)? ★ • Is there assistive technology that can help keep me safe in my home and in the community? • What should I do if I am being abused or victimized by a significant other, support staff, a housemate, or anyone else? • Can I be at home alone or access the community without help? If not, what kind of supports do I need? <p>Public Safety (disaster, fire, police)</p> <ul style="list-style-type: none"> • Do I know who to call if I don’t feel safe or need assistance? ★ • Do I know what to do in case of an emergency by practicing safety drills, and is there a disaster plan in place that takes my needs into account? <p>Legal and Financial (rights, advocacy, planning)</p> <ul style="list-style-type: none"> • Who is partnering with me with in supported decision making? • Do I have a special needs trust in place for “extras” that benefits don’t cover? • What is the distribution plan for my special needs trust to supplement my quality of life? • What other income sources do I have to cover my monthly costs? • Do I need help with filing my taxes, and who can assist me? • If other family members are financially responsible for my well-being, do they have the long term means and ability to do so? 	<p>Personal Safety</p> <ul style="list-style-type: none"> • Are there things happening to me, such as dementia, adding to concerns for my safety? • Who can I go to if I feel I am being abused or victimized by anyone? • Am I at risk 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 need to be in place for me to continue living in my own home/community setting? ★ <p>Public Safety (disaster, fire, police)</p> <ul style="list-style-type: none"> • Are emergency responders aware of my end of life wishes? • Do I know what to do in case of an emergency by practicing safety drills, and is there a disaster plan in place that takes my needs into account? <p>Legal and Financial (rights, advocacy, planning)</p> <ul style="list-style-type: none"> • What are my legal rights and protections as I age? • Is supported decision making or other alternatives to guardianship in place to protect my rights as I age? • Do I have legal documentation of my end of life wishes? ★ • Where and to whom will my remaining assets go when I pass away? • Are my final expenses covered? • Have I updated my LifeCourse materials for future caregivers to easily follow?






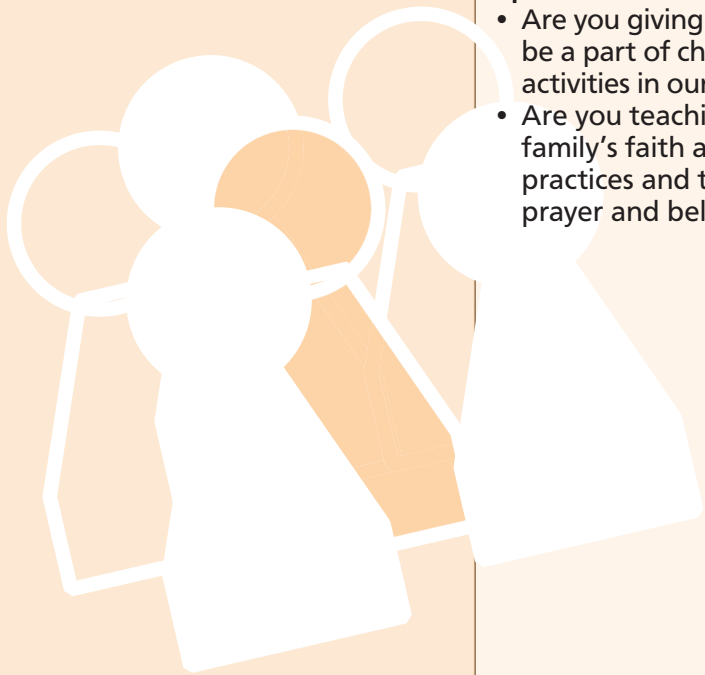
 Prenatal & Infancy	 Early Childhood	 School Age
<p>Healthcare</p> <ul style="list-style-type: none"> • Are you keeping me healthy with well-baby visits and taking me to the doctor when I am sick? • Do your parental instincts tell you something isn't going quite right with my health, growth or development? • Do you know if I am hitting my developmental milestones on time? • Do you know what red flags to watch for? • If I need testing or assessment, will insurance pay for it, or are there other funding sources? <p>Disability/Diagnosis Specific</p> <ul style="list-style-type: none"> • Are you expressing your concerns about my health or development to my pediatrician? • Where are you taking me to find out about my health or development; what kind of testing do I need? • Has anyone else mentioned concerns about my health or development to you? • What are you doing to get the help I need while waiting for a diagnosis and/or services? <p>Fitness and Nutrition</p> <ul style="list-style-type: none"> • Are you taking me to activities such as baby yoga, Mommy and Me classes, etc? • Do I have opportunities at home to get stronger, such as tummy time or a playmat? • Are you introducing a variety of healthy foods in my diet? 	