



Early Intervention in Pennsylvania: Charting the LifeCourse

November 2-3, 2016



About Jane

- Mom of 3 sons, one with a developmental disability
- Partners in Policymaking Graduate (Missouri 1999)
- Community Inclusion and Field Research Specialist
 - National Community of Practice on Supporting Families Staff
 - Missouri Family-to-Family HIC staff
 - Coordinator of activities focusing on supported decision making



Outcomes for Today

- Explore the effect of past and current policies and practices of service systems on available supports
- Highlight the significant role families play across the lifespan
- Introduce the LifeCourse Framework as a foundation for working with children and their families to achieve a “good life”
- View real life examples and strategies that can be used to impact the trajectory towards a “good life”

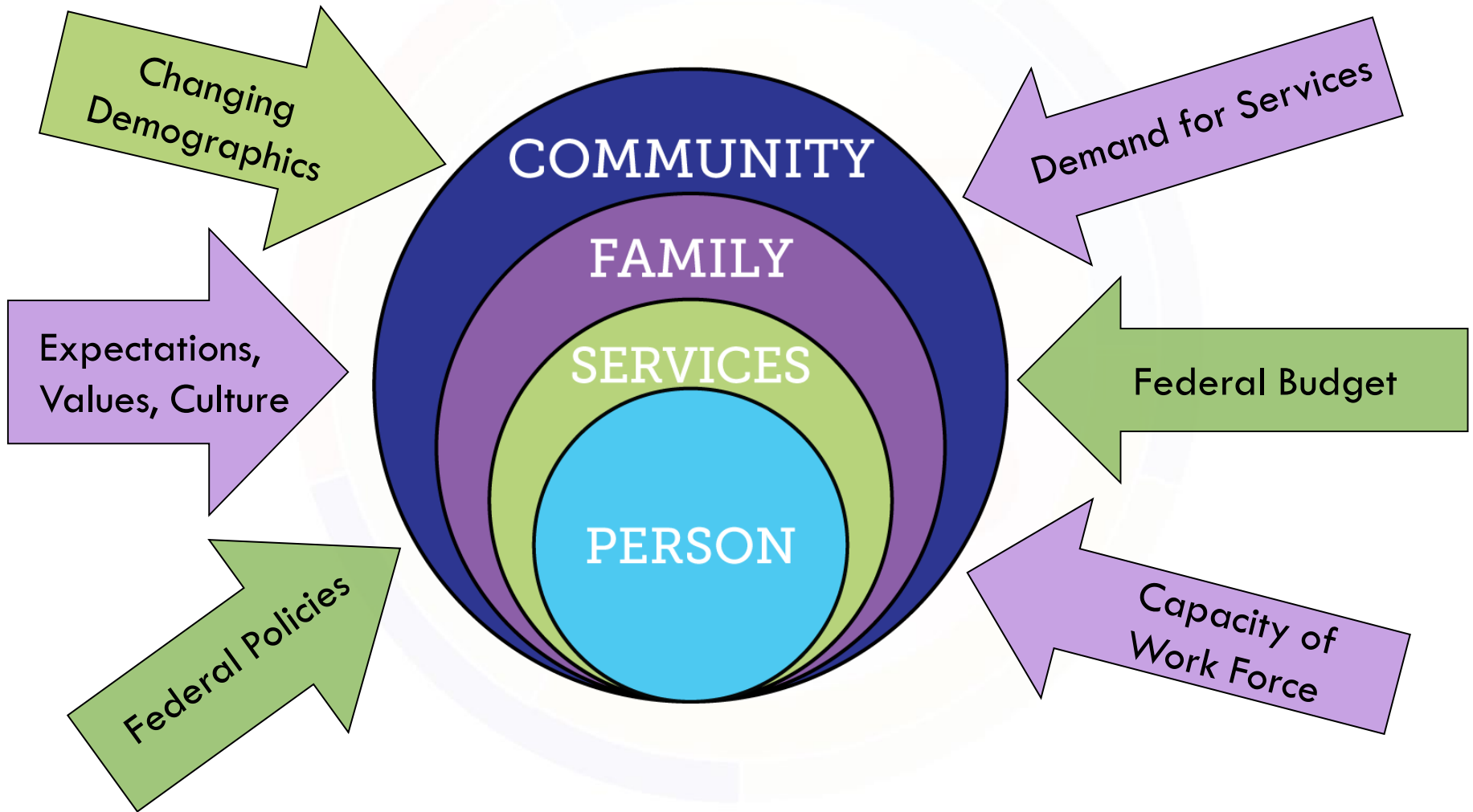




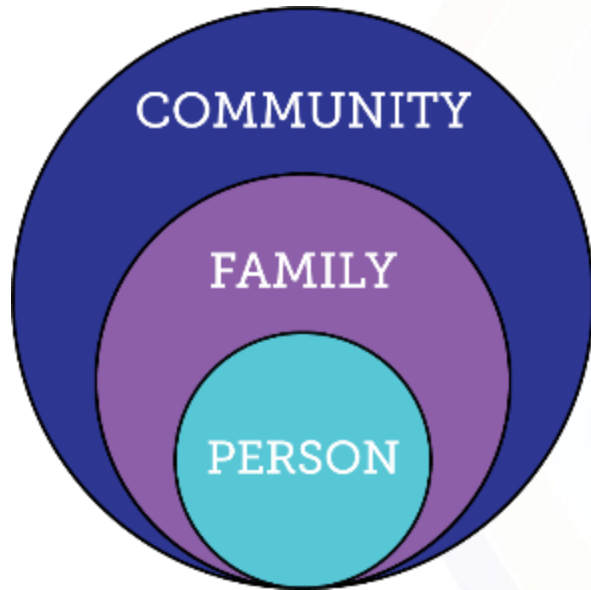
Setting the Stage



Current Reality of Services and Supports



Services and Supports are Evolving



Everyone exists within the context of family and community



Traditional Disability Services



Integrated Services and Supports within context of person, family and community



Joining Forces for a New Vision

1950s Mom-----Parent-----Family Movement

1970s Self-Advocacy and Independent Living Movements (Nothing about me, without me!)

2000s Siblings Movement

1960s Medicaid and Medicare Established

1980s Medicaid Waiver (Community Supports)

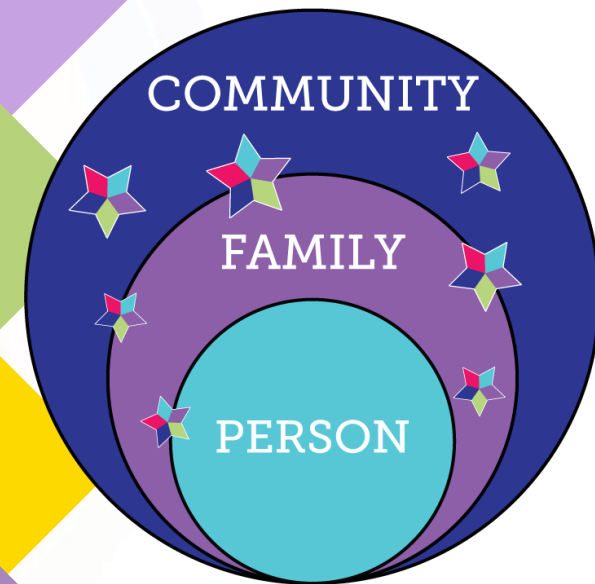
2010s Affordable Care Act

1970s Rehab Act: 504 Plans

1975s Education for All Children

1990s IDEA and ADA

2000's Community and Society



Type of Change that is Needed

Transitional Change

- ⊙ “Retooling” the system and its practices to fit the new model
- ⊙ Mergers, consolidations, reorganizations, revising systematic payment structures,
- ⊙ Creating new services, processes, systems and products to replace the traditional one

Transformation Change

- ⊙ Fundamental reordering of thinking, beliefs, culture, relationships, and behavior
- ⊙ Turns assumptions inside out and disrupts familiar rituals and structures
- ⊙ Rejects command and control relationships in favor of co-creative partnerships

Creating Blue Space, Hanns Meissner, 2013



National Community of Practice for Supporting Families

Project Goal

To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families that include a member with I/DD across the lifespan.

Project Outcome

- State and national consensus on a national framework and agenda for improving support for families with members with I/DD.
- Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families.
- Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems.



Adapted from Title V Maternal Child Health Block Grants

Life Course Health Development Model

Rethinking MCH: The Life Course Model as an Organizing Framework 2010

- ⦿ Today's experiences and exposures influence tomorrow's health
- ⦿ Health trajectories are particularly affected during critical or sensitive periods
- ⦿ The broader community environment—biologic, physical, and social—strongly affects the capacity to be healthy
- ⦿ While genetic make-up offers both protective and risk factors for disease conditions, inequality in health reflects more than genetics and personal choice



Understanding the “Differences”

Based on Theory

- ⊙ Life course vs. LifeCourse
- ⊙ Life span vs. Life Course
- ⊙ Life course Health Development Model

Our Name

- ⊙ Supporting Families LifeCourse framework, developed from the principles of the National CoP on Supporting Families
- ⊙ Charting the LifeCourse framework and tools, developed by UMKC-IHD, UCEDD MoF2F
- ⊙ Shortened version “LifeCourse”





Supporting Families

GOAL



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 the individual to achieve their goal



Recognizing that individuals exist within a family system





GUIDING PRINCIPLES FOR THE SUPPORTING FAMILIES LIFECOURSE FRAMEWORK



What is YOUR Vision for a Good LIFE?

Vision of What I Want for a Quality of Life



Write down your responses on your worksheet & discuss with your table



What DON'T you want??

**Vision of What
I Don't Want**



***Write down your responses on your worksheet
& discuss with your table***





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





Policy, Systems & Community Change:
Person-/Family- Centered and Driven

Partnering with People with Disabilities/SHCN's and their Families



So they can Engage, Lead, and Drive
Policy and Systems Change

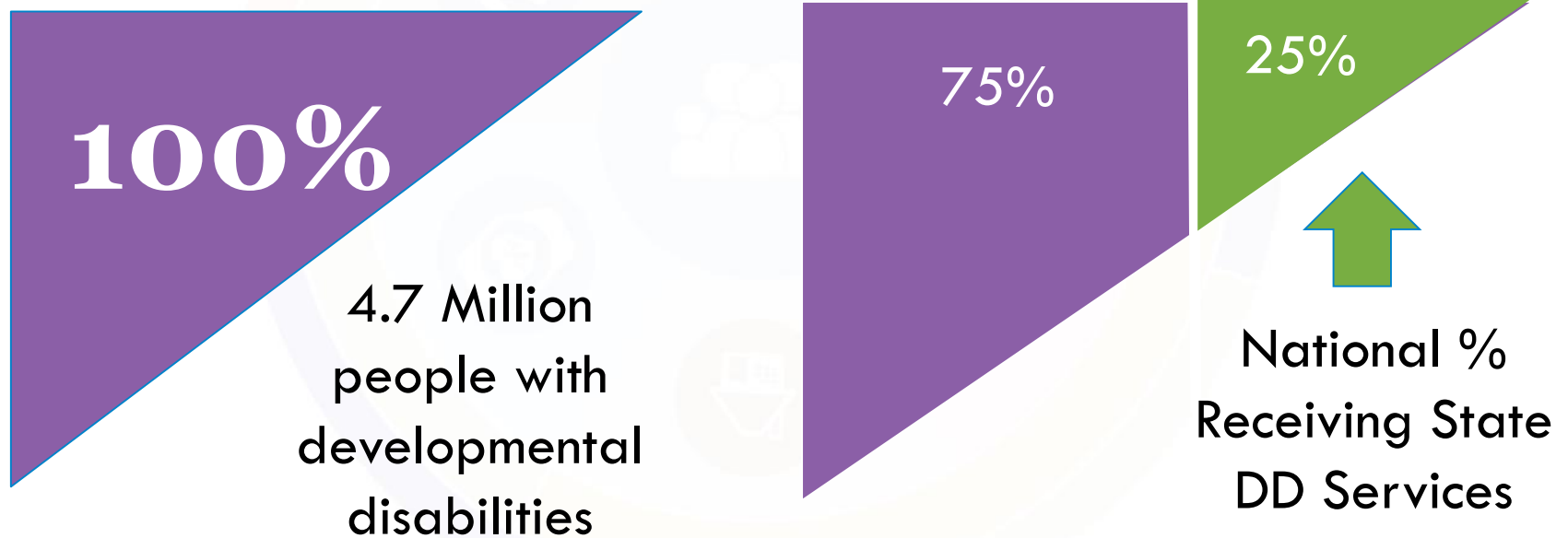
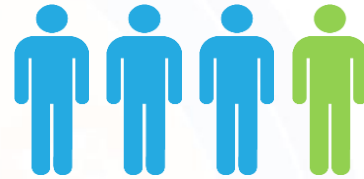




