

Life Stages

A Tool to Help Individuals with Disabilities and Their Families Make Informed Choices to Live an Inclusive and Self Determined Life at Any Age.



The Nevada Governor's Council on Developmental Disabilities (NGCDD) engages in advocacy, system's change and capacity building activities for people with developmental disabilities and their families in order to promote equal opportunity, self-determination, and community inclusion.

Adapted from: Missouri Family to Family. Charting the Life Course: A Guide for Individuals, Families, and Professionals. Kansas City, MO: University of Missouri—Kansas City Institute for Human Development, University Center for Excellence in Disabilities.

This guide does not constitute medical or legal advice and does not necessarily represent official views of the NGCDD, the State of Nevada or any other partners or funding sources.

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For large print or other accessible format please contact us: 775-684-8620 www.nevadaddcouncil.org

Some Things to Keep in Mind at Any Life Stage or Category

- Waitlists for assessments and services can sometimes be up to a year long. Plan ahead!
- Do you see me as a person first and my disability second?
- ◆ As long as my health or safety is not in danger, are you letting me make my own choices and mistakes, so I can learn to advocate and problem solve for myself? ★
- ◆ Are you encouraging and helping me learn to be the expert on myself and my needs? ★
- ◆ Are you helping me learn how to ask for accommodations when I need them? ★
- ♦ How are you encouraging self-determination at all ages, stages, and aspects of my life? ★
- 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 have a system in place so that my daycare, babysitters, schools, friends, neighbors, family members and first responders will have access to information about any specific emergency response or accommodation needs I may have?
- Are you prepared to help me advocate for myself my whole life and do you know that it's ok, and sometimes necessary to ask questions and fight for what I need?
- How will assistive technology, accommodations or adaptations grow with me and my changing needs to ensure I'm living the most independent and inclusive life?
- Do you have the resources and information to help you navigate the complicated health care and service support system for me?
- How are my individual talents and abilities (despite my disabilities) being recognized and encouraged?
- Are you asking yourself what other typically developing peers are doing at my age (for work, fun, etc.) and finding ways I can participate?
- ◆ Are you always looking to the future or the next stages of my life? Are you helping me learn to do the same? ★
- ◆ Taking my needs and desires into account, do you have a vision/expectation of me to: date; attend college; be employed in a competitive, integrated job; live in the community; get married; become a parent? Are you sharing that expectation/vision with me? What supports will I need to be successful? ★
- How is my part in our families dynamics of giving/receiving support balanced so that I do not become the sole focus or center of family life? ★
- Are you balancing my needs for therapy with my needs to just relax and enjoy life?
- Do you have someone to talk to about your feelings, emotions, and concerns?
- Do you work on ways to find a balance between your needs, the family's needs, and my needs?
- Do you have a plan for what will happen if both my parents are taken out of my life? What resources will I have and how will it be managed responsibly and for my benefit? Will I be supported and have access to a happy and fulfilling life? Have you made a Will or Trust describing your plan? Have you shared that plan with others?

How to Use This Tool Guide

The original framework, graphics, and information in this guide was developed by the Missouri Family to Family Resource Center and represents the viewpoints of individuals with disabilities, parents, family members, and professionals including feedback from Self Advocates Becoming Empowered (SABE), the United States' self-advocacy organization. It has been adapted for Nevada's needs by the NGCDD using recommendations from our Council members and the community. For additional resources on Charting the Life Course visit: www.supportstofamilies.org.

The questions that follow reflect things individuals with disabilities and/or their families thought about, or wished they had thought about during their own life experience. They are intended to help you make informed choices to plan a life of inclusion and self-determination at any age or stage of life. It is intended to be a starting point no matter where you are in your life journey.

The picture below represents the different sections in the guide. **Life Stages** are the stages of life from birth through end of life. **Life Categories** are experiences we have with the world as we grow, such as employment, friends, and community living. The guide is divided into Life Stages, showing the different life categories one might experience as they grow. Where the life stage and life category meet you will see questions to ask or think about now and as you plan for the future.

Life Stages Life Categories Daily Life Infancy Surviving the first year What a person does as part of everyday life—school, work, routines. **Early Childhood Community Living** Toddler/Preschool years Community access, transportation, housing, adaptations/modifications. School Age Social Everyday life during the school years Building friendships, relationships, recreational activities. **Transition Advocacy & Family Support** Realizing school is almost over Support for individuals/families-peer support, self advocacy. Adulthood **Healthy Living** Living life as an adult Managing and accessing health care, mental health, behavior, nutrition. **Outside Services & Supports Aging** Aging and preparing for end of life For individuals and families-both funded (agency) and natural supports. ★ Promotes self-determination **Safety and Security** Emergencies, well-being, supported

decision making, legal rights.

