



Charting the LifeCourse
Framework and Tools

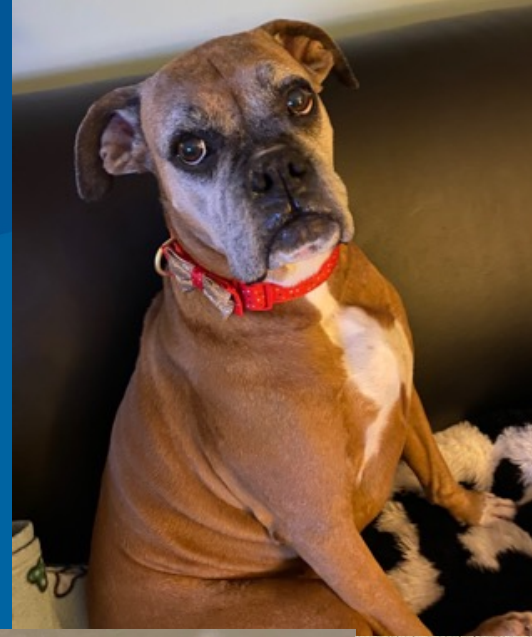
Charting the (Life)Course to Healthy Living

Jane St John, LifeCourse Nexus

www.lifecoursetools.com

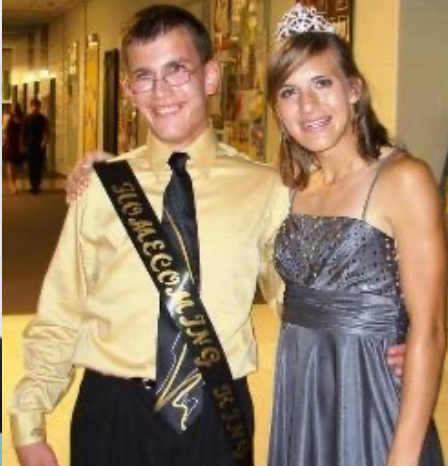
About Jane

- Mom of 3 sons, “Ben’s mom”
- CtLC Nexus at UMKC-Institute for Human Development, UCEDD
 - Product Development and Training
 - Trainer/Coordinator of SDM activities



Today's Objectives

- Brief Overview of Charting the LifeCourse
- Dig into the Life Domain of Healthy Living
- Discover CtLC Tools for Healthy Living
- Explore Ideas for What You Can Do Now



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Charting the LifeCourse Framework and Principles

What is Charting the LifeCourse ?

Framework created for people and families of all abilities and all ages to:

- Explore Life Possibilities
- Share Ideas, Hopes, and Fears
- Set High Expectations
- Have (Difficult) Conversations
- Navigate the Future
- Advocate for a Vision
- Problem-Solve, Plan, & Communicate
- Explore a Variety of Supports



CORE BELIEF

All people and their families have the right to live, love, work, play, learn, and pursue their life aspirations in their community.





Focusing on 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. All families have choices and access to the supports they need.



Person In Context of Family

Life-Long Impact of Family



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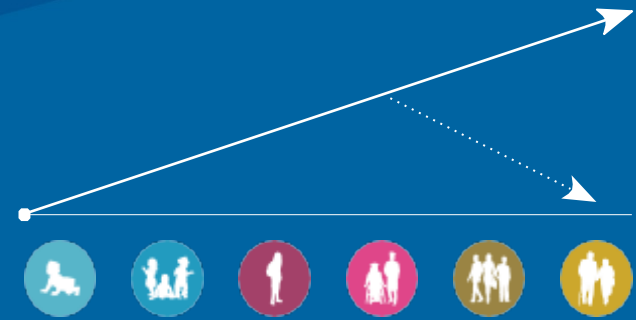
“Good Life for All”



The Individual will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life



Families will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support all individual members to achieve their goals

