



STRATEGIES TO SUPPORT REAL LIVES



Charting the Life Course: *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 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.

MISSOURI FAMILY TO FAMILY RESOURCE CENTER

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 HRSA Family to Family Health Information Center, and is a Parent to Parent USA Alliance Member.

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Charting the Life Course:

A Guide for Individuals, Families, and Professionals
Second Edition

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Missouri Family to Family Resource Center (MoF2F)

Lead Authors:

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

Editing, Design, and Creative Support provided by:

Susan Bird, M.S.
Cori Brown, B.M.E.
Jenny Hatfield-Callen, M.A.
Katharine Ragon, M.S.
Rachel K. Hiles, B.A.

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Charting the Life Course: A Guide for Individuals, Families, and Professionals

Who Should Use the Guide



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.

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.



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Understanding Self-Determination

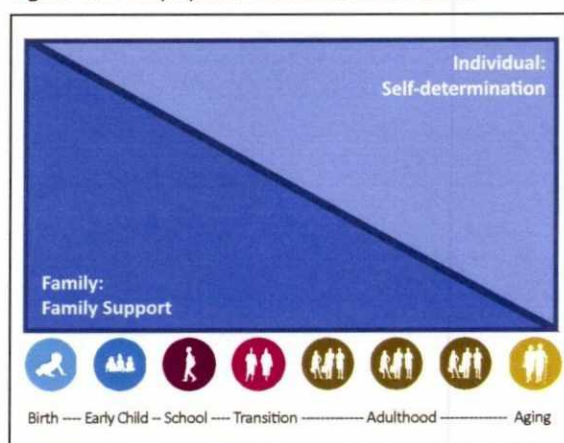
Throughout our lives, we face questions and search for answers that will assist us on the journey to a meaningful life. While this is true for everyone, it is especially relevant for individuals and families that experience disability who are striving to live full and meaningful lives in their communities.

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.

Figure 1. Family System Across the Life Course



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.

















Charting the Life Course: A Guide for Individuals, Families, and Professionals

Navigating the Guide

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

| Life Categories | Life Stages |
|--|--|
|  Daily Life What a person does as part of everyday life— school, employment, volunteering, communication, routines, life skills. |  Prenatal/Infancy Early years, wondering if meeting developmental milestones |
|  Community Living Where and how someone lives— housing and living options, community access, transportation, home adaptations and modifications. |  Early Childhood Preschool age, getting a diagnosis |
|  Social & Spirituality Building friendships and relationships, leisure activities, personal networks, faith community. |  School Age Everyday life during school years |
|  Healthy Living Managing and accessing health care and staying well— medical, mental health, behavior, developmental, wellness, and nutrition. |  Transition Transitioning from school to adult life |
|  Services & Supports Services and supports for individuals and families— both funded (systems) and natural supports; personal/family financial. |  Adulthood Living life as an adult |
|  Safety & Security Staying safe and secure— emergencies, well-being, guardianship options, legal rights and issues. |  Aging Aging and preparing for end of life (parent/family/individual) |
|  Advocacy & Family Support Support for families/individuals— peer support, self-advocacy. |  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 with 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/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 |  Living Adult Life |  Preparing for End of Life | |
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| <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? ★ • 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? | <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 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/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? ★ • 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? | <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? • 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? | <div data-bbox="1406 868 1482 942" data-label="Image"> </div> <div data-bbox="1421 959 1461 1081" data-label="Text"> <p>Daily Life</p> </div> |






| |  Wondering if Meeting Milestones |  Getting the Diagnosis: Entering the World |  Every Day Life During the School Years |
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| Community Living  | <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? • 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? ★ | <ul style="list-style-type: none"> • Have you explored adaptations to our home that will better accommodate my needs? • 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? ★ • 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? | <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 keep my room age appropriate? • 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? ★ • Am I starting to learn to do things to maintain and upkeep a household? ★ • Do I ride the regular school bus or use special transportation? • Is there a neighborhood carpool we could join to take me places and also help me with making new connections? ★ |
| Safety & Security  | <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)? • Do you have local emergency numbers and poison control information easily accessible in case something happens to me? • 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? • Have you arranged for someone to care for me (and my siblings) if something happens to you? | <ul style="list-style-type: none"> • Have you made our home childproof or adapted where we live for my safety? • 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? • Are you leaving me with safe, reliable childcare when you need to go out? • Are you helping me learn who to trust and how to be safe? ★ | <ul style="list-style-type: none"> • Do I feel safe at school and know who to tell if I am being bullied? ★ • Do you know what to do or who to contact if you are concerned about my safety at school? • What are my family's rights and my rights regarding education? ★ • Do you know about procedural safeguards and what it means for me and for you as my advocate? • If I am prone to wandering, have you educated others on how to keep me safe or what to do? • 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? • Are you keeping local emergency providers updated as my needs change? |

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| <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? ★ • 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? ★ • Am I getting the opportunity to learn and practice skills I will need to live in other settings? ★ • If I go to college, will I live in the dorms, at home, or someplace else? • What supports might I need to live away from home while attending college? • Am I learning how to get around in my community (learning to drive, ride the bus, take a cab, etc.)? ★ • Am I learning about new people and places to widen my world and expectations for my life? ★ | <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 want, and how do I find/get 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? Has anyone asked me if I prefer to 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 hiring/firing my staff? ★ • 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? • How do I get around to places I need or want to go? | <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? • How can I be supported to age in place? • Are there "senior citizen" resources in my community (senior center, transportation, Meals on Wheels, etc.)? |  Community Living |
| <ul style="list-style-type: none"> • Are you helping me to get training and knowledge on safety and security issues? ★ • How are you making sure I am safe in diverse settings? • Do I know when and how to call for help at home or in the community? ★ • Are you wondering if I will need guardianship when I turn 18? • Are you exploring alternatives to guardianship so I can retain my right to make my own choices and decisions? ★ • Do you know about things you can do to help keep me safe without getting guardianship? • 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? ★ | <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 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? | <ul style="list-style-type: none"> • 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? ★ |  Safety & Security |