ALL People



1 in 4 Persons with I/DD Receive Formal State DD Services

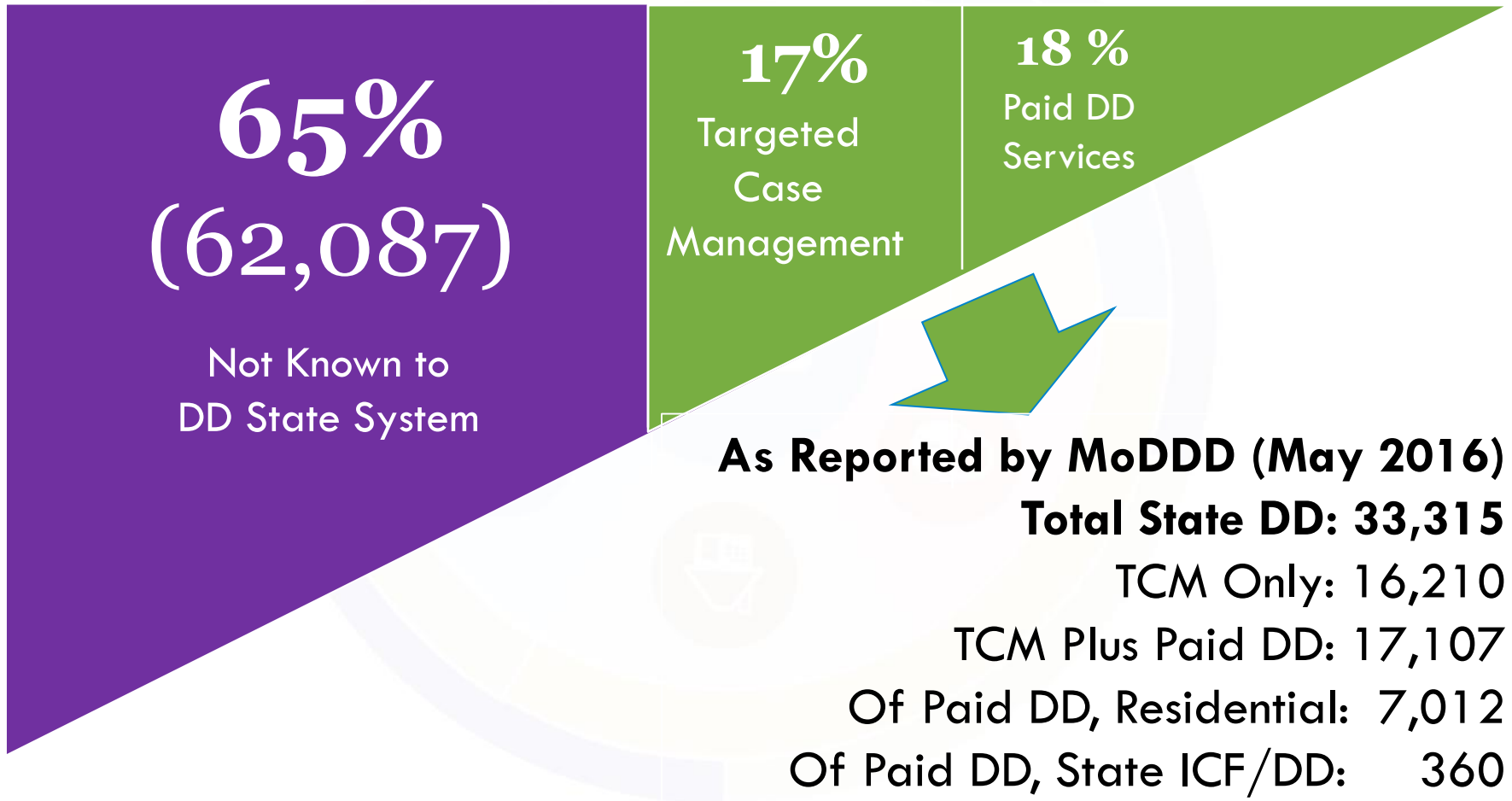


** Based on national definition of developmental disability with a prevalence rate of 1.55%



Missouri Specific Numbers

96,122 estimated Missourians with Developmental Disabilities*

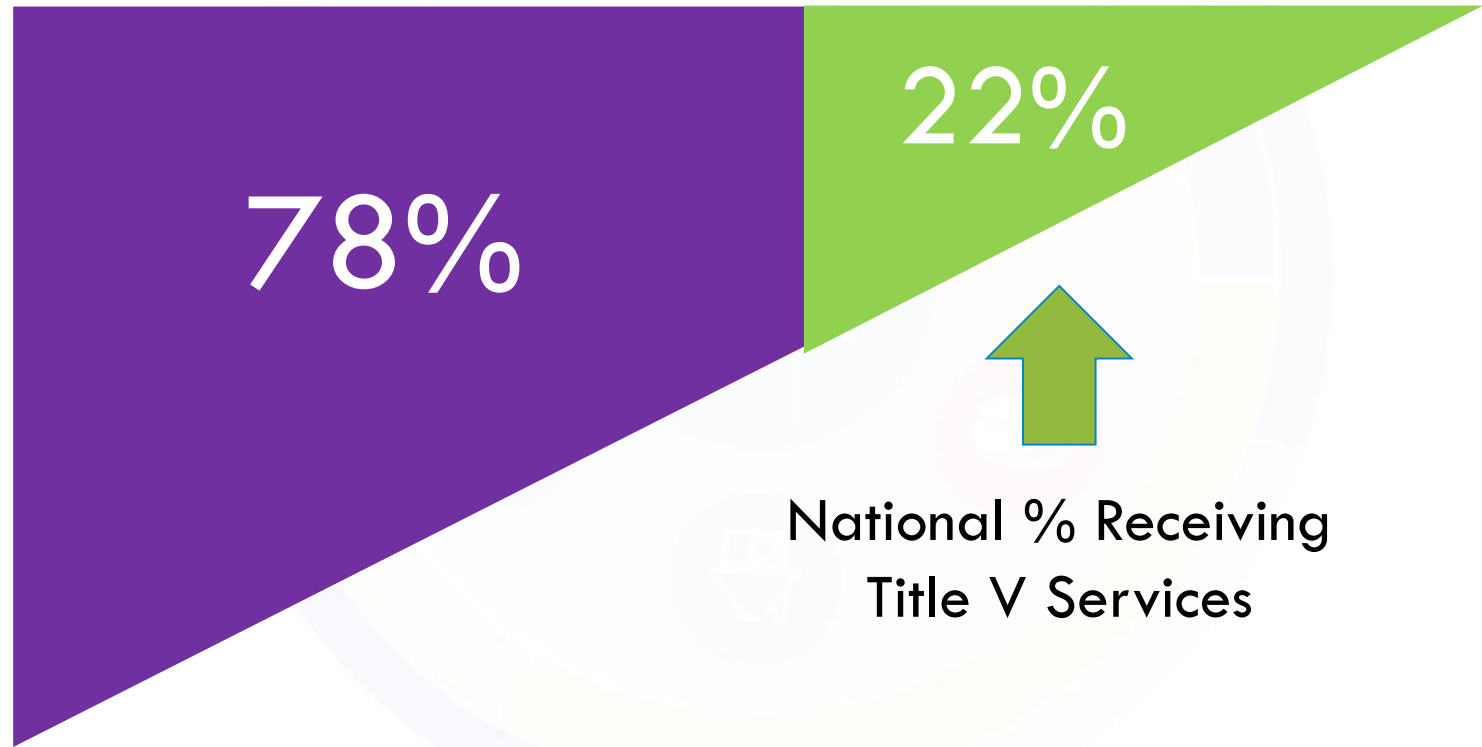


*Based on 1.55% prevalence of 6.1 million, US Census (v2015)



MCH - Focusing on ALL

All 14.6 Million children with special health care needs

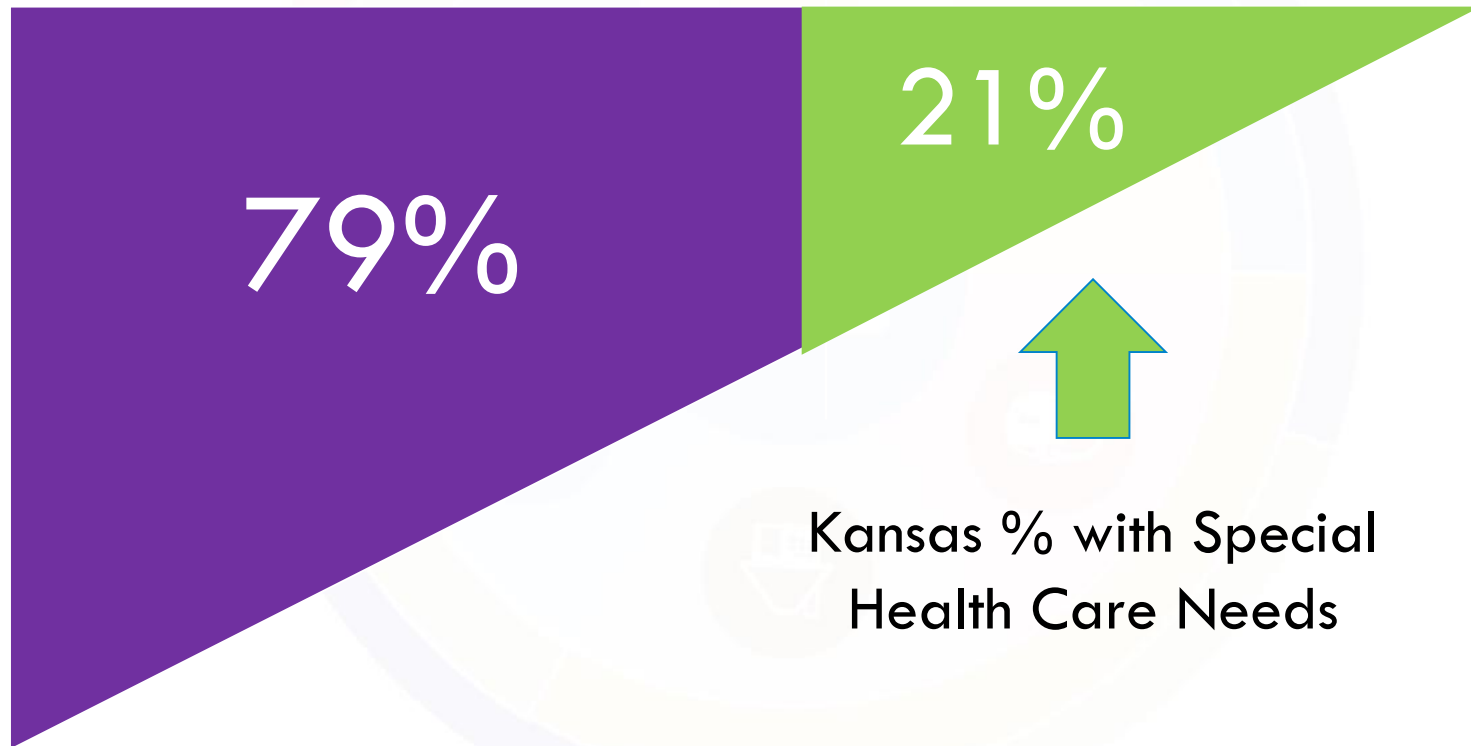


Child and Adolescent Health Measurement Initiative (2013).
“Who Are Children with Special Health Care Needs (CSHCN)”