<p>Healthcare</p> <ul style="list-style-type: none"> • Are you finding or accessing medical and health personnel experienced in caring for children with my diagnosis? • Are you taking me to a pediatrician who understands and meets my needs? • Does our pediatrician refer me to specialists when needed? • Do you feel like you have to go along with everything professionals tell you about me, even if your gut tells you otherwise? • Do you know what to do if we don't like or if you disagree with my medical professionals? • Do you have resources to help pay for my medical or other special care? • Will your health insurance cover my needs? <p>Disability/Diagnosis Specific</p> <ul style="list-style-type: none"> • Will therapies help me to grow and develop? • Am I part of a "medical home?" • Have you invited local emergency personnel to our home to meet me and learn about my needs in case of an emergency? • Do you know if I qualify for special healthcare or disability services? • Have you considered applying for services, such as Supplemental Security Income (SSI), Medicaid, Special Healthcare Needs, or Division of Developmental Disabilities? • Do you know the qualifications and income guidelines for the various programs? • Are you looking for community supports and resources? <p>Fitness and Nutrition</p> <ul style="list-style-type: none"> • Are you teaching me about healthy, nutritious food and how my body works? ★ • Are you helping me get plenty of physical activity? 	<p>Healthcare</p> <ul style="list-style-type: none"> • Are you keeping me up to date with regular childhood checkups and immunizations? • Are you taking me to see specialists for specific issues? • Are you teaching me to greet and interact with doctors and other medical professionals? ★ • Do local emergency providers know our wishes if something happens to me at school? • Do I know how to ask for help or tell when I am sick or just don't feel well? ★ • How are you helping me prepare for and understand puberty? <p>Disability/Diagnosis Specific</p> <ul style="list-style-type: none"> • Are you helping me understand my disability or healthcare needs and how it affects me as I grow and change? ★ • What do you need to tell the school nurse about my needs? • What if I need to take medications or treatments at school? <p>Fitness and Nutrition</p> <ul style="list-style-type: none"> • Do I know what is good (food, sleep, exercise) and bad (drugs, smoking) for my body? ★ • Am I learning about healthy foods and nutrition, and how to make healthy snacks? • Am I getting plenty of exercise and/or physical activity? • Are you considering technology that can monitor my sleep patterns, exercise or activity and other health related things (Fitbit, Dropcam, Fuel Band, etc.)?