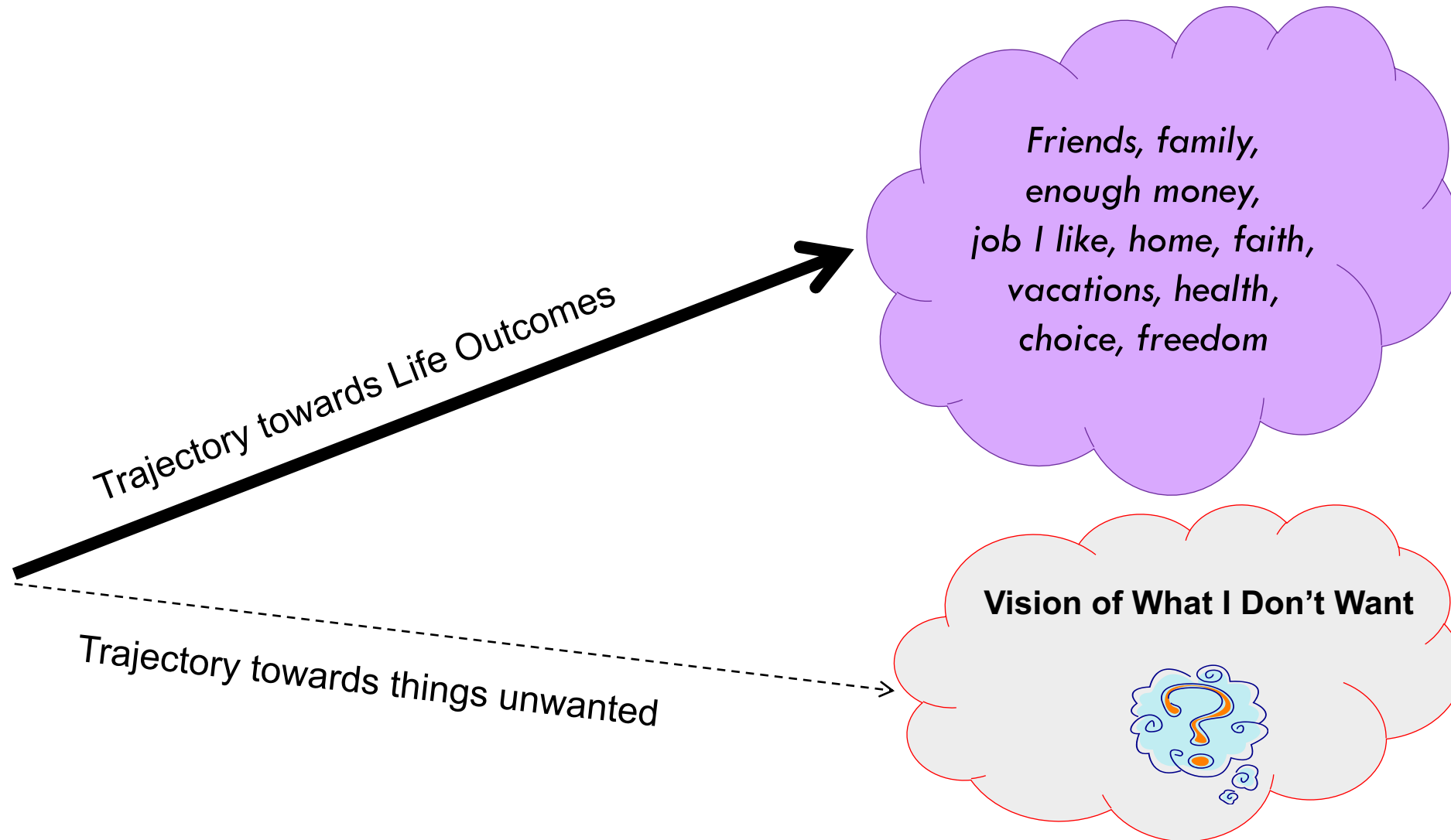


Life Trajectory, Vision, Experiences and Life Stages

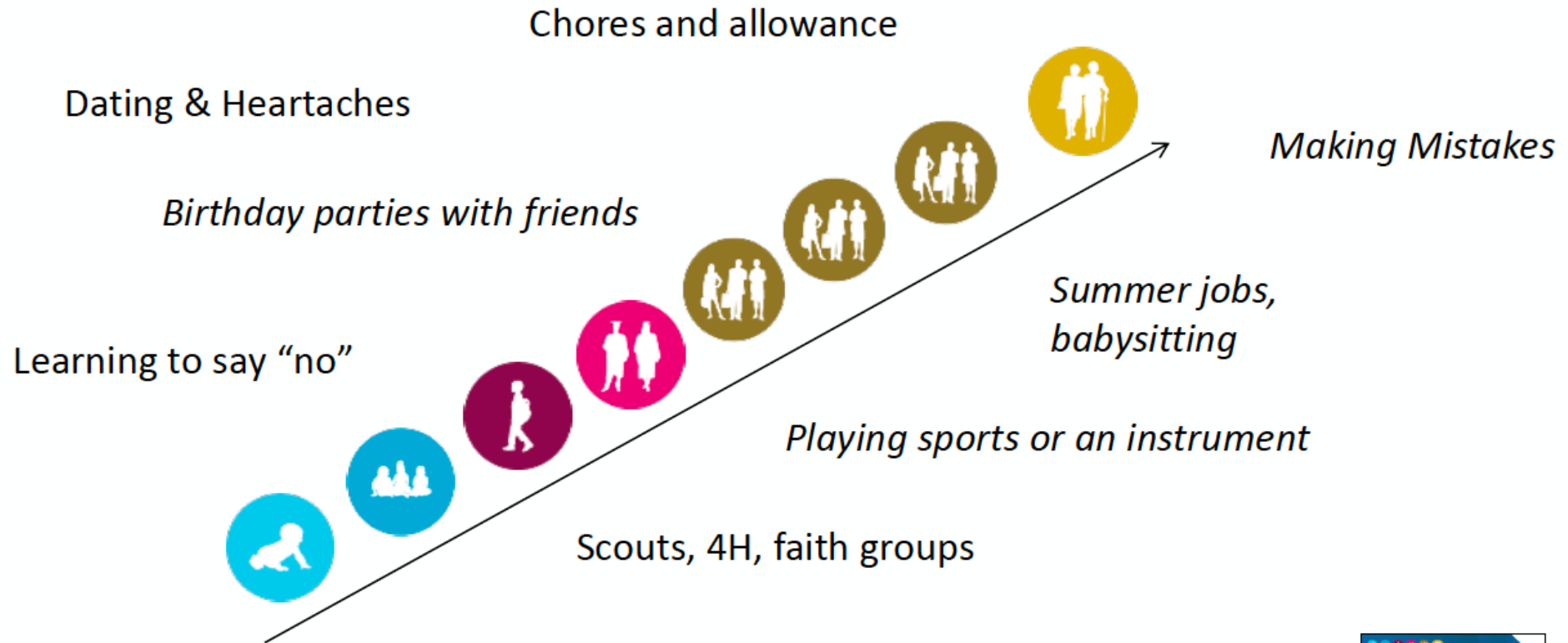


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Vision & Trajectory for a Good Life



Trajectory Across Life Experiences & Stages



“Anticipatory Guidance for Life Experiences”



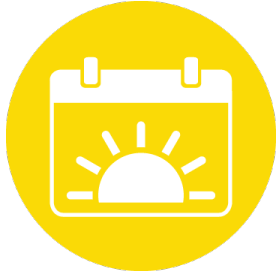


Life Domains, Outcomes and Possibilities



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Connected Life Domains



Daily Life and Employment
(school/education,
employment, volunteering,
routines, life skills)



Healthy Living
(medical, behavioral, nutrition,
wellness, affordable care)



Community Living
(housing, living options, home
adaptations & modifications,
community access, transportation)



Safety and Security
(emergencies, well-being, legal
rights & issues, guardianship
options & alternatives)



Social and Spirituality
(friends, relationships, leisure
activities, personal networks,
faith community)



Advocacy and Engagement
(valued roles, making choices,
setting goals, responsibility,
leadership, peer support)

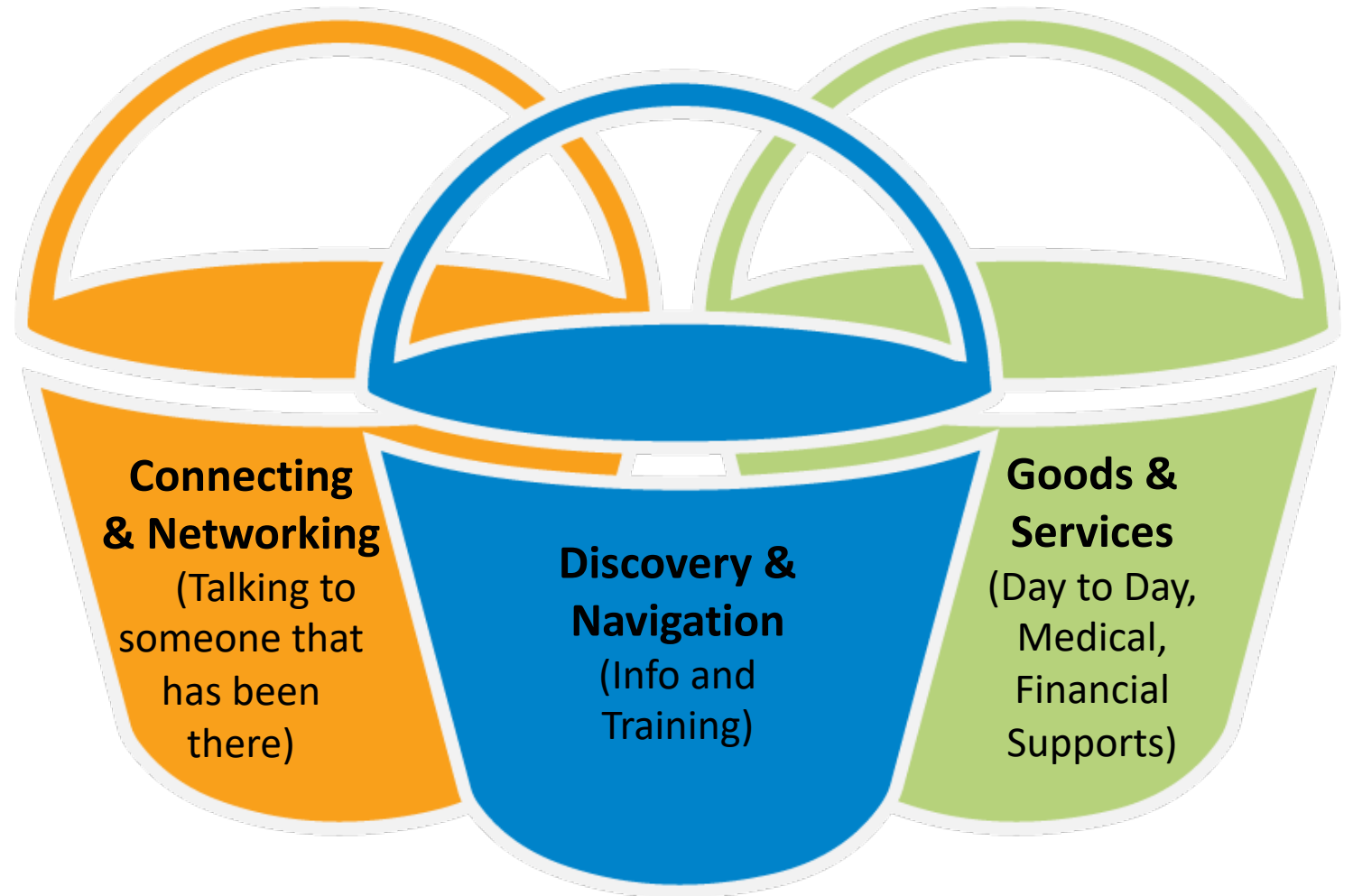


Individualized Supports to Achieve a Good Life



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Supporting the Needs of ALL People The “3 Buckets”





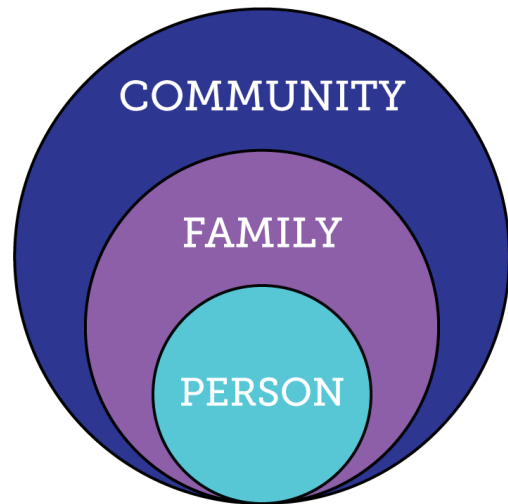
Integrated Supports Star

for Problem Solving and Exploring Options

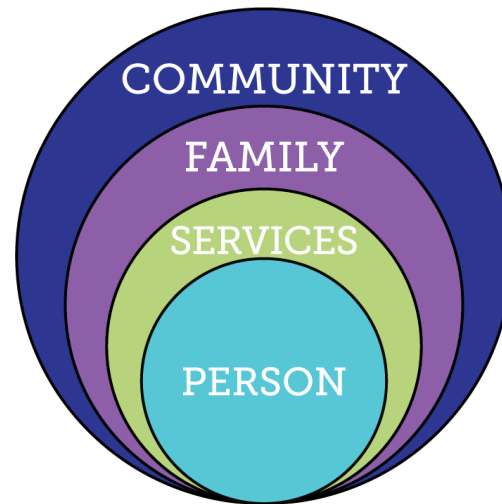


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What We Want to See...