Self-Determination and Why it Matters

Being self-determined means making choices and decisions based on your own preferences and interests. People who are self-determined know what they want and how to get it. They choose and set goals, then work to reach them. They advocate on their own behalf, and are involved in solving problems and making decisions about their lives. Research shows that people who are more self-determined have higher rates of employment, and earn more money, and make better choices about their behaviors and actions to care for their health and lead healthy lifestyles. -National Gateway to Self Determination. www.ngsd.org

Self-determination involves many attitudes and abilities including: self-awareness, assertiveness, creativity, pride, problem solving, and self-advocacy skills. To take charge of your own life, you must be able to set goals, evaluate options, make choices, and then work to achieve your goals. Since self-determination skills are most effectively learned and developed by practicing them, individuals with disabilities should be given ample opportunity to use their self-advocacy, decision-making and socialization skills starting in early childhood to prepare themselves for working and living in their community. Families can help prepare their children with disabilities by giving them a growing number of opportunities to make their own informed decisions. Most importantly, families should prepare themselves to accept their child in his or her new adult role and allow their adult children to take an active role in the decisions that will determine their future. - National Parent Center on Transition and Employment. www.pacer.org/transition

There are no straightforward answers to a "system" that can often be broken, confusing or limited due to a lack of resources, funds, training, politics, and differing viewpoints. This guide is not meant to provide answers or fix the system. It is a tool to help guide and prepare individuals with disabilities and their families along the journey to live a self-determined life. The questions are written to reflect a "first person" perspective across the lifespan to represent the viewpoint of the person with a disability. You will see a ★ after some of the questions. These indicate a question that helps promote self-determination throughout the life span.

You will see resources listed on the following page. This is not a resource guide. They are not meant to be all inclusive, but a starting point on your journey. Because addresses and phone numbers change, only websites are listed. Views expressed by other agencies do not necessarily represent the official views of the state of Nevada, the NGCDD, the Administration on Intellectual and Developmental Disabilities or any other related or supporting agency or organization. The NGCDD holds no responsibility for other agency content and no endorsement should be inferred. If you do not have computer access, feel free to call us at 775-684-8619 for up to date information on these resources.

Within this guide, individuals and/or families can focus on their current situation and stage of life but may also find it helpful to look both back and ahead to see what was missed and to start thinking about an inclusive and self-determined life in the future. Because transition from school to adult life is so complex, you will see extra pages dedicated specifically to this life stage. Families may also find it helpful to use these questions as a guide when talking about their concerns with professionals, service providers, school personnel and healthcare providers. Professionals who serve individuals with disabilities or special healthcare needs and families may also find this Guide useful to build upon their own understanding of the needs of individuals and families and support them in their journey.

Resources

Developmental Services

- Nevada's Aging and Disability Services Division = a division of the Nevada Department of Health and Human Services. Covers state developmental services across the life span (includes Early Intervention Services) www.adsd.nv.gov
- Nevada Parent Advocacy Initiative (Early Intervention resources) http://www.nvparents.com/
- Project ASSIST = resource directory for services and supports for children and young adults up to
 21 years with disabilities, and their families. dhhs.nv.gov/Programs/IDEA/ProjectASSIST
- ◆ Learn the Signs Act Early <u>www.cdc.gov/ncbddd/actearly</u>
- National Parent Helpline <u>www.nationalparenthelpline.org</u>

General Resources

- Nevada 2-1-1 = general resource directory for services and support <u>www.nevada211.org</u>
- Nevada Department of Health and Human Services (includes medical, financial, behavioral and developmental state services from birth to end of life). dhhs.nv.gov
- Family Ties of Nevada <u>www.familytiesnv.org</u>
- ◆ Care Chest of Sierra Nevada www.carechest.org
- The Children's Cabinet www.childrenscabinet.org
- ♦ Relay Nevada 7-1-1 <u>www.hamiltonrelay.com/state 711 relay</u> (blank spaces are underscored)
- Nevada Center for Excellence in Disabilities (includes Positive Behavior Supports, Path to Independence, Partners in Policymaking and Nevada Assistive Technology Resource Center) www.nced.info
- Silver State Fair Housing www.silverstatefairhousing.org
- Bureau of Vocational Rehabilitation (employment) www.detr.state.nv.us
- Centers for Independent Living:

Northern Nevada <u>www.nncil.org</u> Southern Nevada <u>www.sncil.org</u>

Advocacy and Rights

- The Developmental Disabilities Assistance and Bill of Rights Act <u>www.acl.gov</u>
- Americans with Disabilities Act (includes information on Olmstead) www.ada.gov
- Nevada Disability Advocacy & Law Center <u>www.ndalc.org</u>
- People First of Nevada www.peoplefirstofnevada.org
- Self Advocates Becoming Empowered <u>www.sabeusa.org</u>
- Nevada PEP www.nvpep.org

Public Transportation

- ◆ Regional Transportation Commission of Clark County www.rtcsnv.com
- Regional Transportation Commission of Washoe County www.rtcwashoe.com
- Elko Area Transit Service <u>www.elkocountynv.net/departments/transit_service.php</u>



Infancy **Surviving the First Year**





Daily Life



Community Living



Social

- 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?
- Are you playing with me and helping me find ways to learn about & explore my environment? *
- Do you recognize and respond to my signs, signals, babbling, gestures, and words?★
- Are you keeping a baby book for me?

- 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 ways you can structure where I live and other surroundings to give me opportunities to do typical activities that young children do? ★
- Do you have access to safe transportation to take me to doctors appointments and other community outings?

- 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 just 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?



Advocacy and **Family Support**

- Are you prepared for the different feelings you will experience as a parent of a child with a disability or special healthcare needs?
- 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?
- Do you know other parents who have been in a similar situation or had similar concerns? If not, how can you find out?
- Are you taking time to just enjoy being my parent?





Infancy Surviving the First Year





Healthy Living

- Do your parental instincts tell you something isn't going quite right with my health, growth or development?
- Has anyone else mentioned concerns about my health or development to you?
- If I was born with medical or developmental complications, do you know what resources are available outside of the hospital? Have you asked the hospital social worker to assist you in finding out that information?
- Are you keeping me healthy with well-baby visits and taking me to the doctor when I am sick?
- Are you taking me to a pediatrician who understands and meets my specific needs?
- Do you know if I am hitting my developmental milestones on time?
- Are you expressing your concerns about my health or development to my pediatrician? Are they being respected and addressed?
- Does our pediatrician refer me to specialists when needed?
- Am I part of a "medical home"? Do I need to be?



Outside Services and Supports

- 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?
- Where are you taking me to find out about my health or development? What kind of testing do I need?
- Are there specialists in our area to fit my needs or will we need to look out of state? What will our insurance cover? How will we travel if we have to go out of state?
- What are you doing to get the help I need while waiting for a diagnosis and/or services?
- If you go to work or do other things that you can't take me along, are you leaving me with someone reliable?
- Do you know where/how to find a preschool/child care provider who can accommodate my needs?
- If I am receiving Early Intervention services, do you know and understand your rights as a parent? Do you feel comfortable asserting your rights? Do you know you have a choice in providers? Do you feel comfortable asking what other services or supports may be available to help me and/or our family?



- 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?
- Have the adults I will be around taken emergency and first aid classes specifically designed for infants?



Early Childhood Toddler/Preschool Years





Daily Life

- 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/childcare? If so, who will provide any extra help I might need? *
- Are you keeping a vision in mind for my future as I learn and grow? Are you sharing that vision with friends, family, teachers, etc.? ★
- Are you keeping up my baby book and celebrating all my accomplishments, realizing I will do things in my own time, but I will get there?
- 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? ★
- Are you giving me opportunities to make choices between two or three options? ★
- 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? ★

Community Living

- ◆ Am I able to get out and about to explore and learn about my community? ★
- Have you explored adaptations or accommodations I may need for our home or vehicle?
- Do you know what professional or community supports are available if you feel isolated?
- Do you know where/how to find a preschool/child care provider who can accommodate my needs?



Advocacy and Family Support

- Do you know if there are resources devoted to my specific disability?
- Have you found places where you can connect with other families one-onone or in groups?
- What do you tell family, friends, 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 remember to see me as a child first and my disability second? ★
- Do you make sure you are recognized by others as the expert on me and my needs?