 Transition	 Adulthood	 Aging
<p>Healthcare</p> <ul style="list-style-type: none"> • Are you helping me to start looking for practitioners who focus on adults? • What do I need to know about the process of transitioning to adult healthcare? ★ • What health related tasks can I start to help with or do for myself? ★ • Will your health insurance cover me into adulthood? If not, how will I get insurance coverage? • Will I qualify for Medicaid or Medicare to help with medical costs? • Are you helping me prepare for and understand puberty? ★ • Do I feel comfortable asking you or trusted adults about the changes in my body as I become an adult? ★ • Have you talked to me about birth control and reproductive health? ★ <p>Disability/Diagnosis Specific</p> <ul style="list-style-type: none"> • Are you helping me 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 communicate about my disability or healthcare needs with others? ★ • What support or financial assistance is available for me as I become an adult? • Who will pay for the services and supports I need when I am no longer in school? <p>Fitness and Nutrition</p> <ul style="list-style-type: none"> • 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? • Do I make good, healthy food choices for my meals and snacks? • Are you helping me learn how to use technology that can monitor my sleep patterns, exercise or activity and other health related things (Fitbit, Dropcam, Fuel Band, etc.)? 	<p>Healthcare</p> <ul style="list-style-type: none"> • Do I qualify for Medicaid or Medicare coverage? • Can I get my own health insurance coverage? ★ • Am I being supported to help with managing my own medications, talking to my doctors and other medical professionals, and participating in making medical and health decisions? ★ • Do I get regular physicals and routine exams, such as mammograms, prostate checks, and blood pressure monitoring? • Is my reproductive health being looked after? • Do I practice safe sex and/or should I use birth control? ★ <p>Disability/Diagnosis Specific</p> <ul style="list-style-type: none"> • Who else understands my medical needs and information? • Do I communicate with others about my disability or special healthcare needs? • Do I understand my disability or special healthcare needs and how it affects me? <p>Fitness and Nutrition</p> <ul style="list-style-type: none"> • Am I eating healthy meals and snacks and staying physically active? ★ • Do I understand the health risks of behaviors such as smoking, excessive alcohol use, or illegal drug use? ★ • Am I using technology that can monitor my sleep patterns, exercise or activity and other health related things (Fitbit, Dropcam, Fuel Band, etc.)? 	<p>Healthcare</p> <ul style="list-style-type: none"> • Who else understands my medical needs and is available if I need help communicating my needs to others? • Are my supporters aware of how some medications can affect an older person differently? • Who will help me create a will and make my wishes known for medical directives? ★ <p>Disability/Diagnosis Specific</p> <ul style="list-style-type: none"> • Are there disability-related aging and health issues I should be aware of? <p>Fitness and Nutrition</p> <ul style="list-style-type: none"> • Am I preparing and eating healthy meals and snacks? • Am I staying as physically active as possible? • Am I using technology that can monitor my sleep patterns, exercise or activity and other health related things (Fitbit, Dropcam, Fuel Band, etc.)?




 Prenatal & Infancy	 Early Childhood	 School Age
<p>Personal Relationships</p> <ul style="list-style-type: none"> • 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? <p>Leisure & Recreation</p> <ul style="list-style-type: none"> • Are you taking me out to do typical social things as a family? • Is there a playgroup that I can join? <p>Spiritual Enrichment</p> <ul style="list-style-type: none"> • If you enjoy church/worship, are you taking me along so I can become familiar with people and activities there? ★ • Are you having me participate in the rites of passage and rituals of my faith? 	<p>Personal Relationships</p> <ul style="list-style-type: none"> • Are you helping me to learn and practice social skills? ★ • Are you helping me be included with other children in social activities, play dates, and parties? ★ • Are you helping me learn and practice how to take turns and play with other children? ★ • Are you setting limits on my behavior so I can learn to self-regulate and learn to get along with others? ★ <p>Leisure & Recreation</p> <ul style="list-style-type: none"> • 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 taking me to new places and helping me try new things so I can figure out what I like to do? ★ • Are there adaptive recreational devices, toys, or other assistive technology that could help me do what other children do for fun and recreation? <p>Spiritual Enrichment</p> <ul style="list-style-type: none"> • Are you giving me the chance to be a part of children’s groups or activities in our faith community? ★ • Are you teaching me about our family’s faith and spirituality practices and traditions such as prayer and belief? 	<p>Personal Relationships</p> <ul style="list-style-type: none"> • Do I have opportunities to connect with friends after school hours and on weekends? • 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 teaching me about sex, healthy relationships, and boundaries? ★ • If I have trouble communicating, are you helping me explore speech generating devices or other assistive technology? <p>Leisure & Recreation</p> <ul style="list-style-type: none"> • Are you helping me 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 explore organized activities such as scouts or 4H? ★ • Are you encouraging me to try different activities so I can figure out what I like to do in my free time? ★ <p>Spiritual Enrichment</p> <ul style="list-style-type: none"> • Are you helping me explore spirituality and find a welcoming faith community? ★ • Am I learning the spiritual values and cultures of our family and participating in the rites and rituals of our faith?