People not receiving formal paid services



People receiving formal paid services



100%
People receiving integrated services and supports

Charting the LifeCourse Integrated Supports Star



100%



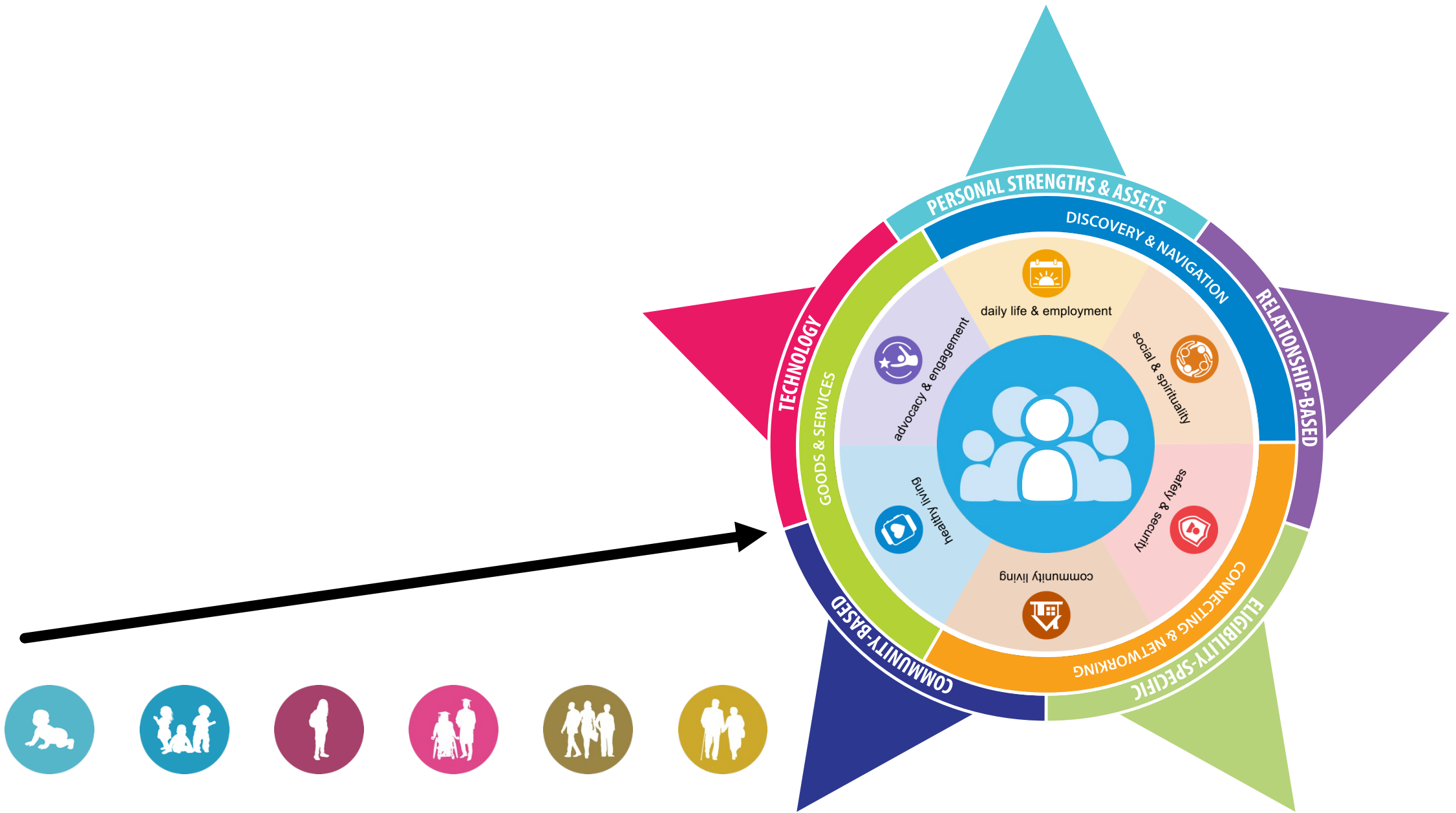


Policy, Systems & Community Change:

Person/Family- Centered and Driven



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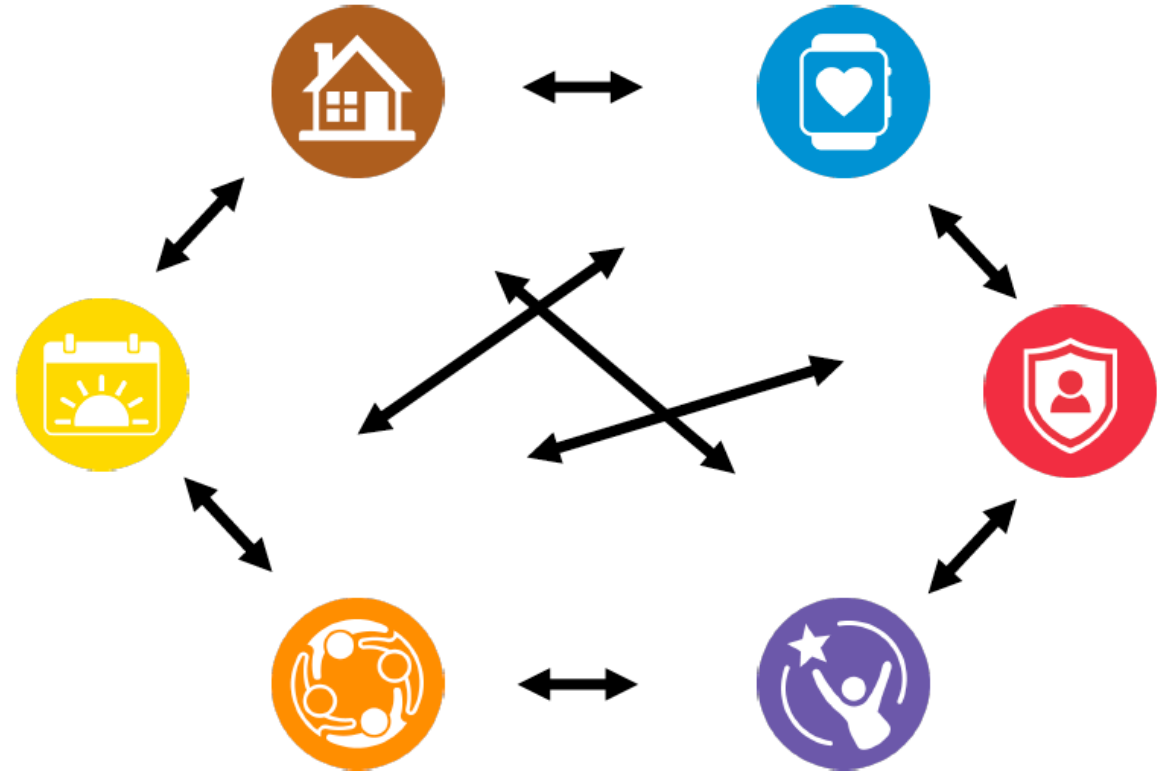
WHY Focus on Healthy Living?



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It's All Connected and Integrated

- Health can impact all the other domains, and vice versa
- What happens early in life can affect adult life and as we age
- We don't normally "plan" for our health
- Navigating environmental and public health issues



What is Healthy Living?



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Life Domain – Healthy Living

Healthy Living

- Managing and accessing health care – medical, mental, and behavioral health, sexual and reproductive health; long term health needs; wellness, fitness nutrition and self-care.