MCH - Focusing on ALL in Kansas

All 923,478 children in Kansas



2009/10 National Survey of Children with Special Health Care Needs
CSHCN Prevalence and Demographics





Person Within Context of Family & Community





ALL individuals Exist within the Context of Family

- Family is defined by the individual
- Individuals and their family may need supports that adjust as roles and needs of all members change
- Not dependent upon where the person lives





Reciprocal Roles of ALL Family Members



Caring About

Affection & Self-Esteem

Repository of knowledge

Lifetime commitment



Caring For

Provider of day-to-day care

Material/Financial

Facilitator of inclusion and membership

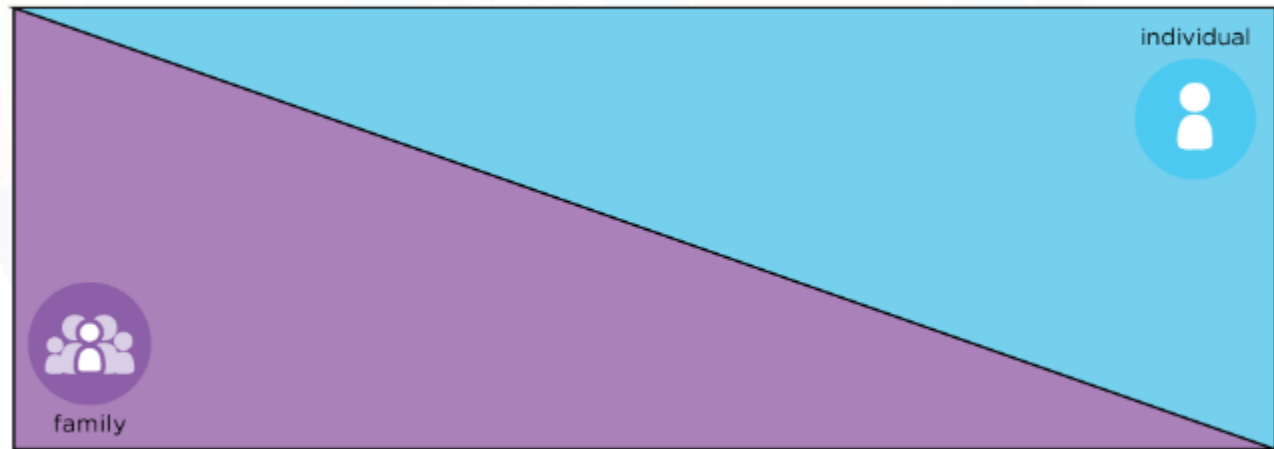
Advocate for support

**Adapted from Bigby & Fyffe (2012), Dally (1988), Turnbull et al (2011)*



Life Stages and Individual and Family Cycles

Individual Life Stages



Family Life Cycle



Lifelong Impact of Family on Individual

Biologically: Likes, dislikes, skills, abilities

Socially: Family and friend network, connection with community members



Environmentally: Neighborhood, socio-economic, education

Policy: Dreams, Aspirations, House rules, cultural rules, expectations





Life Trajectory, Experiences and Life Stages



Vision for a Good Life



©

*The future is not something we enter.
The future is something that we create.
And creating that future requires us to
make choices and decisions that begin
with a dream.*

○ -Leonard L. Sweet



“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



I PITY THE FOOL
WHO DOESN'T LIKE



BEN'S ONE PAGE
PROFILE!

WHAT PEOPLE LIKE & ADMIRE ABOUT ME

- I like to make other people feel good and be happy.
- I have a great smile and a contagious laugh. I frequently "get the giggles"!
- I'm fun, silly and friendly!
- I am a dedicated volunteer in my community
- I am an Eagle Scout and an adult leader in scouting - been involved in service through scouting since first grade.
- I am a man about town!
- My tattoo!!
- My great hugs!
- I am willing to try new things...
- I remember songs and who sings them
- I am not usually a complainer, even though sometimes I am in pain or uncomfortable

WHAT'S IMPORTANT TO ME

- My family and friends
- Volunteering at the Fire Station, wearing my uniform and badge
- Going to the library
- Going to church
- My TV, DVR, and radio/CD player (I like to play them all at once sometimes)
- My iPad
- WWE wrestling – I love when my brother Matt takes me to live shows
- Nascar Racing (Jeff Gordon is my favorite driver)
- Going to country music concerts
- Feeling like I belong
- Being like everybody else, not being treated differently
- Getting a tattoo (already planning my next tattoo)
- Having control over my life as much as possible
- My Excelsior Springs Tigers – especially football
- Riding horses at NTRC
- Facebook friends
- Having an occasional beer with friends
- Having a purpose and being productive

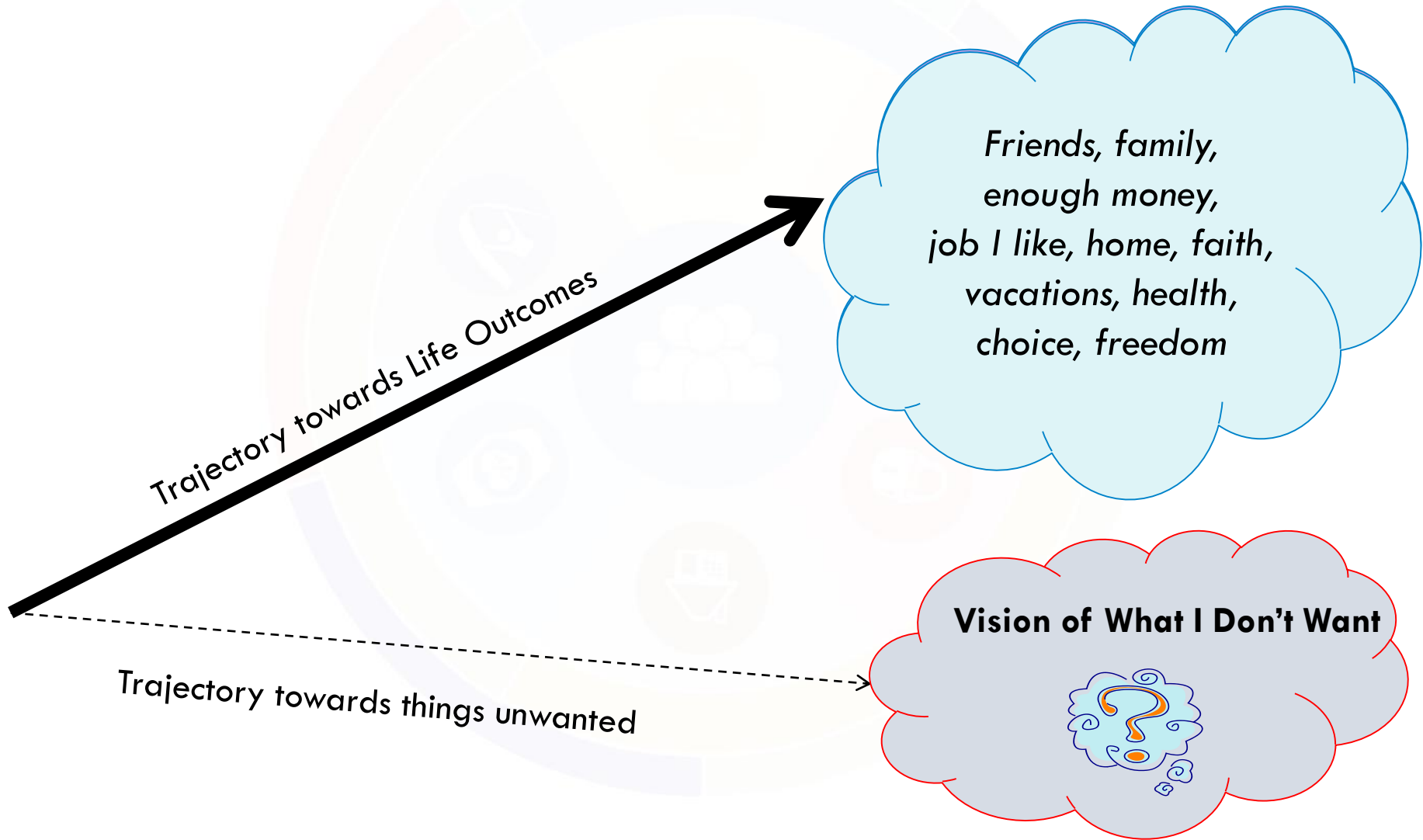
HOW BEST TO SUPPORT ME

- I need help remembering things, like what I did or who I saw today.
- I get confused easily so I need help not getting lost or turned around when I am out and about.
- I know what times I am supposed to take my meds, but I need help getting them out and getting refills.
- I get anxious sometimes, need to be reassured that people I care about will be there for me.
- I don't like to spend time alone, but I am working on it, help me not be so anxious when I am alone for short periods of time.
- I sometimes need someone to steady me if I get off balance.
- I need to rest or extra support if I have to do a lot of walking or standing. If I am shopping, it helps if I am the cart-pusher.
- I need support keeping in touch with friends and family and practicing having good conversations.
- I'm friendly even though I may not look you in the eye at first

Introducing Ben



Trajectory towards Good Life



Ben's Good Life Vision



Family Friends TATTOOS
Vacations Girlfriend
Concerts WWE Nascar
Money Job/own business
Fire Station Church
Tiger Football Royals
Good Food Pepsi Beer
Active Healthy & Fit

Poverty/No Money
Poor Health Diabetes
Heart Disease Guardian
Isolated/Segregated
Institution/group home
Treated Differently



Life Stages: Think Across Generations

Age	0-5	6-18	19-64	65
Total MO Population	362,650 (6%)	1,045,641 (17.3%)	3,747,386 (62%)	888,537 (14.7%)
Approx. DD (1.58%)	5729	16,521	59,209	14,038





Life Experiences = Life Outcomes



Experiences
at age 13

Experiences
at age 3

What We Want

*Friends, family,
enough money,
job I like, home, faith,
vacations, health, choice,
freedom*

What We DON'T Want



Life Experiences and Life Transitions

“Anticipatory Guidance for Life Experiences”

