

CHARTING the life course



PATH
Parent-to-Parent

Family Voices
of Connecticut



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Overview

- Welcome
- What is LifeCourse
- Why we need person-centered-planning
- Context of Family
- Who the individual is
- How to Build a Great Life Using the LifeCourse Tool
- Applying the Star
- Wrap up



Core Belief

All people have the right to live, love, work, play and pursue their life aspirations just as others do in their community.



All individuals exist within the context of family

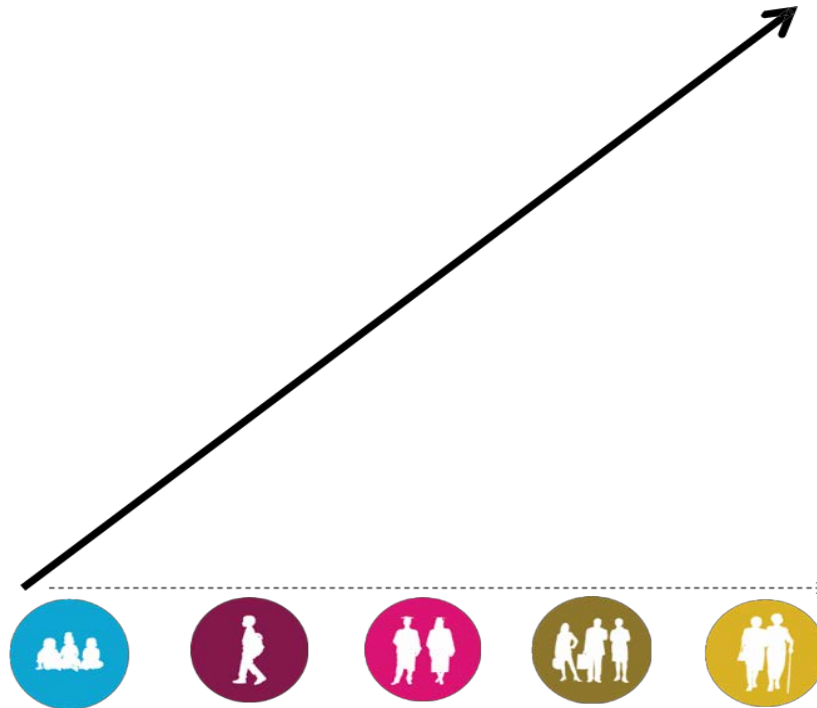
Individuals and their family, as a whole, may need supports that address different facets of life and that adjust as roles and needs of all members change through both the life cycle and the family cycle.



(Regardless of where a person lives)



Discovering WHO



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Life Trajectory Worksheet: **Individual**

Everyone wants a good life. The bubbles on the right will help you think about what a good life means for you or your family member, and identifying what you know you don't want. You can use the space around the arrows to think about current or needed life experiences that help point you in the direction of your good life.

Past Life Experiences

List past life experiences you DON'T WANT

Future Life Experiences

List life experiences to AVOID

VISION for a GOOD LIFE

Friends, family, self determination, community living, social capital and economic sufficiency

What I DON'T Want

Vision of What I DON'T WANT
? ? ? ?



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Life Trajectory Worksheet: **Family**

Everyone wants a good life. The bubbles on the right will help you think about what a good life means for you or your family member, and identifying what you know you don't want. You can use the space around the arrows to think about current or needed life experiences that help point you in the direction of your good life.

VISION for a GOOD LIFE

What I DON'T Want



In order for me to live a Good Life, I need your help!

Journey through School

Past Life Experiences

LIST past life experiences and events that supported your vision for a good life.

Vacations
Birthday Parties
Soccer
Basketball
Luke
Friends
Family
Drawing
Free running
Inclusion in school and community
Scouts

LIST past life experiences that pushed the arrow toward things you don't want.

Getting pulled from class

Action Steps to the Future

LIST current/future life experiences that continue supporting your good life vision.

Community and school inclusion
Leadership roles
Extra time, friends, scouts, Basketball, soccer,
Being in charge to help learn responsibility.
Develop effective organizational skills
Vacations!

LIST life experiences to avoid because they push you toward things you don't want.

Feeling excluded, getting pulled from class.
Not enough time.

VISION for a GOOD LIFE

LIST what you want your "good life" to look like ...