Sub-Domains	Topics
Comprehensive Healthcare	<ul style="list-style-type: none">• Private/Public Health Insurance/Coverage• Primary and Preventative Care (Oral, Vision, Hearing)• Mental Health and Behavioral Support• Access to Care (Telehealth, Transportation, Availability)• Informed Choices for Medical Treatment/Therapies• Understanding Benefits, Medical Bills, Co-Pays, Deductibles• Navigating Specialists, Referrals, Medical Terminology
Long-Term Health Needs	<ul style="list-style-type: none">• Long Term Care Needs• Diagnostic Screening/Testing• Medical Directives (Palliative Care, Hospice, Wishes)• Home Care/Personal Care/Nursing/Specialty• Records Keeping/Care Notebook• Medical Transition
Wellness & Self-Care	<ul style="list-style-type: none">• Fitness/Physical Activity/Inactivity• Healthy Food (Access, Options, Nutrition)• Gender Identity• Sexuality and Reproductive Health, Well-Woman/Man Care and Screening

Comprehensive Healthcare

- Medical Care

- Doctor, Nurse Practitioner, Therapist
- Routine Check-ups/preventive care
- When you're not feeling well
- Procedures



- Dental/Oral Care



- Mental Health/Behavioral Health
- Vision and Hearing

Long Term Health Needs

- Understanding disability/health condition
- Communicating with others
 - Explaining your own disability to your doctors and other health professionals
 - Asking for help or accommodations when needed
- Diagnostic screening/testing
- Home care/personal care/nursing/specialty care
- Records keeping/care notebook
- Medical transition

Wellness and Self-Care

- Healthy meals and snacks/nutrition



- Fitness/physical activity



- Wellness/well-being





Day-to-Day Healthy Living/Routines



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Healthy Living Trajectory

LIFE TRAJECTORY | HEALTHY LIVING

Past Life Experiences

List things in the past that helped me be healthy and make good choices about my health

List things in the past that caused me to be unhealthy or make poor choices about my health

Moving Forward

List what needs to happen to improve my health, make healthy choices, and support my vision for a healthy life

List things that might make it hard to reach my healthy living goals or make healthy choices

Vision for Healthy Living

What do I want my healthy good life to look like?

My vision for a good life

What health issues am I having or am I worried about?

Are there diagnosis or disability specific concerns?

What is my vision around fitness, nutrition and wellness?

What I Don't Want

What are things I don't want to happen with my health?

What I don't want in my life

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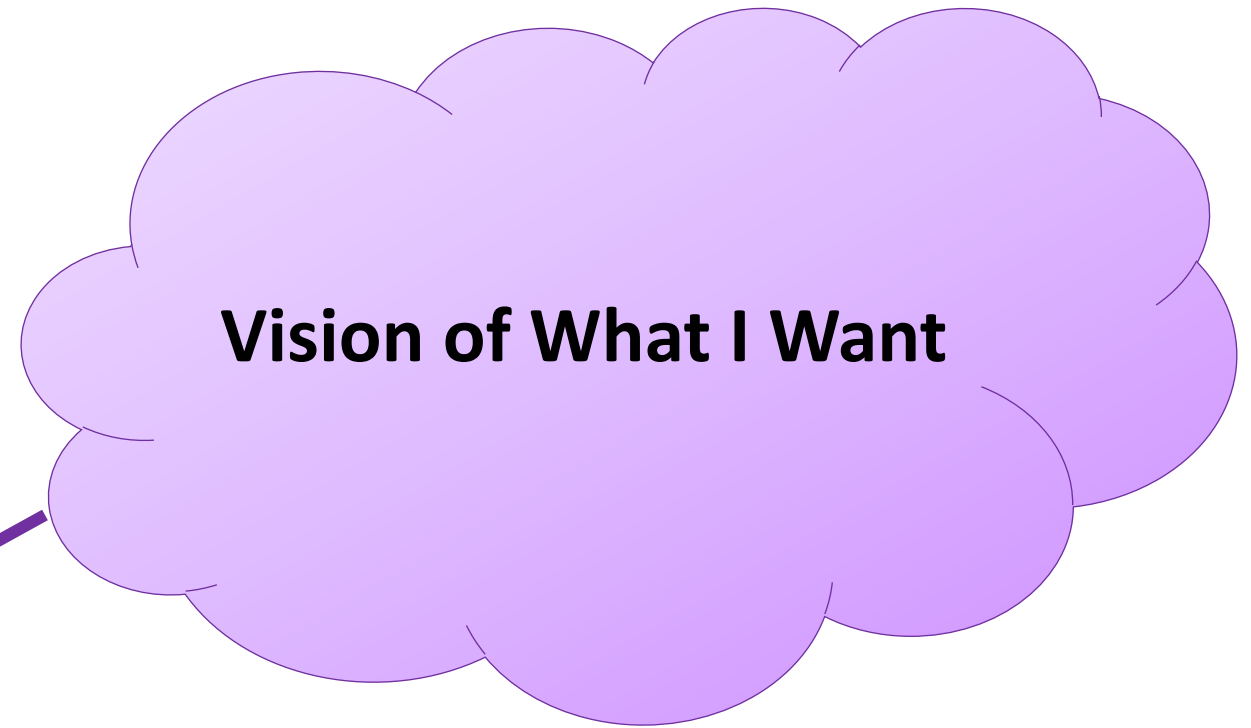
Remember, it's not so much about
“filling out” the tools as it is about the
conversations and the thinking!



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Start With an Overall Vision

-yours
-your child's



LIFE TRAJECTORY | HEALTHY LIVING

Past Life Experiences
List things in the past that helped me be healthy and make good choices about my health.

Moving Forward
List what needs to happen to improve my health, make healthy choices, and support my vision for a healthy life.

Vision for Healthy Living
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What I don't want in my life

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Next, Narrow It Down: Vision for Healthy Living*

**Keep the other Life Domains in mind because health can affect other life domains and vice versa*

Vision for Healthy Living

What do I want my healthy good life to look like?

VISION FOR HEALTHY LIVING

What health issues am I having or am I worried about?

Are there diagnosis or disability specific concerns?

What is my vision around fitness, nutrition and wellness?

What I Don't Want for My Health

What are things I don't want to happen with my health?

WHAT I DON'T WANT FOR MY HEALTH



Vision of What I Want

- Active
- Healthy and Fit/physically strong
- Healthy weight
- Access to fresh food – vegetables, fruit, etc
- Healthy enough to live, work, play where he wants
- Play basketball/workout

Vision of What I Don't Want

- Diabetes/Heart disease/serious issues
- Sedentary/inactive lifestyle
- Unhealthy weight
- Hospital stays/surgeries
- Out of control seizures
- Nursing home/institution

Vision for Ben's Healthy Living



LIFE DOMAIN VISION TOOL | FAMILY PERSPECTIVE

Name of Person Completing: Jane - Ben's mom

Date: October 2020

On Behalf of: Benjamin St John

LIFE DOMAIN	DESCRIPTION	MY VISION FOR MY FAMILY MEMBER'S FUTURE	PRIORITY
	Daily Life & Employment: What do I think my family member will do during the day in their adult life? What kind of job or career might they want?	Continue to volunteer at Fire Station because he loves it and he belongs. We want to help Ben start his own small business, based on his interests, using the Micro-Enterprise model. We want him to be active /not sit home all day.	1
	Community Living: Where and with whom do I think my family member will live in their adult life?	Ideally, we want Ben to either rent or own an apartment, condo or house, and have a roommate or live-in companion. For now, we are looking at options for him to be more	4
	Social & Spirituality: How will they connect with spiritual and leisure activities, and have friendship, and relationships in their adult life?	Ben loves going to weekly mass and a lot of people there talk to him. The fire department also is a source of friendships for him. We want him to keep in touch with friends via social media and invite friends over or out and about with him. We would like him to have a girlfriend and maybe get married someday.	2
	Healthy Living: How will they live a healthy lifestyle and manage health care supports in their adult life?	Ben would work out at least 3-3 times/week, eat healthy food choices, and limit caffeine (Pepsi). We want to get a pill dispenser so he can be more independent taking his meds. We want him to be able to talk to his health care providers and be supported to make choices about his medical care.	3
	Safety & Security: How will my family member be safe from financial, emotional, physical or sexual harm in their adult life?	We want Ben to have lots of friends and family members who keep in touch with him regularly and will notice if something is wrong. He has a trust committee for his SN Trust, and he has family who are his Powers of Attorney. Use available banking options for financial security	
	Advocacy & Engagement: How do I think they will have valued roles, responsibilities, and control of how their own life is lived as an adult?	We would like to see Ben have more active roles at church – maybe ushering or joining the men's group. Maybe find some other volunteer opportunities. Ben should be supported by family and trusted friends to make his own decisions and choices.	
	Supports for Family: What supports does our family unit need now or will need in the future?	Helping Ben self direct his services is helpful so we can continue to work while still being able to hire people we know or that are highly recommended. We need coaching and mentoring for future options.	
	Supports & Services: What supports and services might my family member need in the future to lead the kind of life they want as independently as possible?	By using a combination of technology, family and friends, community options, paid supports, and building on Ben's own skills and abilities, we think he can have the good life he wants.	