 Transition	 Adulthood	 Aging
<p>Personal Relationships</p> <ul style="list-style-type: none"> • 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? ★ • 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 supported to express my own sexuality and choices? ★ <p>Leisure & Recreation</p> <ul style="list-style-type: none"> • 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.)? ★ • Do I have the chance to take risks or make mistakes I can learn from? • Do I have opportunities to make my own choices even if those choices could be risky or I could make a mistake? • Have you asked me if I want to be involved in other activities that are less inclusive, such as Special Olympics? ★ <p>Spiritual Enrichment</p> <ul style="list-style-type: none"> • Am I involved with a youth or young adult group in my faith community? ★ • Am I supported to express my spirituality in age appropriate rituals and rites of passage of my faith? 	<p>Personal Relationships</p> <ul style="list-style-type: none"> • How am I maintaining old friendships and making 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 interact well with others by being a good listener and expressing myself? • Do I have friends who will share decision-making about what we talk about and do together? ★ • What kinds of relationships do I have/want in my life? • Where/how can I find someone to date? ★ • Do I want to get married or have children? ★ • Do I have ways to express my sexuality and choices regarding love and intimacy? ★ <p>Leisure & Recreation</p> <ul style="list-style-type: none"> • What kinds of things can I do in the community for fun and friendship? ★ • 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? • Do I prefer to go on vacation alone or with family or friends? ★ • How much money can I afford to spend on social and recreational activities? <p>Spiritual Enrichment</p> <ul style="list-style-type: none"> • Am I able to participate in faith-based and spiritual practices of my choosing? • Do I have a supportive faith community, and what extra supports do I need to fully participate? • Do I have, or want to have, valued roles in my faith community? 	<p>Personal Relationships</p> <ul style="list-style-type: none"> • What opportunities do I have to make/maintain friendships? ★ • Do I have age appropriate friends (same age peers) that share similar interests? • Is there assistive technology to help me keep in touch with friends and family over the phone or internet? <p>Leisure & Recreation</p> <ul style="list-style-type: none"> • What hobbies or interests am I pursuing in my spare time? ★ • Is there a senior center nearby where I can go for social activities? ★ <p>Spiritual Enrichment</p> <ul style="list-style-type: none"> • Do I need extra support to fully participate in my faith community as I am aging? • Are my beliefs and spiritual wishes being considered and respected? • Have I made my end of life wishes pertaining to my faith known to others? ★



Prenatal & Infancy	Early Childhood	School Age
<p>Leadership</p> <ul style="list-style-type: none"> • Are you trying to find a balance between your needs, the family's needs and mine? <p>Self/Parent Advocacy</p> <ul style="list-style-type: none"> • How do you respond to others' concerns about me? • How do you make sure your concerns about me are being acknowledged? • Are you telling loved ones or friends about your concerns for me and my health/development? <p>Supporting Families</p> <ul style="list-style-type: none"> • Is there someone you can talk to that will understand your concerns and feelings? • 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? • 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? ★ <p>Civic Engagement</p> <ul style="list-style-type: none"> • Are you showing me by example how to be a good neighbor and good citizen of my community? 	<p>Leadership</p> <ul style="list-style-type: none"> • Are you interested in learning about helping other parents or policy/systems change? <p>Self/Parent Advocacy</p> <ul style="list-style-type: none"> • Do you make sure you are recognized by others as the expert on me and my needs? • What do you tell family and friends about my diagnosis/special needs? • What do you tell my siblings about my diagnosis/special needs? • Do you accept me as a child first, not just a child with a disability? ★ <p>Supporting Families</p> <ul style="list-style-type: none"> • 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? • Who can you talk to when our family and friends don't understand what you are experiencing or do not understand things about me? • What do you do for yourself and my siblings to help balance my needs? • 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? ★ <p>Civic Engagement</p> <ul style="list-style-type: none"> • Am I learning to follow rules at home and in other settings? 	<p>Leadership</p> <ul style="list-style-type: none"> • Have you considered joining the PTA at my school? • Are you interested in learning about helping other parents or policy/systems change? <p>Self/Parent Advocacy</p> <ul style="list-style-type: none"> • 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? ★ • Are you making sure I am getting the extra support I need at school (ie. 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 needs? ★ <p>Supporting Families</p> <ul style="list-style-type: none"> • Have you thought about connecting with other families that have children my age? • 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? ★ • What supports do my siblings need? ★ • Do my siblings or other family members understand my disability or special needs? <p>Civic Engagement</p> <ul style="list-style-type: none"> • Are you helping me find valued roles and chances to help others or give back to the community? • Am I learning the importance of following the rules at home, school and in other settings?