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| Services & Supports  | <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? • Do you need help balancing paying for things I need with meeting our family financial obligations? • If I need testing or assessment, will insurance pay for it, or are there other funding sources? • What are you doing to get the help I need while waiting for a diagnosis and/or services? | <ul style="list-style-type: none"> • Do you have resources to help pay for my medical or other special care? • Will your health insurance cover my needs? • Do you need help balancing paying for things I need with meeting our family's financial obligations? • 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? • Are you exploring assistive technology that would benefit me, and do you know how to get it? • Do you know where to find affordable childcare for me? | <ul style="list-style-type: none"> • What does my school provide or pay for? • Do you know what to do if my school district refuses a request or service solely on the basis of money? • 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? • Do I receive an “allowance” or have access to money? ★ • Are you giving me opportunities to decide how to spend money? ★ • Are you engaging in financial planning for my future? |
| Healthy Living  | <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? • 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? | <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 the 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? • 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? • Are you teaching me about healthy, nutritious food and how my body works? ★ | <ul style="list-style-type: none"> • What do you need to tell the school nurse about my needs? • What if I need to take medications or treatments at school? • Do local emergency providers know our wishes if something happens to me at school? • 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 I know how to ask for help or tell when I am sick or just don't feel well? ★ • Are you helping me understand my disability or healthcare needs and how they affect me as I grow and change? ★ • Do I know what is good (food, sleep, exercise) and bad (drugs, smoking) for my body? ★ • How are you helping me prepare for and understand puberty? |

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| <ul style="list-style-type: none"> • 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 your health insurance cover me into adulthood? If not, how will I get insurance coverage? • Will I qualify for Medicaid or Medicare? • Do I have a supplemental special needs trust? • If I want to go to college, are you helping 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? ★ | <ul style="list-style-type: none"> • 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 have to put money into the trust right away? • 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? ★ • Do I understand my rights and responsibilities when it comes to dealing with providers, agencies, and other sources of support? ★ | <ul style="list-style-type: none"> • 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? |  Services & Supports |
| <ul style="list-style-type: none"> • 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? ★ • 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/reproductive health? ★ | <ul style="list-style-type: none"> • Who else understands my medical needs and information? • 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? • Am I being supported to eat healthy and be physically active? ★ • Is my reproductive health being looked after? • Do I practice safe sex and/or should I use birth control? ★ • Do I understand the health risks of behaviors such as smoking, excessive alcohol use, or illegal drug use? ★ | <ul style="list-style-type: none"> • Who else understands my medical needs and is available if I need help communicating those needs to others? • Are my supporters aware of how some medications can affect an older person differently? • Am I eating healthy meals and snacks? • Am I staying as physically active as possible? • Who will help me create a will and make my wishes known for medical directives? ★ |  Healthy Living |

| |  Wondering if Meeting Milestones |  Getting the Diagnosis: Entering the World |  Every Day Life During the School Years |
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| Social & Spirituality  | <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? • 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? ★ | <ul style="list-style-type: none"> • 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? ★ | <ul style="list-style-type: none"> • 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 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? ★ • Are you teaching me about sex, healthy relationships, and boundaries? ★ • Are you helping me explore spirituality and find a welcoming faith community? ★ |
| Advocacy & Family Support  | <ul style="list-style-type: none"> • 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? | <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? • What do 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? | <ul style="list-style-type: none"> • 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 |  Living Adult Life |  Preparing for End of Life | |
|--|--|--|--|
| <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? ★ • 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, such as 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? ★ | <ul style="list-style-type: none"> • 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? | <ul style="list-style-type: none"> • 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? ★ |  Social & Spirituality |
| <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? ★ • Am I making choices and decisions for myself with support from family, teachers and others in my life? ★ • What steps are you taking to start shifting control of my life to me? ★ • What skills/information do you 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? ★ • Are you helping me learn how to share my goals, hopes and dreams at educational and other support meetings? ★ • Are you beginning to view me as an adult? ★ • Are you connected to other families that have experienced or are experiencing transition? | <ul style="list-style-type: none"> • How do I find a self-advocacy group to join? ★ • Are you stepping back and enabling me to make my own choices and decisions about my life (with support as needed)? ★ • Am I making most of my own life decisions and taking responsibility for the outcomes? ★ • Am I able to be assertive without being aggressive? ★ • Do you and others understand what I want and what is important to me? ★ • Have you helped me understand my choices, like moving out of the family home and other options? ★ • How do we understand and mesh supports available to me and our family? • Do I know how to lead a support team, share my vision, life plan and goals and help identify objectives? ★ • Are other family members getting older and in need of supports? | <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? • Have you left a “road map” on how to best support me when you are no longer able? • Who will emotionally support me when a close family member or friend passes away? |  Advocacy & Family Support |



Charting the Life Course: A Guide for Individuals, Families, and Professionals

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 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 (MO F2F) Resource Center team over a two-year period through a series of meetings with the Missouri Family to Family Stakeholders group. The MO F2F Stakeholders group includes representatives from over 35 different organizations, with 75% of the members identifying as a family leader. MO F2F 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.

This second edition is further enhanced by concepts from Susan B. Palmer's article, "Self-Determination: A Life-Span Perspective," (Palmer, S.B. (2010). Self-determination: A Life-Span Perspective. *Focus on Exceptional Children*, 42(6): 1-16.); and feedback from Self Advocates Becoming Empowered (SABE), the United States' self-advocacy organization.

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