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Family Perspective Domain Vision for Ben



What Has Worked or Hasn't Worked?

Past Life Experiences

List things in the past that helped me be healthy and make good choices about my health

WORKING

List things in the past that caused me to be unhealthy or make poor choices about my health

NOT WORKING

GOALS OR NEXT STEPS

PLANNING FORWARD

LIFE TRAJECTORY | HEALTHY LIVING

Past Life Experiences
List things in the past that helped me be healthy and make good choices about my health

Moving Forward
List things that need to happen to improve my health, make healthy choices, and support my vision for a healthy life

Vision for Healthy Living
What do I want my healthy good life to look like?
My vision for a good life

What health issues am I having or am I worried about?

Are there diagnosis or disability specific concerns?

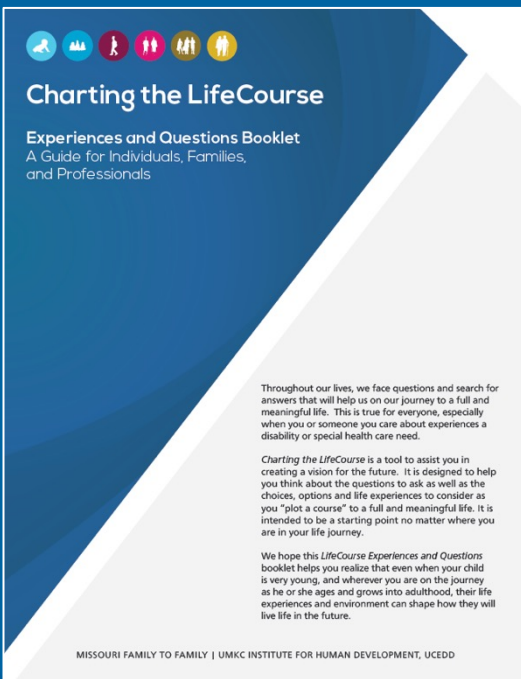
What is my vision around fitness, nutrition and wellness?




What I Don't Want
What are things I don't want to happen with my health?
What I don't want in my life

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BARRIERS TO WATCH OUT FOR

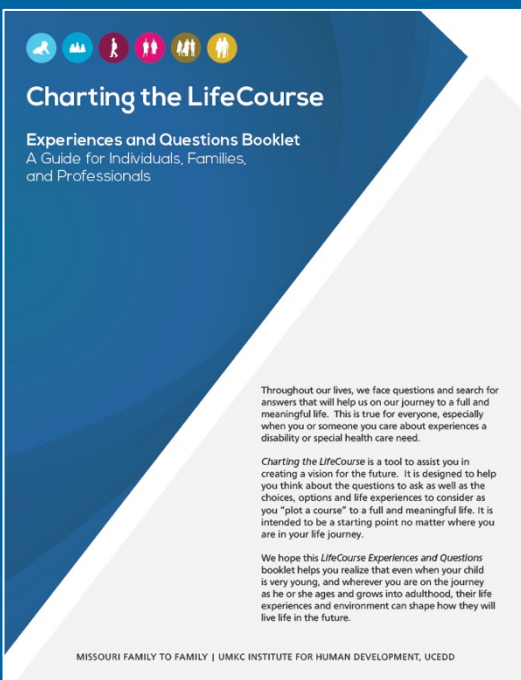
Healthy Living Questions and Life Experiences to Think About






 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.)?



Healthy Living Questions and Life Experiences to Think About



 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.)?



Health Care Visits and Interactions



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UNDERSTANDING MY HEALTH CARE TEAM

My Personal Support Team <i>(Identify your personal supporters and their relationship to you)</i>		Formal Supports <i>(Who are paid people that might be with you and what their role is at the visit)</i>	Who Has Legal Authority <i>(Place a check next to who has legal decision-making authority and identify the person)</i>
Who:	Relationship:	Paid Staff (PCA, DSP):	I have Legal Decision-Making Authority for My Health Care
			Power(s) of Attorney:
			1.
		Residential/Provider Agency Staff:	2.
			Guardian:
			1.
		Other:	Circle: Plenary (full) or Limited
			Conservator:
			1.

UNDERSTANDING MY SUPPORT NEEDS

Areas of Support for Medical Appointments/Events	What I Do/Need and Who Helps Me	Health Professional's Role In Supporting Me
Understanding what the medical professionals are saying, suggesting, recommending or instructing; helping me know my options, pros and cons	<i>Who do I trust to help me understand and how do I communicate with them?</i>	<i>Writing down instructions, using photos or pictures to explain procedures or directions</i>
Communicating my current situation, my decisions/choices, and responding to or asking questions of medical professionals	<i>Who helps me communicate with the medical professionals (doctor/nurse/care coordinator)?</i>	<i>Repeat my answers back to me; ask me to "teach back" instructions; ask me questions</i>
Following through with my medical choices, decisions, or following doctor/nurse/care coordinator's instructions or treatment plan	<i>Who helps with follow through (reminders, set up medications, checking in with me)?</i>	<i>Send out reminders by mail or text; follow-up appointments;</i>



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Health Team Document

2 Sections:

- Understanding My Health Care Team
- Understanding My Support Needs





HEALTH TEAM DOCUMENT

Ben S. March 2021

UNDERSTANDING MY HEALTH CARE TEAM

My Personal Support Team <i>(Identify your personal supporters and their relationship to you)</i>		Formal Supports <i>(Who are paid people that might be with you and what their role is at the visit)</i>	Who Has Legal Authority <i>(Place a check next to who has legal decision-making authority and identify the person)</i>
Who:	Relationship:	Paid Staff (PCA, DSP):	I have Legal Decision-Making Authority for My Health Care <input checked="" type="checkbox"/>
Jane S.	Mom	Steve G.	Power(s) of Attorney: <input checked="" type="checkbox"/>
			1. Jane S
Tom S.	Dad	Residential/Provider Agency Staff:	2. Tom S
			Guardian: <input type="checkbox"/>
Matt S. Zac S	Twin Brother Brother	Other:	1. <input type="checkbox"/>
Zac S.	Brother		Circle: Plenary (full) or Limited <input type="checkbox"/>
			Conservator: <input type="checkbox"/>
			1. <input type="checkbox"/>

UNDERSTANDING MY SUPPORT NEEDS

Areas of Support for Medical Appointments/Events	What I Do/Need and Who Helps Me	Health Professional's Role In Supporting Me
Understanding what the medical professionals are saying, suggesting, recommending or instructing; helping me know my options, pros and cons	<i>Who do I trust to help me understand and how do I communicate with them?</i> I trust Mom and Dad and my brothers. I talk but sometimes others don't understand me. My family understands me most of the time.	<i>Writing down instructions, using photos or pictures to explain procedures or directions</i> I want the doctor to talk directly to me, and treat me like anyone else. It helps me to see photos, and write things down so whoever is with me can explain things later.
Communicating my current situation, my decisions/choices, and responding to or asking questions of medical professionals	<i>Who helps me communicate with the medical professionals (doctor/nurse/care coordinator)?</i> Mom & Dad or my brothers are best. Ericka can help too. If I am with my staff, my mom has probably written things down to help tell the doctor.	<i>Repeat my answers back to me; ask me to "teach back" instructions; ask me questions</i> When you ask me a question, be patient and give me time to process and answer. Don't ask another question until I have answered the first one. Rerword if needed.
Following through with my medical choices, decisions, or following doctor/nurse/care coordinator's instructions or treatment plan	<i>Who helps with follow through (reminders, set up medications, checking in with me)?</i> I know when to take my medication, but I need help with getting the right doses and with getting refills	<i>Send out reminders by mail or text; follow-up appointments;</i> Send me and my mom/dad reminders about appointments. Text or email works fine.