Social

- Are you helping me to learn and practice my social skills? ★
- Are you helping me to be included with other children in school, 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?
- Do you set an example for me by having your friends over or participating in other social activities you enjoy?



Early Childhood Toddler/Preschool Years





Healthy Living

- Are you taking me to a pediatrician who understands and meets my specific needs?
- 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? Are they being respected and addressed?
- Am I part of a "medical home"? Do I need to be?
- Do you know that early intervention in the first 3 years can make a huge impact on my learning and development throughout my life?
- Are you finding or accessing medical and health personnel experienced in caring for children with my diagnosis?
- Does our pediatrician refer me to specialists when needed?
- ◆ Do you know what to do if we don't like, or, disagree with my professionals? ★
- Are you teaching me about healthy, nutritious food and how my body works? ★

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Outside Services and Supports

- If I am receiving Early Intervention services, do you know and understand your rights as a parent? Do you feel comfortable asserting your rights? Do you feel comfortable asking what other services or supports may be available to help me and/or our family? Do you know what will happen when I age out? ★
- Do you know if I qualify for special healthcare/disability financial services? What does my insurance cover?
- Are you exploring assistive technology for me and do you know how to get it?

Preparing for School

- Do you know what tests they will give me to determine my eligibility and what services I will get?
- Do you know what an IEP is? Do you have a friend, parent or other advocate you can take with you to my IEP meetings?
- Do you know your rights as a parent and my rights as a student? ★
- Will the education I receive in school include life and social skills as well as academic skills?
- Will I ride the regular school bus or use special transportation? What supports will be in place for my safe transportation?



- 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?
- If I have medical concerns, have you set up a system so that first responders will have my information
- Are you helping me learn who to trust and how to be safe?



School Age Everyday Life During the School Years





Daily Life

Community Living



Social

- How am I included at school with typical peers? ★
- Is there technology to assist me with school activities?
- Are you sending me to the school's "before/after school" program? 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? ★
- Do I receive an "allowance" or have access to money? *
- Are you teaching me about money and giving me opportunities to decide how to spend money?
- Am I expected to follow rules and given consequences when I don't? ★
- ◆ Are you giving me the opportunity to make choices and decisions? ★
- Are you helping me understand that doing my best and being responsible for my actions is a part of life?

- Have you provided a place in our home that takes into account my sensory or other needs, where I can do 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 (cooking, laundry)? ★
- Is there a neighborhood car pool we could join to take me places and also help me with making new connections?

- Am I learning how to make friends and maintain relationships? ★
- Are there opportunities or strategies at my school or other services I receive to help me make friends?
- Are you helping me to get involved and be included in clubs or extracurricular activities at school and/or the community such as scouts or 4H that encourage my interests? ★
- Are there parks and recreation programs where I can meet and make new friends?
- Are you helping me with positive ways to communicate to make my thoughts, ideas, and needs known to others?
- Are you encouraging me to try different activities so I can figure out what I like to do in my free time? ★
- Do I know when it's okay or appropriate to talk, who it's okay to talk to, or what to say? ★
- Am I learning social and daily living as well as academic skills at school? ★
- Am I learning to use social media safely and responsibly (Facebook, Twitter, Instagram, Snapchat, etc.) to connect with and maintain contact with friends?



Advocacy and Family Support

- ◆ Are you helping me learn to be part of personcentered planning IEP 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 wishes and desires?



School Age Everyday Life During the School Years





Healthy Living

Outside Services and Supports

- 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 and dating?
- ◆ Are you teaching me about sex, healthy relationships, and boundaries? ★

- Am I in the least restrictive environment in school? ★
- Have you reached out to an advocacy organization or another parent to support and help you navigate my IEP meetings?
- Have you talked with my IEP team about my transition planning, knowing that it should start when I am 15 or 16 years old and include a comprehensive action plan for services and supports well before I graduate?
- Will I graduate/leave school at age 18 or continue until I am 21, and will I receive a high school diploma or a certificate of completion?
- 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?
- If I want to go to a private school or be homeschooled does my home district pay for anything? Will I receive the same supports?
- Are you engaging in financial planning for my future? Do you know about resources and laws to help me save for my future?

- 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?
- 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? Have you looked into resources to help keep me safe?
- 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 friends, family, neighbors, school personnel and local first responders updated as my needs change?