Inclusion
Leadership
Responsibility
Friends
Having fun
Manage time effectively
Sports
Community
Getting a good education to get a great job to afford a Lamborghini!

What I DON'T Want

LIST the things you don't want in your life...

Exclusion, pull outs

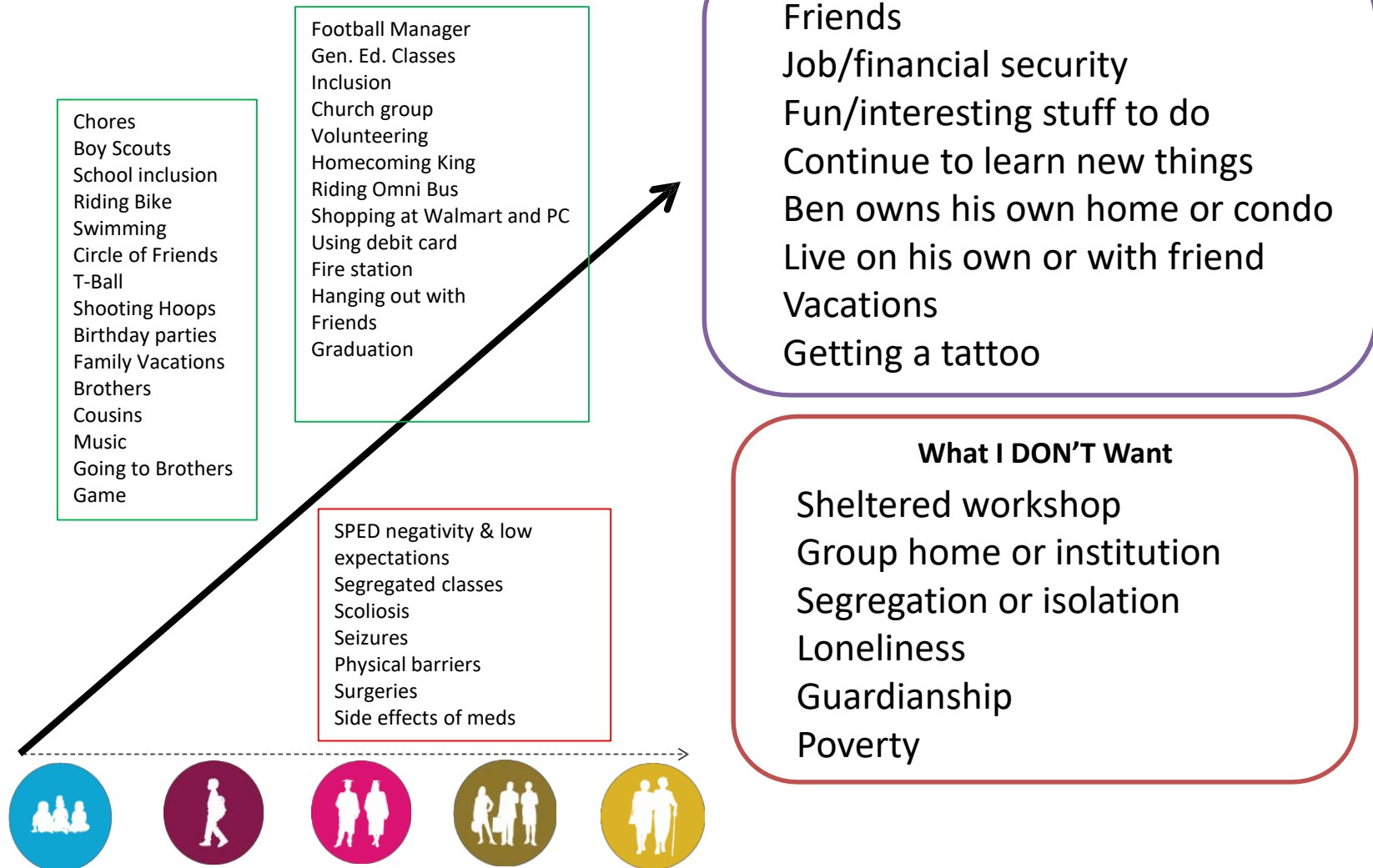
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Life Trajectory Worksheet: Ben





Discovering How



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Integrated Services and Supports

People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for a good life.