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Ben's Support Team





COMPLETE BEFORE THE VISIT

My Name: _____

Today's Date: _____

Who is with me today? _____

Current list of my medications, pills, and vitamins
(attach it for the doctor or nurse)

Do I have a plan or card that pays for my medicine?

Yes / No (list) _____

Did I recently go see any other doctor or dentist?

Yes / No (who?) _____

What was the reason? _____

Why am I at the doctor's or clinic today?

*(Things like illness, check-up, follow-up from previous visit,
need forms filled out, need medication change or refill, etc.)*

QUESTIONS I WANT TO ASK TODAY

ANSWERS TO MY QUESTIONS

MY TAKE-AWAY INFORMATION

Were there any Medication or Diet Changes?

YES / NO If yes:

Medication Name: _____

I am to take this _____ times per day, at _____

I am to stay on this for _____ days (or specify _____)

Why do I need to take this? _____

Medication Name: _____

I am to take this _____ times per day, at _____

I am to stay on this for _____ days (or specify _____)

Why do I need to take this? _____

Are there medications I don't need to take
anymore, or anything else I should know?

Information about today's treatment plan,
recommendations, and/or follow-up

*(Things like illness, check-up, follow-up from previous visit,
need forms filled out, need medication change or refill, etc.)*

medical professional signature

date

staff or provider signature

date



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Today's Health Care Visit

- How do you prepare for a visit?
- How do you remember/relay what happened at the visit?





TODAY'S HEALTH CARE VISIT

COMPLETE BEFORE THE VISIT

My Name: Jane
 Today's Date: March 23
 Who is with me today? Tom (husband)
 Current list of my medications, pills, and vitamins
 (attach it for the doctor or nurse)
 Do I have a plan or card that pays for my medicine?
 Yes / No (list) UHC1234
 Did I recently go see any other doctor or dentist?
 Yes / No (who?) Dr. K-chiropractor
 What was the reason? Shoulder pain

Why am I at the doctor's or clinic today?

*(Things like illness, check-up, follow-up from previous visit,
 need forms filled out, need medication change or refill, etc.)*

I am visiting the doctor because my asthma has been really bad and I think I might need different medication to help control it. I used to take a daily medication, but the asthma got better and for the last few years I just used a rescue inhaler as needed. But I have been needing to use it a lot lately.

QUESTIONS I WANT TO ASK TODAY

Is there a medication that won't interact with my other meds or cause unwanted side effects?

ANSWERS TO MY QUESTIONS

MY TAKE-AWAY INFORMATION

Were there any Medication or Diet Changes?

YES / NO *If yes:*

Medication Name: _____

I am to take this _____ times per day, at _____

I am to stay on this for _____ days (or specify _____)

Why do I need to take this? _____

Medication Name: _____

I am to take this _____ times per day, at _____

I am to stay on this for _____ days (or specify _____)

Why do I need to take this? _____

Are there medications I don't need to take anymore, or anything else I should know?

Information about today's treatment plan, recommendations, and/or follow-up

*(Things like illness, check-up, follow-up from previous visit,
 need forms filled out, need medication change or refill, etc.)*

medical professional signature

date

staff or provider signature

date



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Example



Understanding Health Care Legal Issues

Thinking Ahead




www.lifecoursetools.com

When Your Child Becomes an Adult....

Health Care Transition Changes:

- Parent/Family no longer makes all the decisions about health care
- Young adult controls who goes in with them and who sees medical info and records

Health Decision Making Portfolio

 LIFE TRAJECTORY | HEALTHY DECISIONS

Past Life Experiences

What helps me UNDERSTAND my health issues and options?

What helps me communicate my health preferences, choices, and decisions?

What helps me follow through on health instructions, programs, or recommendations?

List past barriers that made it hard for me to understand, communicate, or follow through with health decisions, instructions, programs or recommendations

Moving Forward

What helps me UNDERSTAND my health issues and options?

What helps me communicate my health preferences, choices, and decisions?

What helps me follow through on health instructions, programs, or recommendations?


List what needs to happen to avoid barriers that make it hard for me to understand, communicate, or follow through with health decisions, instructions, programs or recommendations

Vision for What I Want

What decisions about my health do I want to make myself or with help from my supporters?

What I Don't Want

What decisions about my health do I NOT want someone else making for me or without my input or approval?

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What Decision Making Supports are Needed?



This tool was designed to assist individuals and supporters with exploring decision making support needs for each life domain.

Name of Individual: _____

Name of person completing this form: _____

Relationship to individual (circle one): Self Family Friend Guardian Other: _____

How long have you known the individual? _____

For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.

--	--	--

Daily Life & Employment

Can I decide if or where I want to work?			
Can I look for and find a job? (read ads, apply, use personal contacts)			
Do I plan what my day will look like?			
Do I decide if I want to learn something new and how to best go about that?			
Can I make big decisions about money? (open bank account, make big purchases)			
Do I make everyday purchases? (food, personal items, recreation)			
Do I pay my bills on time? (rent, cell, electric, internet)			
Do I keep a budget so I know how much money I have to spend?			
Am I able to manage the eligibility benefits I receive?			
Do I make sure no one is taking my money or using it for themselves?			

Healthy Living

Do I choose when to go to the doctor or dentist?			
Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use?			
Can I make health/medical choices for my day-to-day well-being? (check-ups, routine screening, working out, vitamins)			
Can I make medical choices in serious situations? (surgery, big injury)			
Can I make medical choices in an emergency?			
Can I take medications as directed or follow a prescribed diet?			
Do I know the reasons why I take my medication?			
Do I understand the consequences if I refuse medical treatment?			
Can I alert others and seek medical help for serious health problems?			
Do I make choices about birth control or pregnancy?			
Do I make choices about drugs or alcohol?			
Do I understand health consequences associated with choosing high risk behaviors? (substance abuse, overeating, high-risk sexual activities, etc.)			
Do I decide where, when, and what to eat?			
Do I understand the need for personal hygiene and dental care?			

Continue on back >



For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.

--	--	--

Social & Spirituality

Do I choose where and when (and if) I want to practice my faith?			
Do I make choices about what to do and who to spend time with?			
Do I decide if I want to date, and choose who I want to date?			
Can I make decisions about marriage? (if I want to marry, and who)			
Can I make choices about sex, and do I understand consent and permission in regard to sexual relationships?			

Safety & Security

Do I make choices that help me avoid common environmental dangers? (traffic, sharp objects, hot stove, poisonous products, etc.)			
Do I make plans in case of emergencies?			
Do I know and understand my rights?			
Do I recognize and get help if I am being treated badly? (physically, emotionally or sexually abused, or neglected)			
Do I know who to contact if I feel like I'm in danger, being exploited, or being treated unfairly? (police, attorney, trusted friend)			

Community Living

Do I decide where I live and who I live with?			
Do I make safe choices around my home? (turning off stove, having fire alarms, locking doors)			
Do I decide about how I keep my home or room clean and livable?			
Do I make choices about going places I travel to often? (work, bank, stores, church, friends' home)			
Do I make choices about going places I don't travel to often? (doctor appointments, special events)			
Do I decide how to get to the places I want or need to go? (walk, ask a friend for a ride, bus, cab, car service)			
Do I decide and direct what kinds of support I need or want and choose who provides those supports?			

Advocacy & Engagement

Do I decide who I want to represent my interests and support me?			
Do I choose whether to vote and who I vote for?			
Do I understand consequences of making decisions that will result in me committing a crime?			
Do I tell people what I want and don't want? (verbally, by sign, device), and tell people how I make choices?			
Do I agree to and sign contracts and other formal agreements, such as powers of attorney?			
Do I decide who I want information shared with? (family, friends etc.)			



Taking medication or following prescribed diet?

- Medication reminders
- Pill or medication dispensers
- Visual schedule on tablet or phone

Make choices around day-to-day health, fitness, wellness?

- Health app on smart phone
- Wearable exercise tracker/reminder
- Exercise equipment (especially the ones that can be connected to internet to guide, encourage, etc.)

Alert others or seek help for serious medical issue?

- Remote monitoring
- Smart watch that detects falls, heart issues, etc
- Medical alert service (fallen & can't get up)



Healthy Living

Do I choose when to go to the doctor or dentist?
Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use?
Can I make health/medical choices for my day-to-day well-being? (check-ups, routine screening, working out, vitamins)
Can I make medical choices in serious situations? (surgery, big injury)
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Can I take medications as directed or follow a prescribed diet?
Do I know the reasons why I take my medication?
Do I understand the consequences if I refuse medical treatment?
Can I alert others and seek medical help for serious health problems?
Do I make choices about birth control or pregnancy?
Do I make choices about drugs or alcohol?
Do I understand health consequences associated with choosing high risk behaviors? (substance abuse, overeating, high-risk sexual activities, etc.)
Do I decide where, when, and what to eat?
Do I understand the need for personal hygiene and dental care?