Chores and allowance

Summer jobs, babysitting

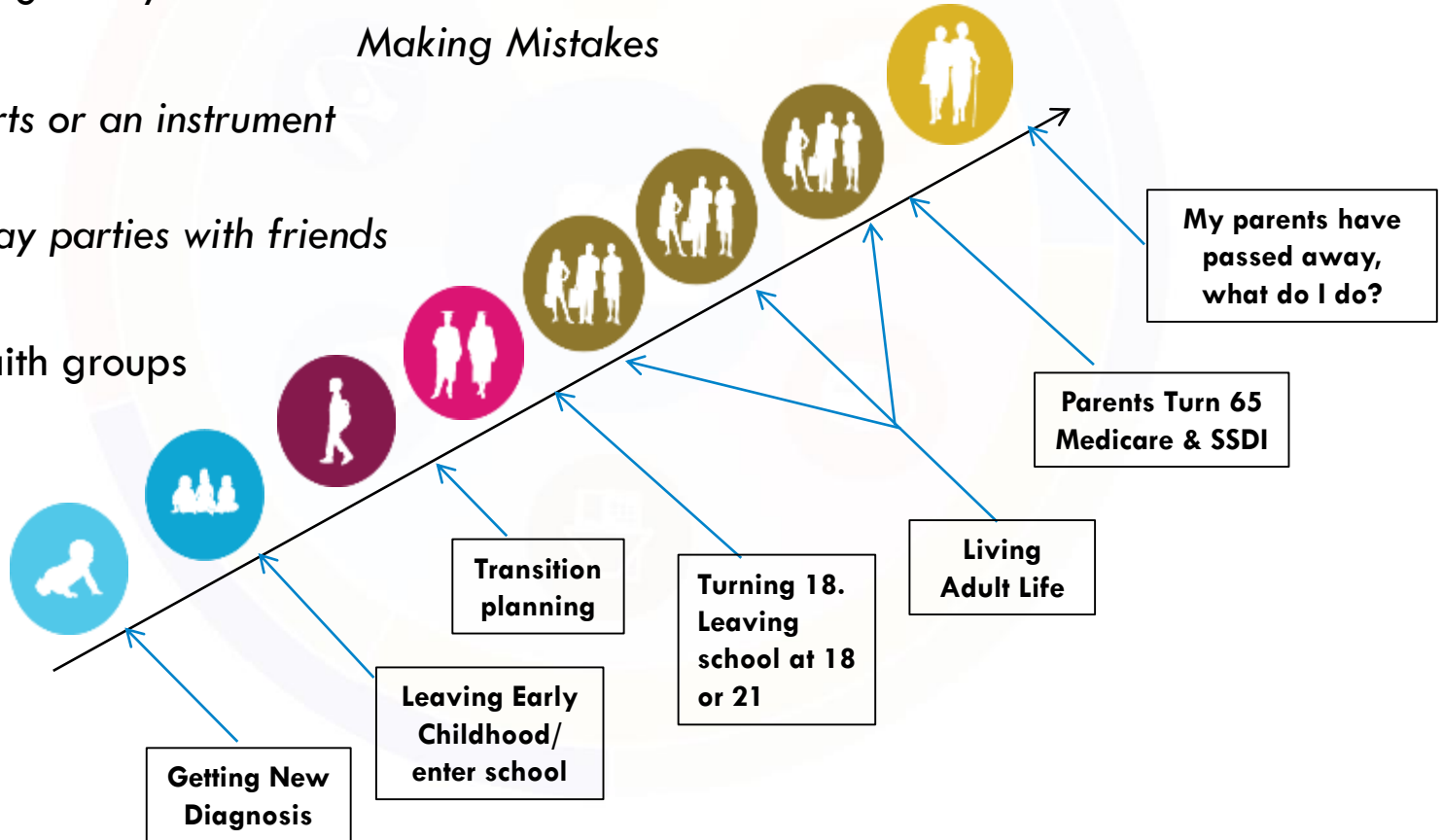
Learning to say “no”

Making Mistakes

Playing sports or an instrument

Birthday parties with friends

Scouts, 4H, faith groups



Ben's Life Trajectory

Life Trajectory Worksheet

Past Life Experiences

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

Chores; Boy Scouts;
School Inclusion/Circle of Friends; Birthday parties;
Riding bike; Debit card;
Family Vacations;
Church youth group;
Football manager;
Homecoming king;
Volunteering;
High School Diploma

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

Special Education low expectations;
Para glued to Ben's side;
Pressure to segregate;
Medication side effects;
Scoliosis;
Seizures;
Physical barriers

Future Life Experiences

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

Volunteer at fire station;
Find more volunteer ops;
Work out regularly;
Keep in touch w/ friends;
Increase home alone time;
Go out with friends;
Spend daytime hours out of the house;
Explore micro-enterprise

LIST life experiences to avoid that push you toward what you don't want.

Sitting at home watching TV all day;
Relying only on paid supports;
Gaining weight;
Eating unhealthy foods or drink too much Pepsi (caffeine)

Write current age here
26

VISION for a GOOD LIFE

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

Family and friends
Girlfriend
Vacations
Concerts, WWE, Nascar
Tattoos
Money; Job or my own business
Volunteer at Fire Station
Being Tiger football manager
Church
Healthy and fit
Good food; Pepsi
Basketball
Royals baseball
Chiefs football
Staying active

What I DON'T Want

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

Poor health, heart disease, diabetes;
Poverty/no money;
Guardianship; Institution/Group home;
Segregation/Isolation; Being lonely;
Being treated differently than peers;



My LifeCourse Portfolio is a template of the Family to Family LifeCourse Network | UMKC IHD, UCEDD. More materials at lifecoursetools.com
May 2016

Dignity of Risk and Mistakes

Never be defined by your past. It was just a lesson, not a life sentence.

*Friends, family,
enough money,
job I like, home,
faith, vacations,
health, choice,
freedom*

Poverty, loneliness,
segregation, restrictions,
lack of choice, boredom

Spirit Science





Life Domains, Life Outcomes, and Life Possibilities



Achieving Outcomes for 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 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)



Comprehensive, Integrated & Coordinated Systems Across Life Domains & Stages

Pediatrician, Families and Friends,
Faith based

IDEA Part C, Parents as Teachers,
Health, Headstart

School, Special Education, Health,
Recreation

Vocational Rehab, Health Employment,
College, Military

Disability Services, Health, Housing,
College, Careers

Retirement, Aging System, Health



Looking at Life Possibilities

Innovative

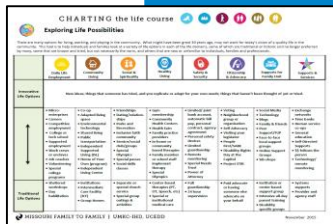
Very new or undiscovered

Islands of Excellence

Exists in a lot of places but not everywhere









Traditional Options

Services that have existed for a long time





Tool for Developing a Vision - Family

LIFE DOMAIN		My Vision for My Family Member's Future	priority	Current Situation/Things to Work On
 Daily Life Employment	What do I think my family member will do during the day in his/her adult life?	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	<p>Priority #1: We need to help Ben figure out how one of his interests can be used to help him start a small business and make money. We also need to explore how to do this and maintain his eligibility for Medicaid. We also need to work with his daytime staff and help them with ideas on ways to get him out of the house more.</p> <p>Priority #2: We need to take a more active role to help Ben invite friends to do things with him, especially the firemen outside the station.</p> <p>Priority #3: Explore buying a medication dispenser that he can start learning how to use while we are around to supervise and help him. We also think it is a good idea for him to start a small container garden to grown some of his own vegetables.</p> <p>Priority #4: We would like to finish our basement as a possible apartment for Ben or at least a hangout space where he can spend time with friends away from mom and dad.</p>
 Community Living	Where and with whom do I think my family member will live in his/her 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 independent within our family home.	4	
 Social & Spirituality	How will he/she connect with spiritual and leisure activities; have friendships & relationships in his/her 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.	2	
 Healthy Living	How will he/she live a healthy lifestyle and manage health care supports in his/her adult life?	Ben would work out at least 3-5 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 I ensure safety from financial, emotional, physical or sexual harm in 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.		
 Citizenship & Advocacy	How can I make sure he/she has valued roles and responsibilities, and has control of how his/her 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 will our family need to help support him/her to live a quality life as an adult?	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	How will he/she be supported in adult life to lead the kind of life he/she wants 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.		

Ben's Tool for Developing a Vision

*Getting
more
specific in
each life
domain*





Individualized Supports to Achieve a Good Life



Three Types of Supports



Types of Supports

Discovery & Navigation: Knowledge & Skills	Connecting & Networking Mental Health & Self-efficacy	Day-to-Day Services Instrumental Supports
<ul style="list-style-type: none">• Information on disability• Knowledge about best practices and values• Skills to navigate and access services• Ability to advocate for services and policy change	<ul style="list-style-type: none">• Parent-to-Parent Support• Self-Advocacy Organizations• Family Organizations• Sib-shops• Support Groups• Professional Counseling• Non-disability community support	<ul style="list-style-type: none">• Self/Family-Directed services• Transportation• Respite/Childcare• Adaptive equipment• Home modifications• Financial assistance• Cash Subsidies• Short/Long term planning• Caregiver supports & training