Daily Life

- Do I have a plan for what I will do when I graduate? Have you helped me understand what graduation will mean for me and what all of my options are? ★
- What will I do during the day when I am not at school or work?★
- ♦ What are the things I really like to do or want to do? ★
- Can I turn an interest of mine into a way to earn income/start or my own business? ★
- Who can help me to get a job or start my own business ★
- Have you talked to me about attending college? Getting a job? ★
- Have we visited with a vocational rehabilitation program or disability services center at my local college to see what they have to offer?
- Am I on waitlists for services I may need after I graduate?
- 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 in school as part of my transition plan? ★



Daily Life

- Does my transition plan balance work experience, social skills and academics according to my needs, desires and abilities?
- What kind of supports will I need during the day, who will provide needed supports, and how will this impact finances or other family members ability to work?
- 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?
- Am I learning about all the different roles people have in life and how they are interrelated? ★
- Are you helping me understand that doing my best at school and being responsible will help me get a job that I like someday? *
- Do I have responsibilities at home, school, or in the community? ★
- 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.? ★



Community Living

- Have you talked with me about where I might want to live after school ends/when I am an adult? ★
- Have you helped me explore all my housing options, knowing waitlists for accessible and affordable housing can be long?
- Have you helped me figure out what supports I'll need based on my living arrangement choices?
- Will my living arrangements allow me to be as independent as possible but still be safe and supported? ★
- Am I getting the opportunity to learn and practice skills I will need to live in other settings? ★
- If I go to college or take college classes, will I live in the dorms, at home, or someplace else? What supports will I need to ensure I'm successful?
- What supports might I need to live away from home while attending college?
- How will I get around? Do I live inside an ADA zone for public transportation? Do I qualify for paratransit services? Do I know how to ride a bus?
- Do I know how to get to places in my community (by car, bus, cab, etc.)? ★
- Am I learning about new people and places to widen my world and expectations for my life? ★







Social

- Are you providing me with opportunities to explore employment, college, housing and community recreation programs in my community well before high school graduation by utilizing our own network of relatives and friends?
- What opportunities do I have for making new friends at school and in the community? ★
- How are you helping me build lasting relationships outside our family circle?
- How will I maintain and make new friendships when I graduate?
- Are you helping me use social media safely 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? ★
- 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?

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Healthy Living

- ◆ When should you help me start looking for doctors and specialists who focus on adults and what do I need to know about the process so I can participate in choosing my own healthcare providers? ★
- 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?
- 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? *
- How do I find adult health providers who will understand my disability and special healthcare needs as I grow?



Advocacy and Family Support

- 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? ★
- Considering my abilities, are you stepping back and enabling me to make my own choices and decisions about my life (with support as needed)? ★
- What steps are you specifically taking to enable me 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 we connected to other families that have experienced, or are experiencing transition?







Outside Services and Supports

- What support or financial assistance is available for me as I become an adult?
- Who will pay for my services and supports when I am no longer in school?
- Will I qualify for Medicaid and/or Medicare as an adult?
- If I am applying for SSI at age 18, do I need a representative payee?
- If I get a job, how might those benefits affect my future ability to earn income?
- Will your health insurance cover me into adulthood? If not, how will I get insurance coverage?
- 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? ★
- Are you helping me to learn to take control of my money and manage my services and supports?



Outside Services and Supports

- Would a limited or joint bank account, automatic bill pay or a debit card help me learn money management skills? ★
- Do you know that transition from school to adult life will be one of my biggest life changes and challenges, and that I will need your help to advocate for the services and supports I will need to live my life as independently as possible?
- What kinds of community (non-eligibility based) supports might help me now and as an adult (for example, public transportation)?
- Are you teaching me to ask for accommodations for my learning and/or physical limitations when I need them? ★
- Have we signed up for any assessments, services or supports I may need as an adult, knowing that wait lists for assessments and services can sometimes be up to a year long?



- 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 how to recognize if I am being abused, or taken advantage of by a friend, employer, co-worker, significant other, support staff or someone I live with?
- Do I know when and how to get help at home or in the community?★
- Do we both understand the legal aspects of when I turn 18 and officially become an adult in the eyes of the law?
- Are you wondering if I will need guardianship when I turn 18?
- Do you know about things you can do to help keep me safe without getting guardianship?
- Are you exploring alternatives to guardianship, like supported decision making, so I can retain my right to make my own choices and decisions? ★
- Does my transition plan include learning skills that will help me to be my own person?★
- What skills and abilities am I learning and practicing now so I may not need a guardian when I turn 18? ★