Supports for Healthy Living



www.lifecoursetools.com



How I Stay Healthy



Long Term Services & Supports

Innovative

- A new possibility

Islands of Excellence

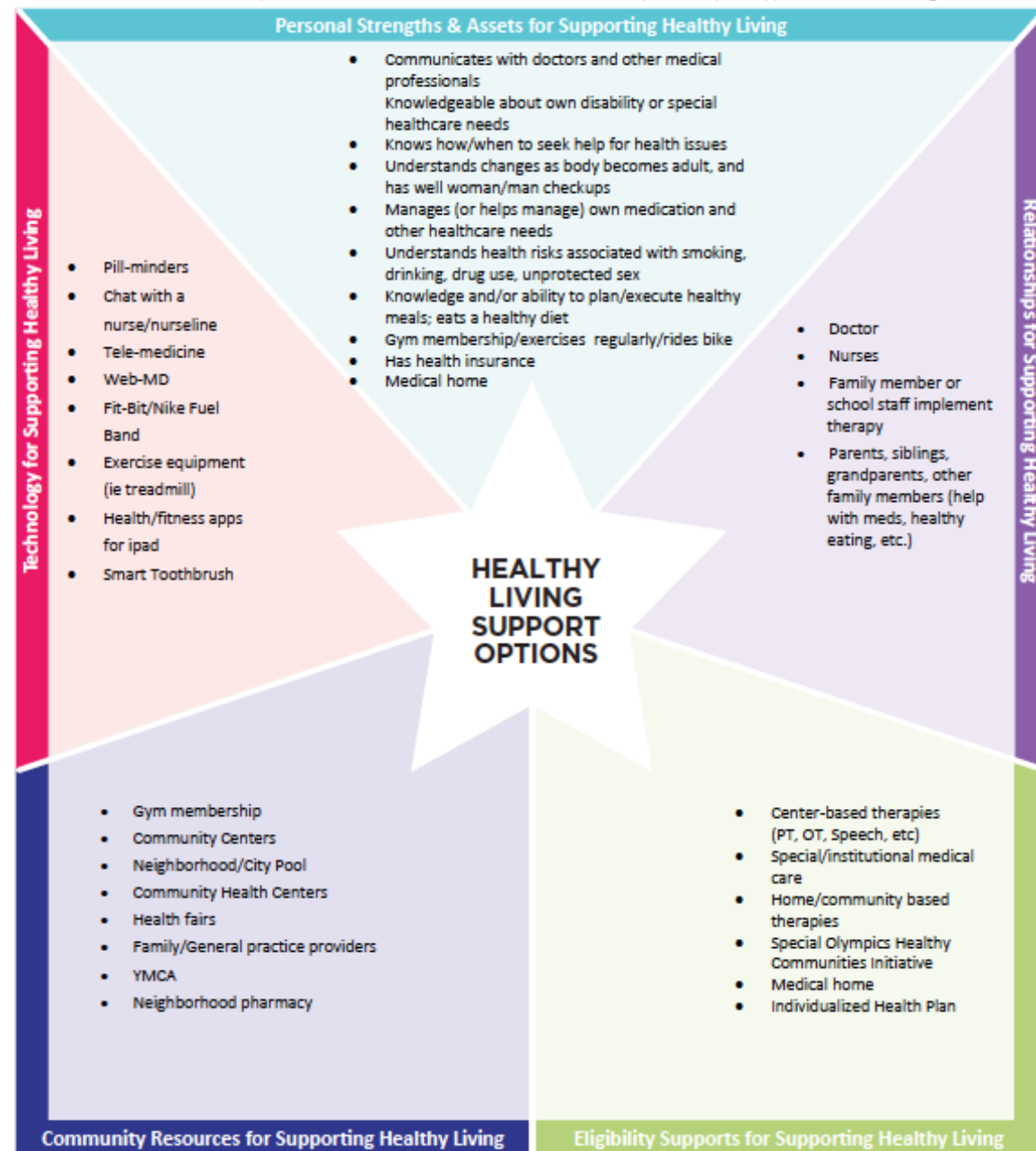
- Gym membership
- Community Health Centers
- Health fairs
- Family practice providers
- In-home or community-based therapies
- Family member or school staff implement therapy
- Special Olympics

Traditional Options

- Center-based therapies (PT, OT, Speech, etc)
- Special or institutional medical care

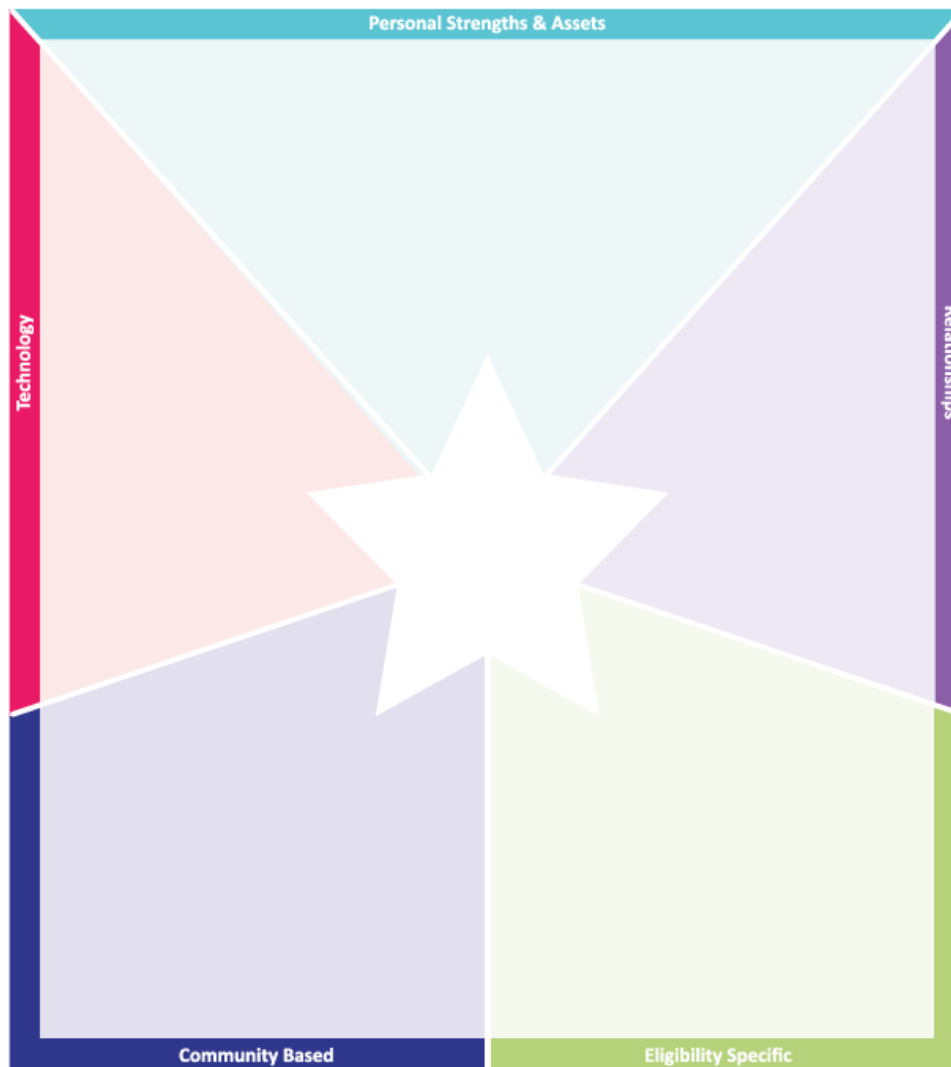


Healthy Living “Starter Star”





Your Own Star "Map" of Supports



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What Can We Do?

Now and In the Future



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Things YOU Can Do Now

- Talk to your child about their specific disability or condition and how that affects their overall health
- Talk about the different doctors they see and why they see each one (general practitioner vs pediatrician vs specialists, etc)



Things YOU Can Do Now

- Encourage medical professionals (doctors, nurses, dentists, hygienists, technicians, etc.) to speak directly to your child
- Encourage your child to greet and interact with health care professionals
- Follow your child's lead – if they are consistently uncomfortable around a practitioner, consider finding a new one!