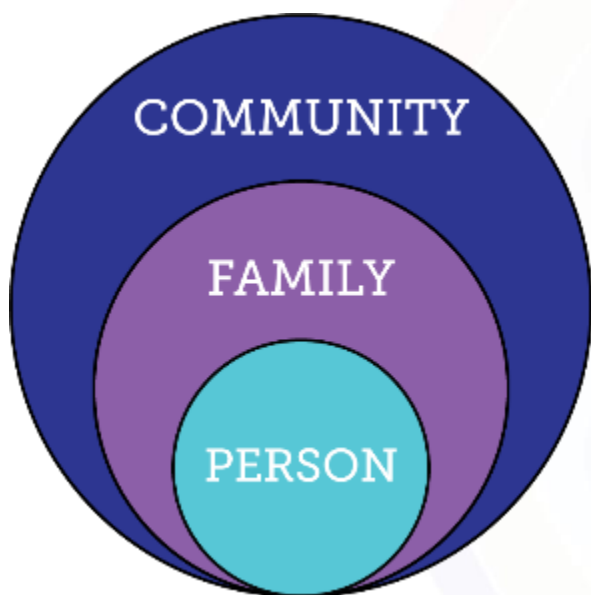




Integrated Star for Problem Solving & Exploring Options



Integrating Services and Supports



75%
People with I/DD not
receiving formal
DD services



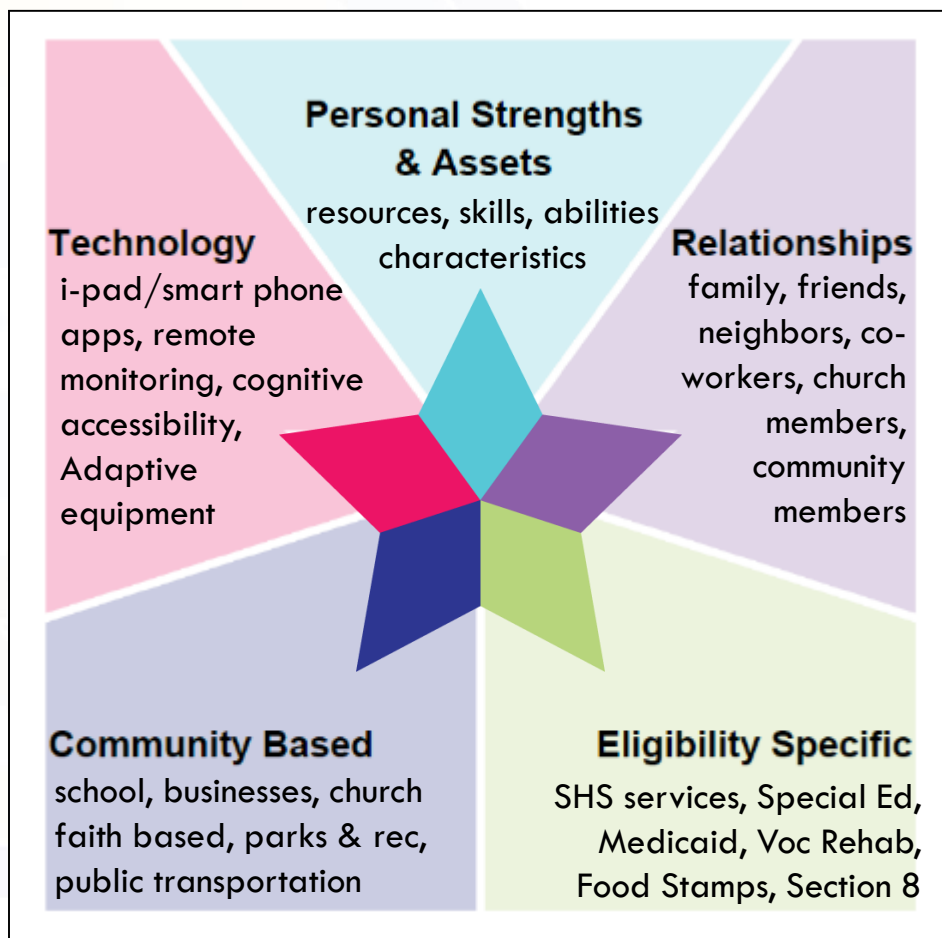
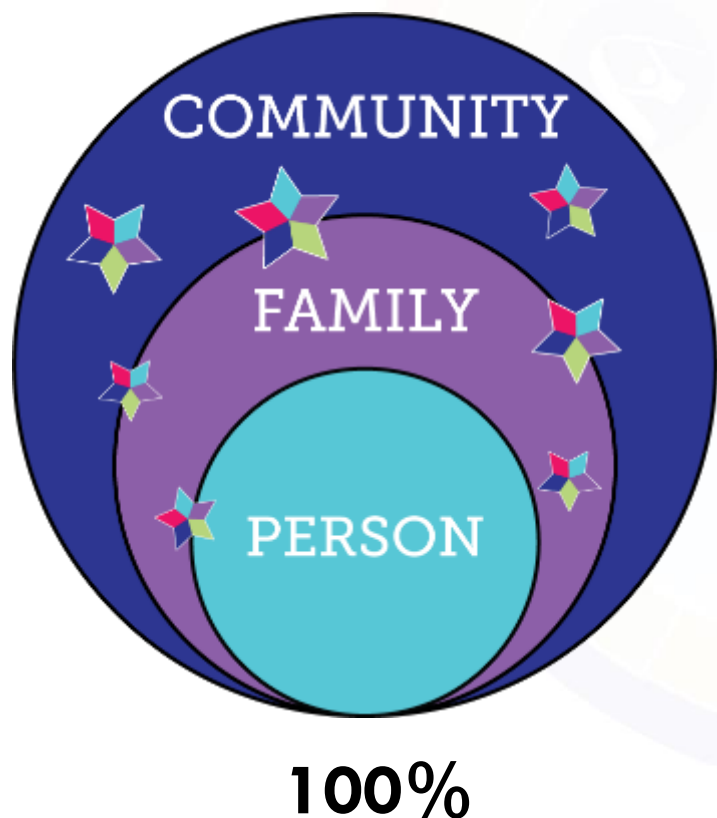
25%
People with I/DD
receiving formal
DD services



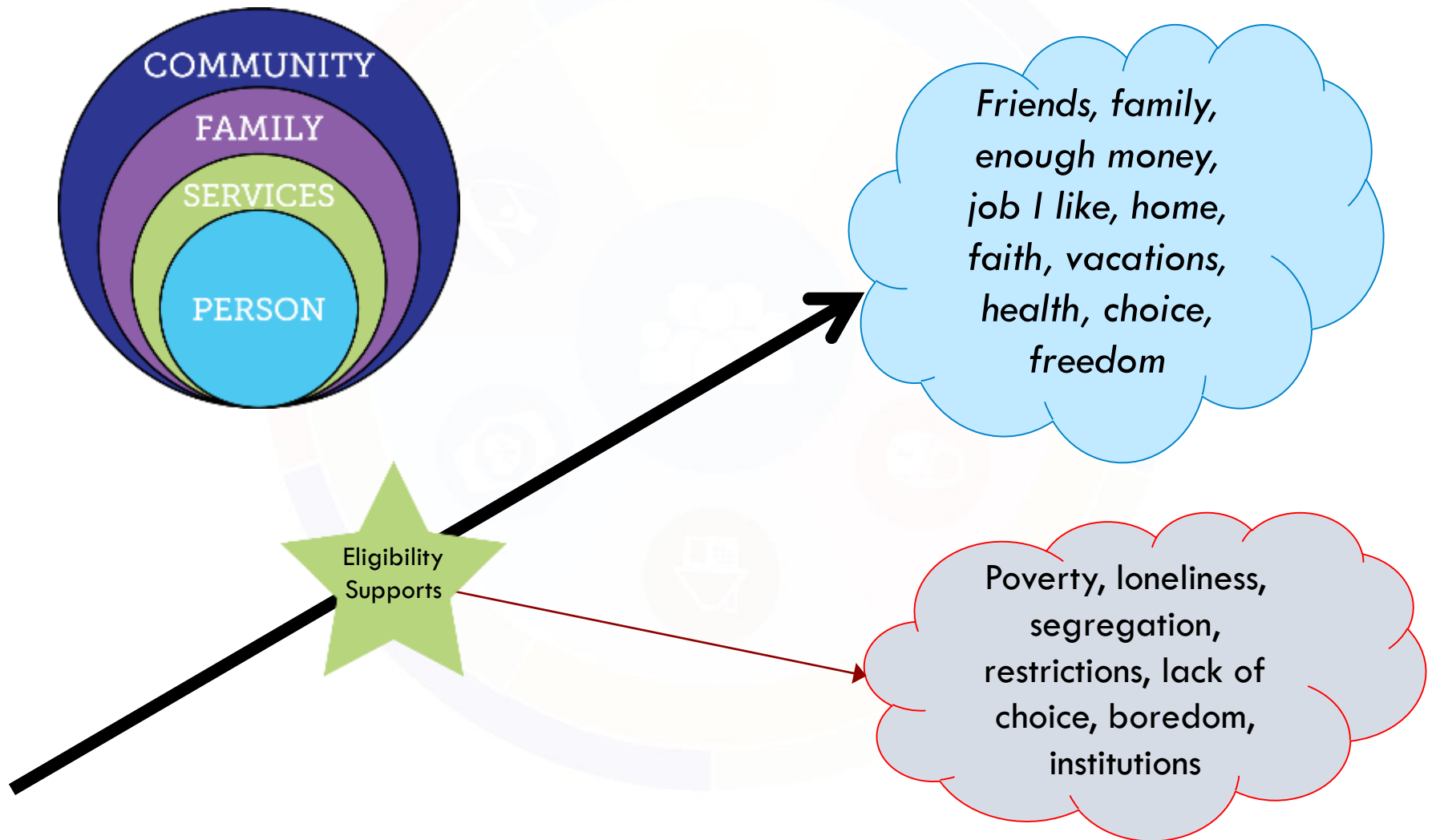
100%
People with I/DD
receiving integrated
services and supports