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Thinking Across All 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 and 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)



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







Integrated Services and Supports

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LIFE DOMAIN	Personal Strengths & Assets	Relationship Based Supports	Technology	Community Resources	Eligibility Based Supports
 Daily Life Employment	<ul style="list-style-type: none"> • Work/volunteer experience • Summer jobs • Vision or dream for job or career • Responsibilities at home or school • Makes choices and decisions • Communicates ideas, needs, thoughts to others • Knowledge of a variety of different jobs/careers • Good social skills • Practices everyday living skills 	<ul style="list-style-type: none"> • Coworkers • Parents, siblings, spouse, children, grandparents, other family • Friends • Teacher • Mentors • Parents/family of friends • Business partner 	<ul style="list-style-type: none"> • Electronic reminders • Alarm clock • Cell phone • Ipad educational/life skills apps • Online resume builders • Online classes or training • Internet job search • Calculator • Computer • Iphone/smart phone • Ipad apps 	<ul style="list-style-type: none"> • Volunteering • Competitive employment/careers • Colleges, universities, tech school • Micro-enterprises • Self employment • Tutors • Parent/Teacher Association (PTA) • Summer Reading Program (library) 	<ul style="list-style-type: none"> • Work crews/enclaves • Job coaches • Supported employment • Special college programs • Special Education/IEP's • HeadStart • Vocational Rehabilitation • Case manager/support coordinator • Sheltered workshops • Day habilitation
 Community Living	<ul style="list-style-type: none"> • Knowledge of how to navigate community • Drives, rides bus, cab, or other public transportation • Housekeeping skills • Can prepare simple meals/snacks • Can spend time alone or away from family • Knowledge of different types of living options 	<ul style="list-style-type: none"> • Parents, siblings, spouse, children, grandparents, extended family • Friends • Roommates • Neighbors • Same age peers (college age, aging) 	<ul style="list-style-type: none"> • Adapted living space • Environmental technology • Remote monitoring • Ipad apps • Facetime/Skype • Electronic reminders 	<ul style="list-style-type: none"> • Home Ownership • Rental home/apartment • Co-op for housing or transportation • Public transportation (bus, train, taxi) • Universal design • Neighborhood Watch • Home Owner's Association • Food Pantries 	<ul style="list-style-type: none"> • Independent Supported Living (ISL) • Independent Living Center • Shared Living/host family • Institutions • Intermediate Care Facility (ICF) • Group Homes • Meals on Wheels • Section 8 Housing Vouchers
 Social & Spirituality	<ul style="list-style-type: none"> • Has hobbies and interests and needed supplies • Knowledge/experience playing games or other social activities • Outgoing, friendly personality • Understands social cues and norms • Has money/budget for social activities • Interest in/belief in faith/higher power • Belongs to/has roles in a faith community • Exposure/experience going to weddings/funerals • Good conversation skills 	<ul style="list-style-type: none"> • Friendships • Dating/relationships • Members of your faith community • Friends of parents/siblings and other family members • People with a shared interest or hobby 	<ul style="list-style-type: none"> • Online social clubs • Social media (Facebook, Twitter, Instagram, Pinterest, etc) • Online games • Email • Texting 	<ul style="list-style-type: none"> • Parks and Recreation • Service/social club/groups • Inclusive faith community • Sports teams and clubs • Preschool • Playground • Community Centers • Churches/Places of Worship 	<ul style="list-style-type: none"> • Separate or special church service • Special group outings & activities • Special Olympics • Special passes • Social skills classes
 Healthy Living	<ul style="list-style-type: none"> • Communicates with doctors and other medical professionals • Knowledgeable about own disability or special healthcare needs • Knows how/when to seek help for health issues • Understands changes as body becomes adult, and has well woman/man checkups • Manages (or helps manage) own medication and other healthcare needs • Understands health risks associated with smoking, drinking, drug use, unprotected sex) • Knowledge and/or ability to plan/execute healthy meals; eats a healthy diet • Has health insurance • Gym membership/exercises regularly/rides bike • Medical home 	<ul style="list-style-type: none"> • Family member or school staff implement therapy • Parents, siblings, grandparents, other family members (help with meds, healthy eating, etc.) 	<ul style="list-style-type: none"> • Pill-minders • Chat with a nurse/nurseline • Tele-medicine • Web-MD • Fit-Bit/Nike Fuel Band • Exercise equipment (ie treadmill) • Health/fitness apps for ipad • Smart Toothbrush 	<ul style="list-style-type: none"> • Gym membership • Community Centers • Neighborhood/City Pool • Community Health Centers • Health fairs • Family/General practice providers • YMCA • Neighborhood pharmacy 	<ul style="list-style-type: none"> • Center-based therapies (PT, OT, Speech, etc) • Special/institutional medical care • Home/community based therapies • Special Olympics Healthy Communities Initiative • Medical home • IHP