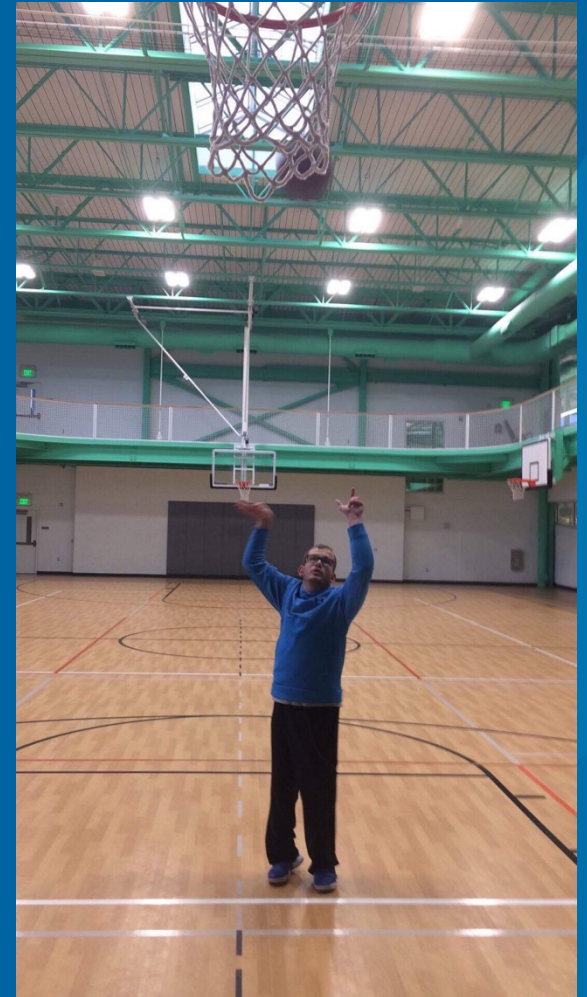
MORE Things YOU Can Do Now

- Talk to them about what medications they take and why
- Involve them in taking their own medication (reminders, pill dispenser, etc.)
- Teach them about insurance, co-pays, deductibles - what it is, how it works, etc.



MORE Things YOU Can Do Now

- Teach about healthy choices for meals and snacks
- Involve child in shopping for and preparing meals & snacks
- Make fitness fun! (play games, step count competition, nature walks, parks & rec activities)



Things Older Kids Can Start Doing NOW

- Asking questions – of parents, doctors, etc
 - About their specific health care issues and concerns
 - About medications they take and why
- Carrying insurance card, presenting it at appointments
- Paying for their prescriptions and co-pays

What Life Experiences can help them prepare for healthcare transition?



Things Older Kids Can Start Doing NOW

- Make a list of what they like about their pediatric health care providers (and what they don't like)
- Decide what they want an adult health care provider to be like and what they don't want (*hint hint – trajectory!!*)

What Life Experiences can help them prepare for healthcare transition?



Resources



www.lifecoursetools.com

Focus on Aging
Quick Guide in the *Life Experience Series*

Aging is the period of life when we experience the effects of old age.
As we age, our lives can change a lot. Retirement can be both welcome and challenging. Family we lean on may not be around as much as we once were. Experiences can help make the golden years more meaningful.

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Focus on ADULTHOOD
Quick Guide in the *Life Experience Series*

Adulthood is the period of life when we transition from school and young adulthood to the time when we enter the workforce.
For most of us, adulthood is the longest period of our lives. The school years have ended, you are entering the workforce, and you are taking on more responsibility throughout your adult life.

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Focus on TRANSITION TO ADULTHOOD
Quick Guide in the *Life Experience Series*

Transition means that you are moving from young adulthood to adulthood.
There are many things to think about during this time. Change is a point in time when things are exciting, and sometimes fear a little.

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Focus on SCHOOL AGE
Quick Guide in the *Life Experience Series*

School age is the years from early childhood to middle school.
For now that your child is school age, you are spending a lot of time with people other than the family. In this stage, your child is growing and learning. There are many opportunities to have life experiences. Encourage your child to excel at home, at school, and in their community as they become young adults.

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Focus on EARLY CHILDHOOD
Quick Guide in the *Life Experience Series*

Early childhood is the time in a child's life before they begin school full time.
You may think it's too soon to be thinking about your young child's future, but before you know it, they will be in school and then becoming adults! You will want to give your child the best possible start to prepare them for the next stages of life, and help them reach their vision for an inclusive, productive, full "good life" in the future.

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<http://www.lifecoursetools.com/lifecourse-library/exploring-the-life-stages/>

School Age Quick Guide



FOCUS ON SCHOOL AGE



SOCIAL & SPIRITUALITY

Building friendships and relationships, leisure activities, personal networks, and faith community

The school years are when children learn how to get along with others, and more importantly, how to make friends and be a good friend to others. They need lots of time and chances to practice these important social skills in a variety of settings and discover what they like to do for fun and recreation. This is also a time to explore if they desire to engage in a faith community.

- How am I learning about making friends and maintaining relationships?
- How are you encouraging me to try different activities so I can figure out what I like to do in my free time?
- How can I get involved and be included in extracurricular activities at school, parks and recreation or other community activities where I can meet and make new friends?
- How 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?



HEALTHY LIVING

Managing and accessing health care and staying well – medical, mental health, behavioral health, developmental, wellness and nutrition

Your child won't always be around healthy choices, so it's important to help them learn the skills to know the right foods to eat, how to stay physically active and fit, and say no to things that may harm them. School age children can start to take a more active role in their healthcare and understand their own health and specific information about their diagnosis or disability.

- How are you helping me learn to ask for help or tell someone when I am sick or just don't feel well?
- What are you doing to teach me to how to greet and interact with doctors and other medical professionals?
- How are you helping me understand my disability or healthcare needs and how it affects me as I grow and change?
- How are you helping me know what is good (healthy foods, sleep, exercise) and bad (drugs, smoking) for my body?
- How am I learning about healthy foods and nutrition and making healthy snacks?



ADVOCACY & ENGAGEMENT

Building valued roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived

You are your child's best advocate and teacher. This is a time when you can help them learn and begin advocating for themselves in planning meetings, at school, in the community. Making choices, speaking up for what they want and giving back to their community help children prepare to be a good citizen and advocate when they are an adult.

- Are you interested in helping other parents or engaging in policy or systems change?
- How am I being supported to learn leadership skills and take on leadership roles at home, school, or in the community?
- How are you helping me learn to be part of and start to lead school or person-centered planning meetings?
- Do you present yourself as an expert regarding me and my needs, and how are you helping me learn to be the expert on myself and my needs?
- How am I learning the importance of following rules at home, school, and other places?
- How are you helping me find valued roles and chances to help others or give back to the community?





Charting the LifeCourse

Framework and Tools

Healthy Living Page:

<https://www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/healthy-living/>

Exploring the Life Domains

Healthy Living

Managing and accessing health care and staying well – medical, mental health, behavioral health, developmental, wellness, and nutrition.

Health is connected closely to many other life domains. If you aren't healthy, you might not be able to have the job you want or be able to live where you would like. You might not be able to spend time with family and friends or be involved in the community and other desired activities. Planning for and looking after one's health and wellness can be an important factor in living the kind of life that you want. Making sure you get proper medical care, paying attention to nutrition and fitness, and looking after your mental health are all part of healthy living.

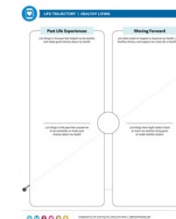
Getting Started



Integrated Support Star for Healthy Living

The Healthy Living Integrated Supports Star helps you explore supports that can help you reach your goals for living a healthy life.

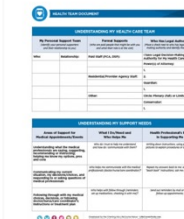
 Download Tool



Trajectory for Healthy Living

Develop a vision for a healthy life, consider past experiences that helped or not, and plan steps for being healthy and well.

 Download Tool



My Health Care Team and Support Needs

Map your health care support team and how you can best be supported when working with health care professionals and accessing care.

 Download Tool



Today's Health Care Visit

Keep track of everything you want to share or ask about, as well as remember what happened during a health care visit, with this tool.

 Download Tool

Questions or Reflections?



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THANK YOU!

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