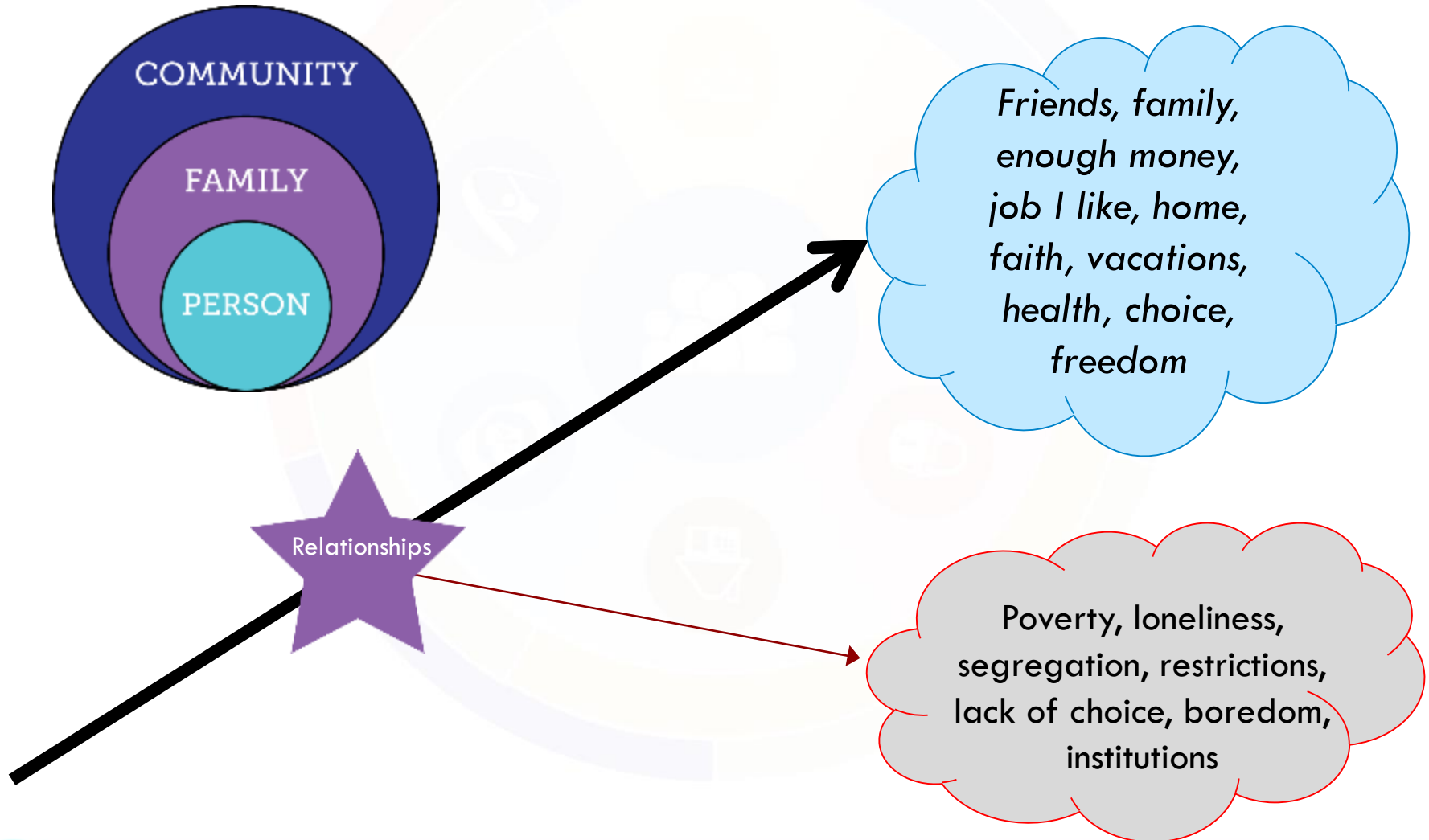
LifeCourse Integrated Supports STAR

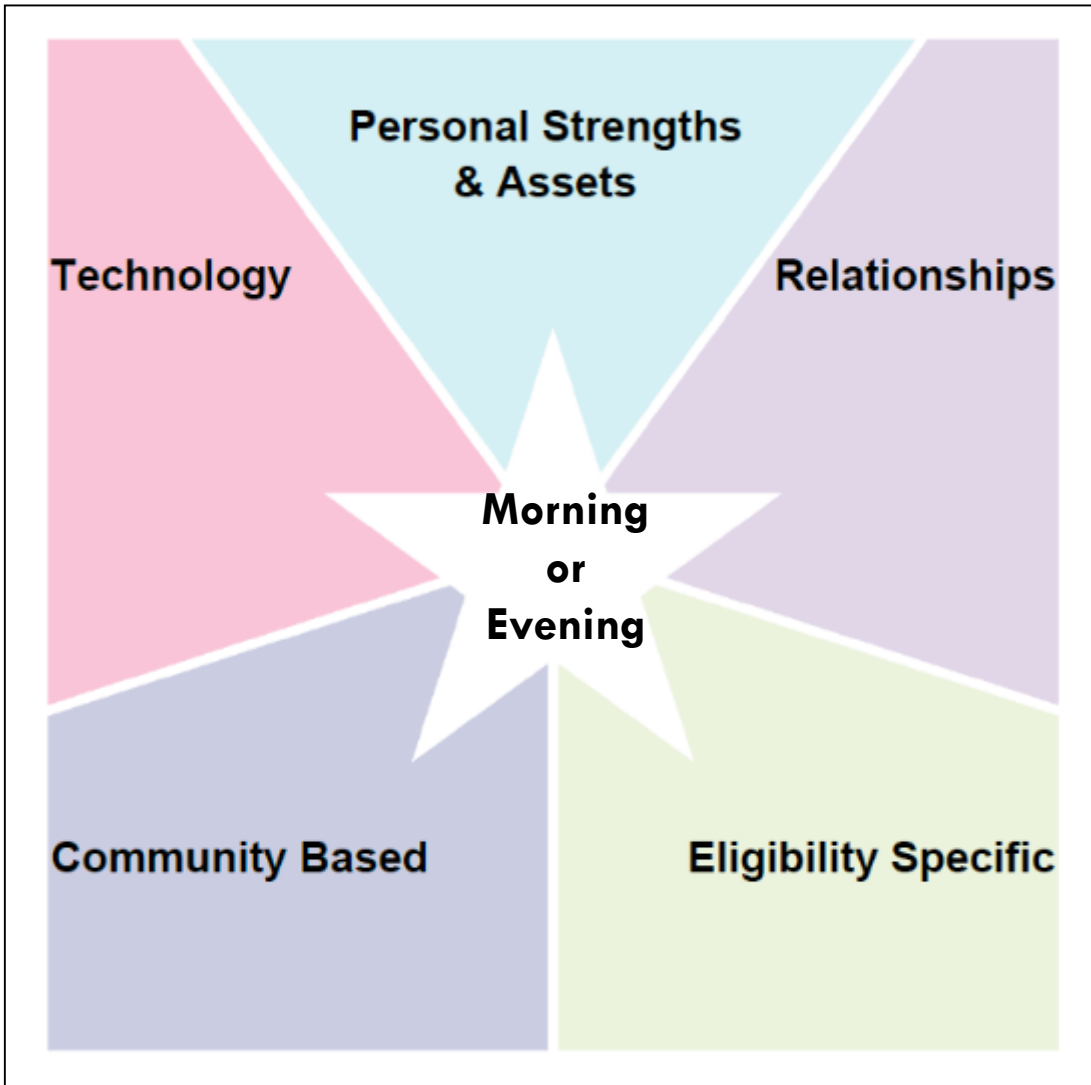


Focusing ONLY on Eligibility Supports



Relying ONLY on Family & Friends

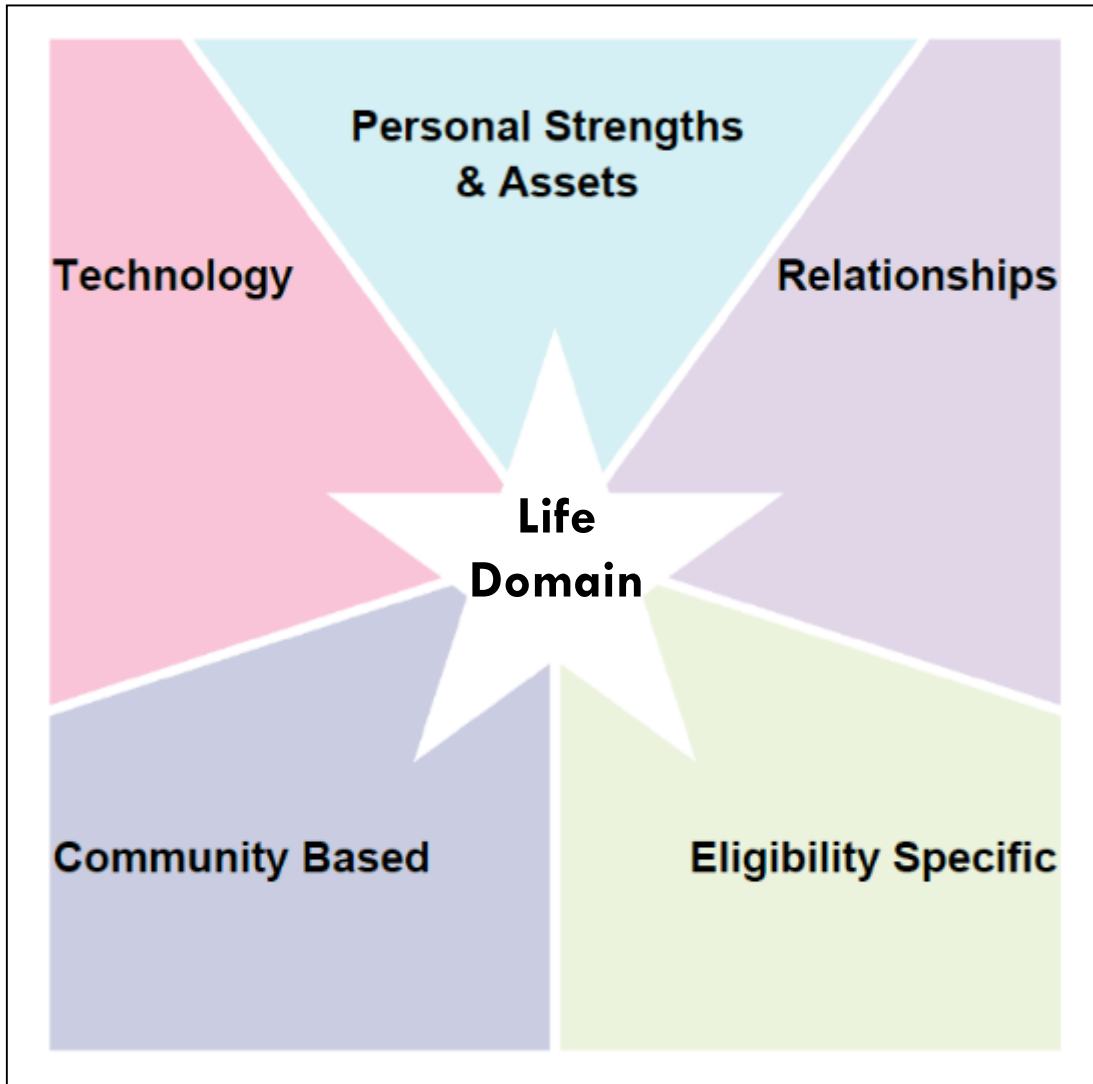




Daily Routine

Day	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Activities	Morning Routine, Personal Care, Meals, Work/Study	Morning Routine, Personal Care, Meals, Work/Study	Morning Routine, Personal Care, Meals, Work/Study	Morning Routine, Personal Care, Meals, Work/Study	Morning Routine, Personal Care, Meals, Work/Study	Morning Routine, Personal Care, Meals, Work/Study	Morning Routine, Personal Care, Meals, Work/Study





Problem Solving: *Life Domain*

Area of Concern	Description of Issue	Assessment	Action Plan
1. Safety	Client reports feeling unsafe at home due to partner's aggression.	High risk of physical harm.	Develop safety plan, identify safe places, contact law enforcement if needed.
2. Mental Health	Client experiences frequent panic attacks and anxiety.	Severe anxiety disorder.	Refer to mental health services, provide crisis support, teach coping strategies.
3. Financial Stability	Client has lost their job and has no income.	High risk of homelessness.	Apply for unemployment benefits, seek emergency financial assistance, connect to food banks.
4. Social Support	Client is isolated and lacks a support network.	Increased vulnerability.	Facilitate support group, connect with community resources, encourage family contact.
5. Legal Issues	Client is unaware of their legal rights regarding domestic violence.	Need for legal advocacy.	Refer to legal services, explain options for restraining orders, provide information on tenant rights.