Transition	Adulthood	Aging
<p>Leadership</p> <ul style="list-style-type: none"> • Are you helping me learn how to share my goals, hopes and dreams at educational and other support meetings? ★ • What steps are you taking to start shifting control of my life to me? ★ • What skills/information do I need to help me learn to make decisions and take control of my own life? ★ • What increasing levels of involvement can I assume (ie: IEP meetings) and what skills do I need? ★ <p>Self/Parent Advocacy</p> <ul style="list-style-type: none"> • Are you helping me explore if I want to join a self-advocacy group? ★ • Am I learning self-advocacy skills at home and school? ★ • Have you talked to me about my vision of life as an adult and what resources I will need to make it happen? • Am I making choices and decisions for myself with support from family, teachers and others in my life? ★ • Are we finding a balance between things that are important TO me and important FOR me? ★ • Are you helping me learn to take control of my money and manage my services and supports? ★ • Am I learning to present myself as the expert on myself and my needs? ★ <p>Supporting Families</p> <ul style="list-style-type: none"> • Are you beginning to view me as an adult? ★ • Are you connected to other families that have experienced or are experiencing transition? <p>Civic Engagement</p> <ul style="list-style-type: none"> • When I turn 18, will I register to vote and learn more about the political process? • Am I volunteering or giving back to my community in other ways? 	<p>Leadership</p> <ul style="list-style-type: none"> • Do I know how to lead a support team, share my vision, life plan and goals and help identify objectives? ★ • Am I making most of my own life decisions and taking responsibility for the outcomes? ★ • Am I able to be assertive without being aggressive? ★ <p>Self/Parent Advocacy</p> <ul style="list-style-type: none"> • How do I find a self-advocacy group to join? ★ • Are my parents and others stepping back and enabling me to make my own choices and decisions about my life (with support as needed)? ★ • Does my family and others understand what I want and what is important to me? ★ • Do I understand my choices, like moving out of the family home and other options? ★ • Do I understand my rights and responsibilities when it comes to dealing with providers, agencies, and other sources of support? ★ • Do I present myself as the expert on myself and my needs? ★ • Do I know how to find or ask for help when I need it? ★ <p>Supporting Families</p> <ul style="list-style-type: none"> • How do we understand and mesh supports available to me and to our family? • Are other family members getting older and in need of supports? • Who in my life knows me well and promotes my success? <p>Civic Engagement</p> <ul style="list-style-type: none"> • Am I registered to vote and do I understand the political process? • Have I explored an accessible voting machine? 	<p>Leadership</p> <ul style="list-style-type: none"> • Am I leading my planning and support meetings? • Am I involved in policy/systems change activities? <p>Self/Parent Advocacy</p> <ul style="list-style-type: none"> • Have you left a “road map” on how to best support me when you are no longer able? • Have I made my wishes for my senior years and end of life known? <p>Supporting Families</p> <ul style="list-style-type: none"> • Who will “be there” for me when both of my parents have died? • Are my extended family members and other supporters knowledgeable about the things that are important to me? • Who will emotionally support me when a close family member or friend passes away? • 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? <p>Civic Engagement</p> <ul style="list-style-type: none"> • Am I interested in volunteering? • Do I still exercise my right to vote? • Do I need extra assistance to vote at the polls, or do I want to vote with an absentee ballot?

Connect with us



(800) 444-0821
mofamilytofamily.org