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	Personal Strengths & Assets	Relationship Based Supports	Technology	Community Resources	Eligibility Based Supports
 Safety & Security	<ul style="list-style-type: none"> • Home security/alarm system • Knows address, phone numbers, other contacts • Knows how to appropriately use 911 • Family/person has an emergency/disaster plan • Able to lock/unlock door (with key or code) • Carries identification or specific information in wallet or on person • Home is modified for safety • GPS tracking device • Reciprocal knowledge with First Responders • Has and knows how to use a debit card • Family/person has engaged in financial planning 	<ul style="list-style-type: none"> • Parents, siblings, grandparents, other family members • Friends • Neighbors • Familiar staff/workers at local stores, restaurants, etc. 	<ul style="list-style-type: none"> • Automatic bill pay/direct deposit • Limited/joint bank account • Personal safety devices • Remote monitoring • Ipad/smart phone apps 	<ul style="list-style-type: none"> • Powers of Attorney • Neighborhood watch • Local Police Department • Online banking • Living Trust • LifeLock (identity theft protection) • Neighborhood Watch 	<ul style="list-style-type: none"> • Full guardianship • 24 hour supervision • Limited guardianship • Special Needs Trust
 Citizenship & Advocacy	<ul style="list-style-type: none"> • Registered to vote, has voter ID, and understands how to vote • Knowledge of and membership in advocacy groups or organizations • Volunteers • Political awareness and advocacy • Has had leadership training and/or experience • Understands right/wrong, importance of doing the right thing and being a law-abiding citizen • Is able to speak up for self- parents modelling, social experiences, group participation 	<ul style="list-style-type: none"> • Parents, siblings, grandparents, other family members • Self-advocate peers • Friends 	<ul style="list-style-type: none"> • Ipad advocacy apps • Communication devices • Online service group sites 	<ul style="list-style-type: none"> • Voting • Neighborhood group or organization • Visiting your legislator • Scouting/Camp Fire/Optimist Club 	<ul style="list-style-type: none"> • Paid advocate • Self Advocacy Groups • Disability Rights Day at the Capitol • Self Advocacy Training
 Supports for Family Unit	<ul style="list-style-type: none"> • Family is active and engaged in community, networks, support groups, or mentoring • Understands rights and responsibilities • Well organized, keeps track of things • Has end of life plan/plan for when parents can no longer fulfill their many caring for and caring about roles • Has and utilizes social capitol/community connections • Willing to share their story 	<ul style="list-style-type: none"> • Grandparents, aunts, uncles, extended family • Neighbors • Other parents/families • Church/worship community 	<ul style="list-style-type: none"> • Family calendar/schedule apps • Online support groups or facebook pages 	<ul style="list-style-type: none"> • Mom's Day Out programs • Preschool • Library • Counselors • Utility assistance programs • Child Care • After school programs 	<ul style="list-style-type: none"> • Respite • Sibshops • Face to Face support groups • Special after school care programs • Specialized child care centers
 Supports & Services	<ul style="list-style-type: none"> • Knowledge of different sources of support and how to navigate systems and organizations • Ability to integrate different kinds of support into family and individual's life • Knows who to contact for help or guidance • Has someone who can/will provide paid services (potential staff and networks to recruit) 	<ul style="list-style-type: none"> • Parents, siblings, grandparents, spouse, children, other family • Neighbors • Classmates/former classmates • Church/Worship community • Teachers 	<ul style="list-style-type: none"> • Smart Home • Remote Monitoring Devices • GPS Devices 	<ul style="list-style-type: none"> • Financial planner • Piggybank • Free/Reduced school lunch • Bank • Community Centers • Community clubs (Elks, Eagles, Lions) • Pets • Service animals 	<ul style="list-style-type: none"> • Vocational Rehabilitation • Division Developmental Disabilities • Health and Senior Services • Medicaid/Medicare • Social Security • Food Stamps • Medicaid Waivers • Mental/Behavioral Health Centers • Independent Living Centers • Meals On Wheels



Applying the Star





Integrated Services and Supports

People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for a good life.