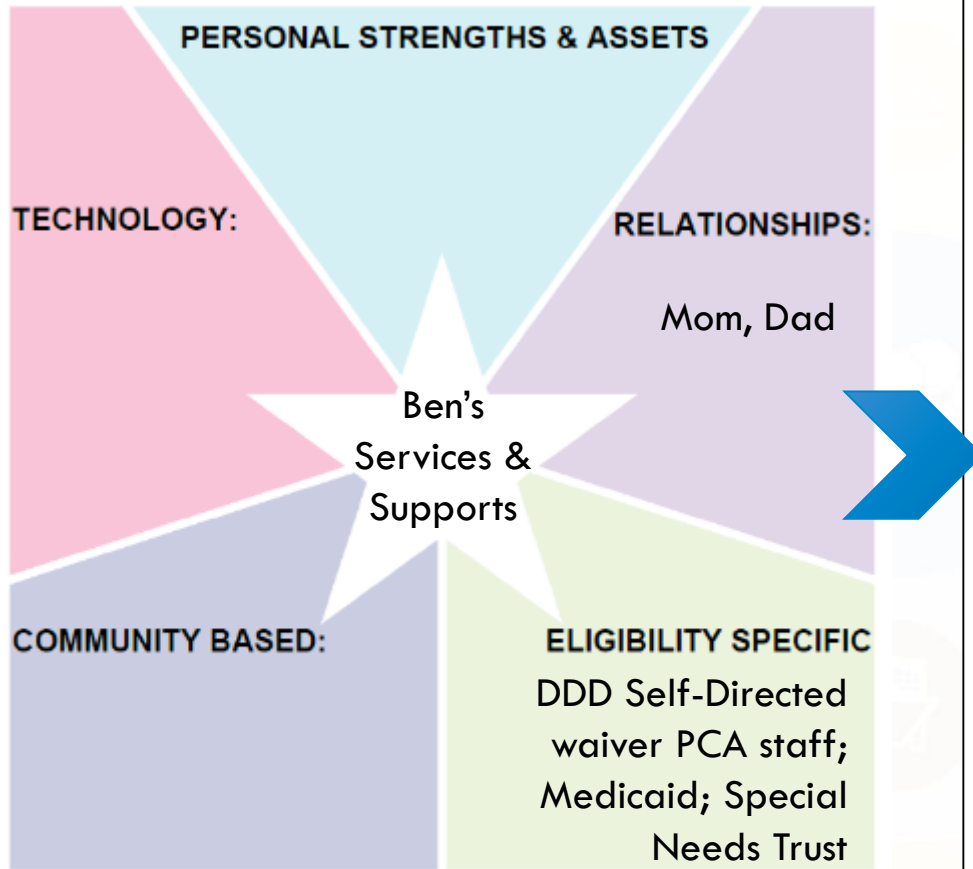




LifeCourse Star to Calendar



BEFORE: Services and Supports



Long Term Service and Support Needs

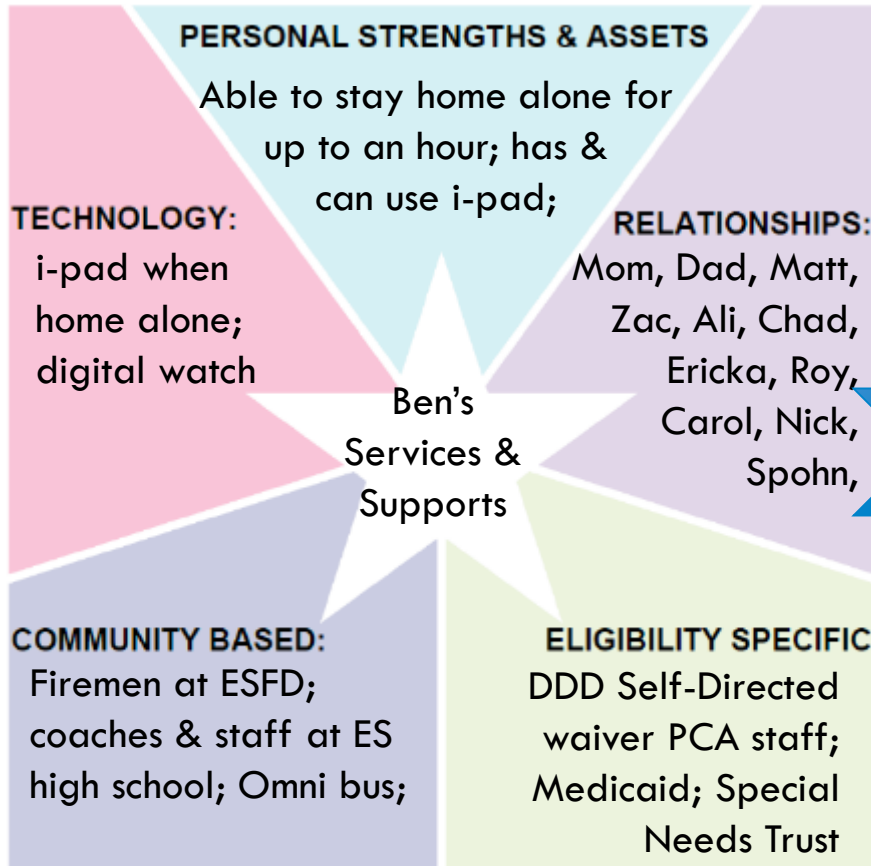
Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
6-8:30 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day						
8:30-7 AM							
7-7:30 AM							
7:30-8 AM							
8-8:30 AM	Waiver Self-Directed PCA					Parents are weekend support	
8:30-9 AM							
9-9:30 AM							
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							
6:30-7 PM	Mom and Dad are overnight staff						
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							

Template by Missouri family to family @ UMKC-HD, UCEDD

December 2014



AFTER: Services and Supports

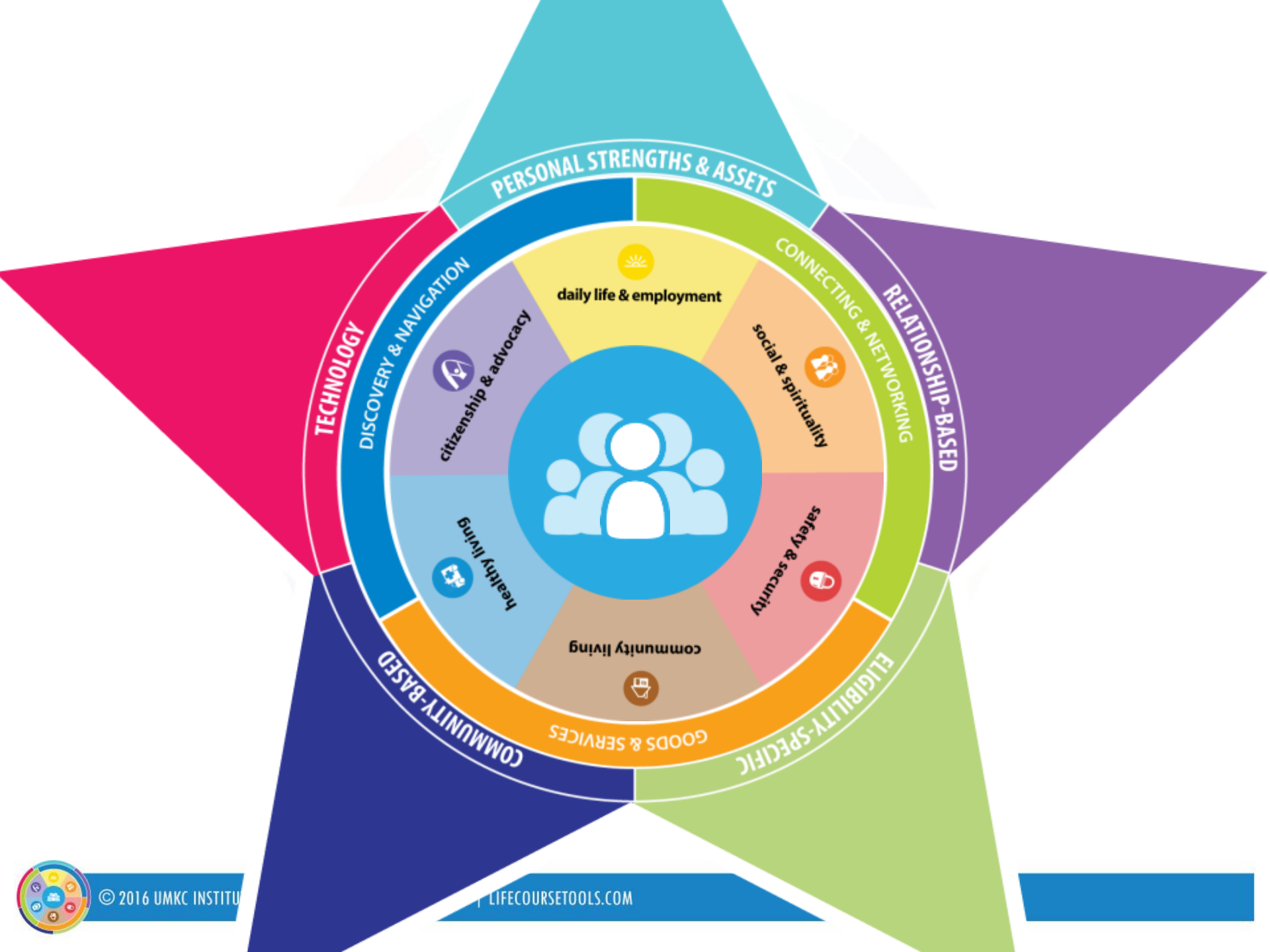


Long Term Service and Support Needs

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		
8:30-9 AM							
9-9:30 AM							
9:30-10 AM	Waiver Self-Directed PCA						St. Ann's w/ mom
10-10:30 AM							
10:30-11 AM							
11-11:30 AM							
11:30-12 PM						Home alone while Mom walks	
12-12:30 PM							
12:30-1 PM		Waiver Self-Directed PCA		Waiver Self-Directed PCA			
1-1:30 PM							
1:30-2 PM							
2-2:30 PM							
2:30-3 PM	Volunteer at high school, supported by coaches and friends						
3-3:30 PM							
3:30-4 PM							
4-4:30 PM							
4:30-5 PM							
5-5:30 PM							
5:30-6 PM	Mom and/or Dad prepare meal and assist as needed					Dinner w/ Roy & Carol & family	
6-6:30 PM							
6:30-7 PM	Home alone while Mom walks						
7-7:30 PM	WWE With Matt		Horseback Therapy w/ Dad			Nick's Birthday Party with Matt and friends	
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM	Mom and Dad are overnight staff						

Template by Mission Family to Family @ UMKC-IND, UCEDD January 2015





LifeCourse in Action

- Prepare for IFSP/IEP/ISP meetings
- Problem Solving
- Working on self-directing or self-determination skills
- Exploration & Planning



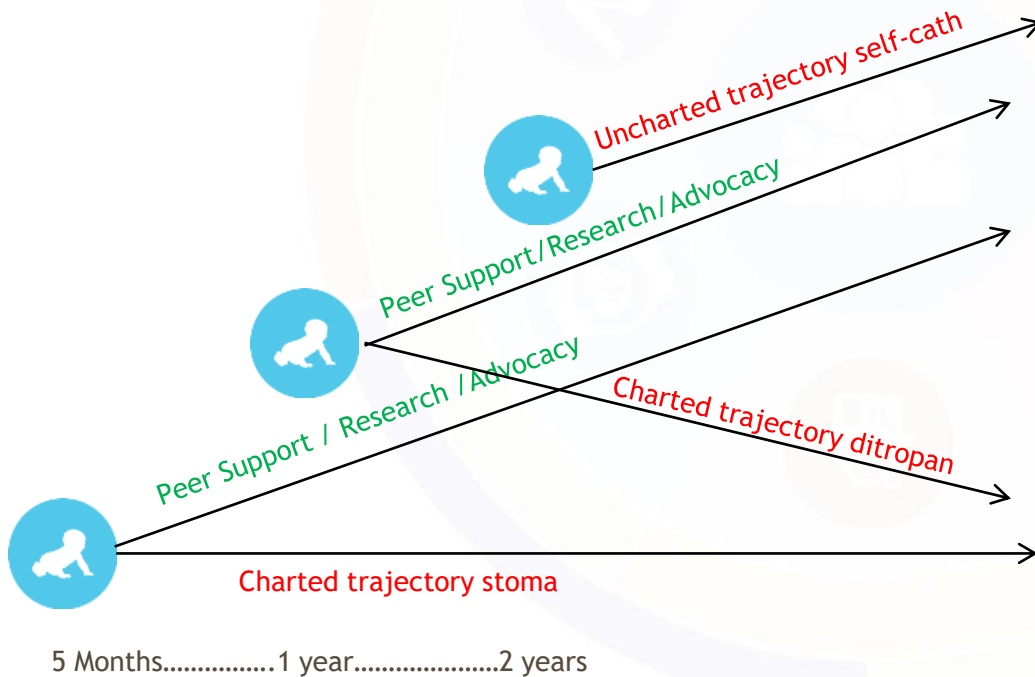
Where do you “plan” with professionals and others?

- ⊙ Schools
- ⊙ Doctors
- ⊙ Lawyers
- ⊙ Support Coordinators
- ⊙ Family Members
- ⊙ Community Settings





Elizabeth's Health Trajectory As Told by Her Mother



VISION for a GOOD LIFE

Self determination
Choice
Privacy

What I DON'T Want

Unnecessary medications
Unnecessary procedures
Limiting choices
Limiting self-determination



ELIZABETH's ONE-PAGE PROFILE

What people like & admire about me

I cheer people up. People think I am cute - and smart. I help others be good friends. I like to try new things.