Some ideas, options and terms we may want to research together for where I may live, or how I might spend my time after I graduate:

Employment

- Microenterprise
- Competitive, integrated employment
- Supported employment
- Employment First
- Work crews
- ◆ Enclaves
- Sheltered workshop
- ◆ ERC= Employment Resource Center
- Job coach

Post Secondary Education/College

- DRC = Disability Resource Center
- Path to Independence

Housing

- Independent supported living
- Group homes
- 24 Hour supervision
- Accessible housing
- Section 8 housing
- CIL's = Centers for Independent Living

Community Living

- In home vs. community based therapies
- Money Follows the Person
- Systems supports
- HCBS = Home and Community Based Services

Decision Making/Financial

- Designated payee
- Limited/joint bank account
- Full vs. partial guardianship
- Supported decision making
- Special Needs Trust
- Power of Attorney
- ABLE Act
- Self-Directed supports



Adulthood Living Life As an Adult





Daily Life

- 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 to do, 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? ★
- Are you accepting of my wishes and choices (as long as I am safe) even though they might not be what you feel is best, or want me to do?

Community Living

- Wherever I am living, am I in control of hiring/firing my staff? ★
- 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?
- Do I want to get involved in civic engagement or leadership? ★



Advocacy and Family Support

- 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 others understand what I want, and what is Important to me? ★
- Do I understand the supports available to me and our family?
- Do I know how to lead a support team, identify my life plan goals and objectives and share my vision with others? ★
- Are other family members getting older and in need of supports?



Social

- 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 in the decision making about what we talk about and do together? ★
- Do I interact well with others by being a good listener and expressing myself appropriately?
- How am I exploring or developing my interests or finding new ones? ★
- 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? ★



Adulthood Living Life As an Adult





Healthy Living

- Who else understands my medical needs and information?
- ◆ When am I eligible for 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? ★
- Has someone talked to me about how I want to be medically treated if I become very ill?
- Have I made my wishes known for how I want to be medically treated if I become very ill? ★



Outside Services and Supports

- ◆ 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 need a Special Needs Trust in place for "extras" that benefits don't cover?
- Do you, as my parent need a living trust or will for yourself?
- Has someone talked to me about a Will? Have I created one? ★
- 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?



- 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.)?
- 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?
- Do I know how to recognize
 if I am being abused or taken
 advantage of by a friend,
 employer, co-worker,
 significant other, support
 staff or someone I live with?
- Do I know when and how to get help at home or in the community if I don't feel safe or need assistance?★



Aging Aging and Preparing for End of Life





Daily Life

- What supports do I need to continue living where I want and as independently as possible 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 you, what will happen when you 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?
- ◆ Have I made my wishes known for how I want to spend my remaining years? ★



Community Living

- What home adaptations or other living options are available to help me stay in my home and community as I age? ★
- How can I be supported to age in place?
- What modifications need to be made to my home to accommodate barriers of aging?
- Are there "senior citizen" resources in my community (senior center, transportation, Meals on Wheels, etc.)?



Social

- 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 community as I am aging?



Advocacy and Family Support

- Who will "be there" for me when both of my parents have died?
- Is my support system 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?



Aging Aging and Preparing for End of Life





Healthy Living

- 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?
- ◆ Has someone talked to me about how I want to be medically treated if I become very ill? ★
- ◆ Have I made my wishes know to others? ★
- Do I have legal documentation of my wishes?



Outside Services and Supports

- Do I need help with budgeting or paying bills?
- What kind of benefits do I have or could I qualify for to help support myself as a senior?
- Do I have a burial plan and prepaid arrangements in place?
- Has someone talked to me about a Will? Have I created one? ★
- Who will make my final arrangements (especially if my parents or immediate family are already deceased)?
- Who will handle my final expenses and settle my estate?



- Are there things happening to me, such as dementia, adding to concerns for my safety?
- Am I in danger of falling or other hazards?
- Are there home modifications that will help me stay safe?
- Is there assistive technology that will help me stay safe as I age?
- What supports do I need to be in place to continue living in my own home/community setting? ★
- What are my legal rights and protections as I age?
- ♦ Where do I go to find out?
- Do I know how to recognize if I am being abused or taken advantage of by a friend, significant other, support staff or someone I live with?
- Do I know when and how to get help at home or in the community if I don't feel safe or need assistance?★

NOTES

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For other resources on Charting the Life Course visit: www.mofamilytofamily.org