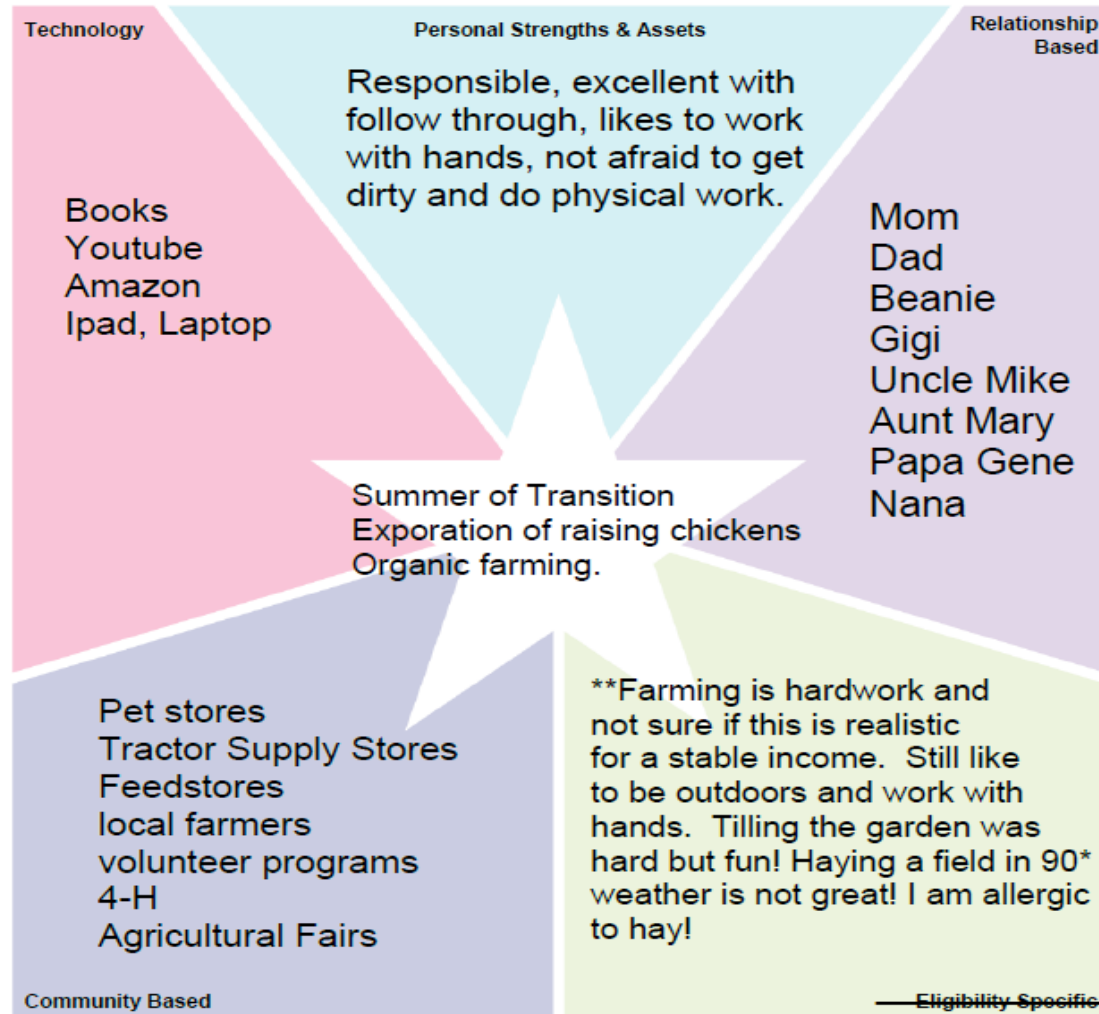


Access the LifeCourse framework and tools at lifecoursetools.com



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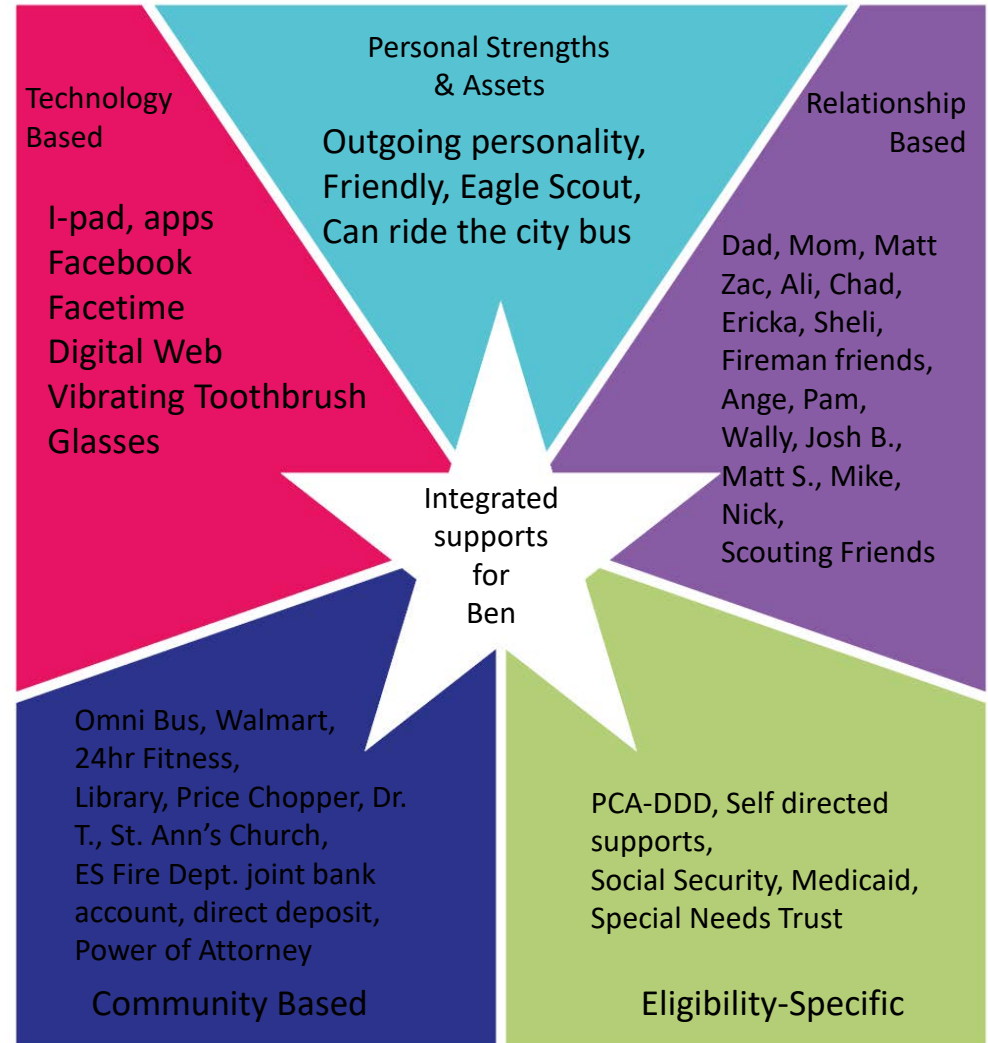
Developed by Missouri Family to Family at the UMKC Institute for Human Development, UCEDD mofamilytofamily.org | MAY 2016

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Applying the STAR: Individual Level

Meet Ben





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Long Term Service and Support Needs

TIME	MON	TUES	WED	THURS	FRI	SAT	SUN
6-6:30 AM							
6:30-7 AM							
7-7:30 AM							
7:30-8 AM							
8-8:30 AM							
8:30-9 AM							
9-9:30 AM							
9:30-10 AM							
10-10:30 AM							
10:30-11 AM							
11-11:30 AM							
11:30-12 PM							
12-12:30 PM							
12:30-1 PM							
1-1:30 PM							
1:30-2 PM							
2-2:30 PM							
2:30-3 PM							
3-3:30 PM							
3:30-4 PM							
4-4:30 PM							
4:30-5 PM							
5-5:30 PM							
5:30-6 PM							
6-6:30 PM							
6:30-7 PM							
7-7:30 PM							
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM							



Personal Assets and Strengths	
Relationship Based – Parent or Primary (unpaid) Caregiver	
Relationship Based – everybody else	
Community Based	
Technology	
Eligibility Based	

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Long Term Support Needs – Before and After Integrated Support

Long Term Service and Support Needs

Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
6:6:30 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day						
6:30-7 AM							
7:7:30 AM							
7:30-8 AM							
8:8:30 AM	Waiver Self-Directed PCA					Parents are weekend support	
8:30-9 AM							
9:9:30 AM							
9:30-10 AM							
10:10:30 AM							
10:30-11 AM							
11:11:30 AM							
11:30-12 PM							
12:12:30 PM							
12:30-1 PM							
1:1:30 PM	Mom and Dad provide all support, including meals, transportation and support for activities, etc.						
1:30-2 PM							
2:2:30 PM							
2:30-3 PM							
3:3:30 PM							
3:30-4 PM							
4:4:30 PM							
4:30-5 PM							
5:5:30 PM							
5:30-6 PM							
6:6:30 PM	Mom and Dad are overnight staff						
6:30-7 PM							
7:7:30 PM							
7:30-8 PM							
8:8:30 PM							
8:30-9 PM	Mom and Dad are overnight staff						
9:9:30 PM							
9:30-10 PM							
10 PM-6 AM							

Long Term Service and Support Needs

Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun	
6-6:30 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day							
6:30-7 AM								
7-7:30 AM	Parents support Ben							
7:30-8 AM								
8-8:30 AM	Waiver Self-Directed PCA	Volunteers Fire Dept Supported as needed by firemen	Waiver Self-Directed PCA	Volunteers Fire Dept Supported as needed by firemen	Waiver Self-Directed PCA	St. Ann's w/ mom		
8:30-9 AM								
9-9:30 AM								
9:30-10 AM								
10-10:30 AM						Home alone while Mom walks		
10:30-11 AM								
11-11:30 AM	Waiver Self-Directed PCA	Waiver Self-Directed PCA	Waiver Self-Directed PCA					
11:30-12 PM								
12-12:30 PM								
12:30-1 PM								
1-1:30 PM								
1:30-2 PM								
2-2:30 PM	Volunteer at high school, supported by coaches and friends					Home alone while Mom walks		
2:30-3 PM								
3-3:30 PM	WWE With Matt	Mom and/or Dad prepare meal and assist as needed	Horseback Therapy w/ Dad		Dinner w/ Roy & Carol & family			
3:30-4 PM								
4-4:30 PM								
4:30-5 PM								
5-5:30 PM								
5:30-6 PM								
6-6:30 PM	Home alone while Mom walks					Nick's Birthday Party with Matt and friends		
6:30-7 PM								
7-7:30 PM	Mom and Dad are overnight staff							
7:30-8 PM								
8-8:30 PM								
8:30-9 PM								
9-9:30 PM								
9:30-10 PM								
10 PM-6 AM								

LifeCourse Resources

www.lifecoursetools.com

www.supportstofamilies.org

<http://www.ct.gov/dds/cwp/view.asp?a=2042&q=518842&ddsNav=|>





Figure 8's

Become A LifeCourse Ambassador

Parent to parent support is at an all-time high in the United States of America, but we know that it has not even begun to reach a saturation point in terms of what is possible. Whether you are a new parent who is just beginning the journey of disability or a veteran parent who has accumulated wisdom that can only come from experience – we urge you to enlarge the “figure 8’s” of the Parent to Parent movement.

Figure 8’s are unbroken loops of reciprocal support between two people in which the receiver becomes the giver. This is exemplified in the following excerpt from a parent in our research study:

When our son with Down syndrome was born 3 years ago, my husband and I were shocked and devastated. We called our Parent to Parent program, which supplied us with invaluable information, as well as sent a “support couple” to talk with us. It was important to us to meet with the couple –not just the mother-since my husband takes as much responsibility for caring for our children as I do. Also important was that we were matched with a couple whose child also had been through open heart surgery (our son had major heart defects). The couple that our Parent to Parent program sent to help us were such warm, optimistic, “normal” people – they gave us hope. About a year later, my husband and I were trained by our program to be support parents. The Parent to Parent office has many requests for visits from both father and mother. My husband was one of the very few men willing to go through formal training.

May you build figure 8’s in your own life and in the lives of other families who have a child with special needs. Building this reciprocity is the essence of creating the kind of society in which we are fully nurtured.

Ann and Rud Turnbull
Beach Center on Families and Disabilities
The University of Kansas, Lawrence

Thank You

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