What's Important to ME

Jesus
Going to Church
My family
Having good friends
Being a good friend
Going to WI
Going to the park
School
Becoming a scientist

How to Best Support ME

Don't push my chair without asking
Be patient when I try to explain what I want or mean.
Be patient when I try to figure out how to do something on my own

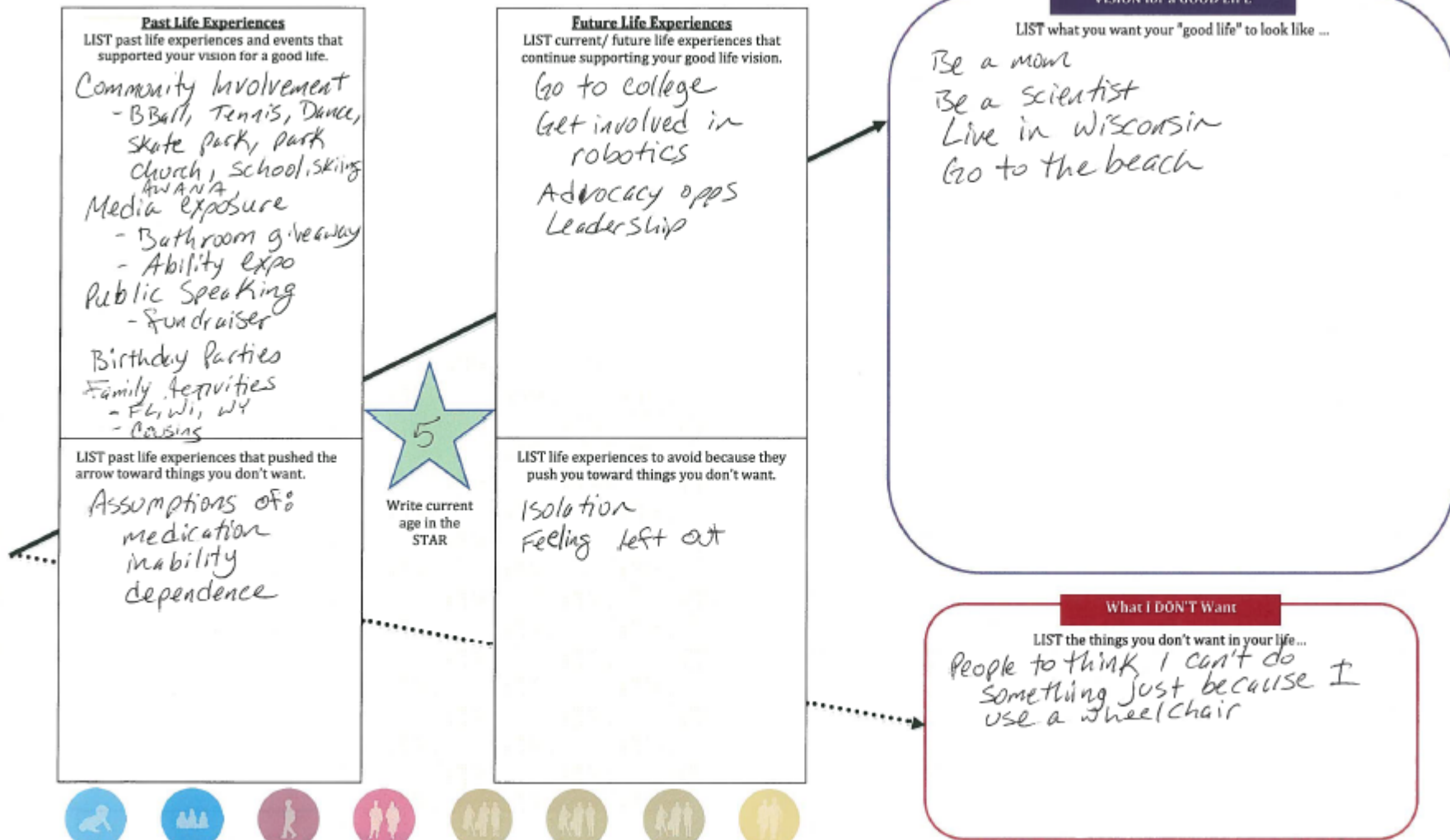


Elizabeth,
age 6



Elizabeth's Life Trajectory

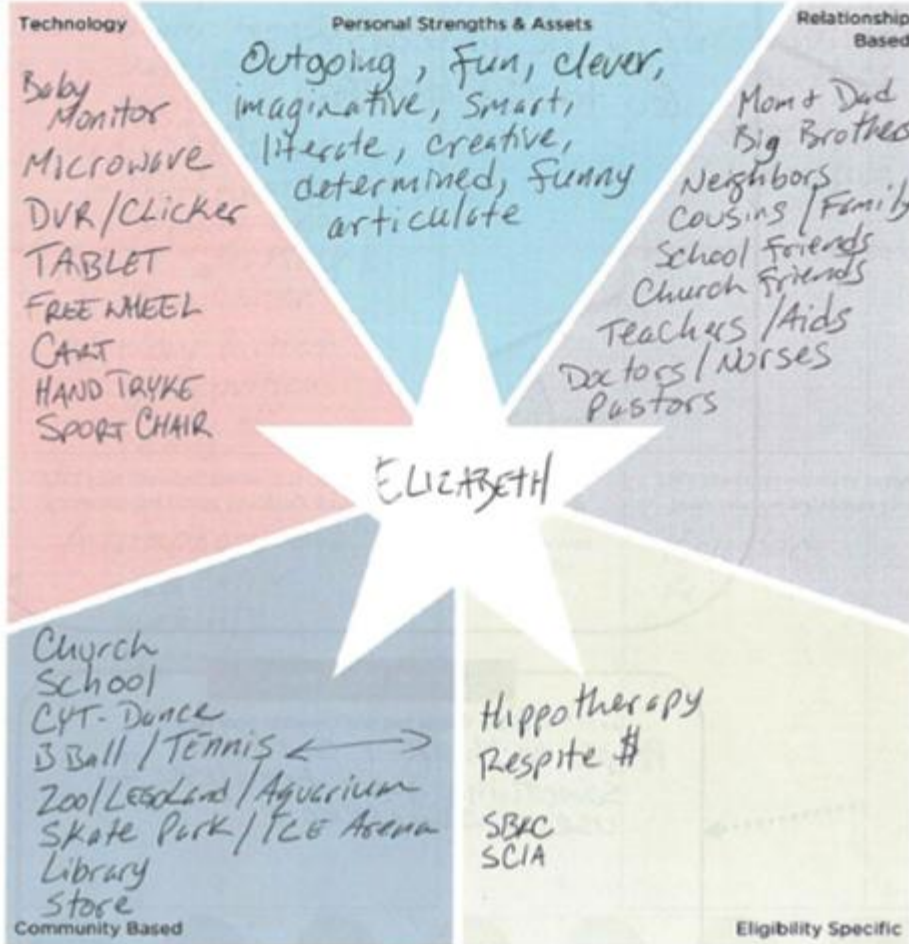
Life Trajectory Worksheet





Integrated Services and Supports

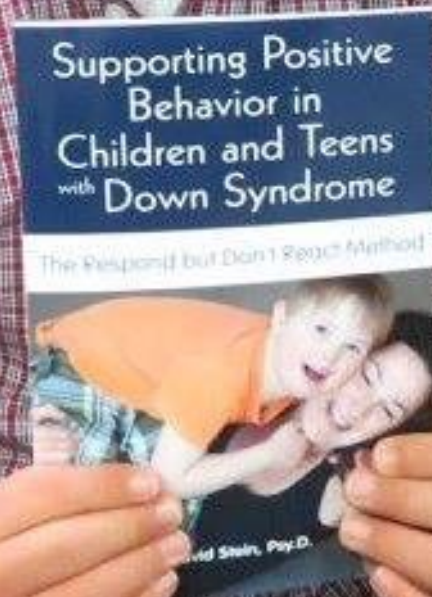
People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for a good life.



Elizabeth's Integrated Star: Mapping Supports



Peyton's Plan for Inclusion in School Using the LifeCourse Tools to Transform the Way the School Thinks about Inclusion for Peyton



Peyton 2016-17



Peyton 2016-17



Peyton self-leading IEP



CHARTING the life course



Tool for Developing a Vision - Family

Tony 7/17/15

Forming a vision and beginning to plan for the future in each of the life domains helps plot a trajectory for a full, inclusive, quality life in the community. This tool is to help families of all ages – those with a very young child, an adult or somewhere in between, start to think about a vision for how their family member will live their life as an adult.

LIFE DOMAIN	My Vision for My Family Member's Future	rank	Current Situation/Things to Work On	rank
Daily Life Employment	What do I think my child will do during the day in his/her adult life? become a chef	3	Tony loves to help cook	
Community	Where and with whom do I think my child will live in his/her adult life? I think Tony will progress well and hopefully live on his own (endless possibilities)		Tony likes to be independent	
Social & Spirituality	How will my child connect with spiritual and leisure activities, have friendships and relationships in his/her adult life? I think if Tony is directed right he can have friends and do activities		We are working on going to the YMCA to do leisure activities	
Healthy Living	How will my child live a healthy lifestyle and manage health care supports in his/her adult life? I am trying to get Tony to eat different & healthy foods			
Safety & Security	How will I ensure the safety of my child from financial, emotional, physical or sexual harm in his/her adult life? I will do the best; can't see who Tony is influenced by to get him ready for	2	I monitor who Tony plays with what he hears adults talk about	
Citizenship & Advocacy	How can I make sure my child has valued roles and responsibilities, and has control of how his/her own life is lived as an adult? I can have Tony start making his bed and we are starting to work on dishes		I remind Tony that keeping his room clean helps him maintain cleanliness for his own house	
Supports for Family	What will our family need to help support my child to live a quality life as an adult? We will always need to have an eye on each other and work on problems as they come	1	We always talk out our problems and look out for each other	
Supports & Services	How will my child be supported in his/her adult life to lead the life he/she wants as independently as possible? Tony will always have my support to be independent and be comfortable in the things he chooses		Tony is always given the chance to make his own choices first	

1
want to be independent

2
very important rather be alone & he doesn't have to

3
important

Tony – 7 years old

CHARTING the life course



Tony 7/17/15

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

Continue to progress in public school
Get his own friends
Get over fear of animals

What I DON'T Want

Become violent
Have bad situations in his life
Be taken advantage of

Go to zoo to help fear of animals - learn to share & understand others emotions - learn to cope with feelings & sensory overload



Bentley – age 5

CHARTING the life course

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.

Technology
has VSmile TV Tablet at school
Wish had Better communication
Wish had tablet at home

Personal Strengths & Assets
has people person
have mom dad Sister brother paternal grandparent great aunt
Wish had maternal

Relationship Based
Wish had Bentley 7/8/15
Autism Chapter
have PCS, Medicaid, Social Security, Food stamps, Food pantry, Program at school for autism
Wish had state police, day care, or autism school, day care, credit repair
Autism Foundation
Dr. Strand

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

CHARTING the life course

Tool for Developing a Vision - Family Bentley 7/8/15

Forming a vision and beginning to plan for the future in each of the life domains helps plot a trajectory for a full, inclusive, quality life in the community. This tool is for both families of all ages – those with a very young child, an adult or someone in between, start to think about a vision for how their family member will live their life as an adult.

LIFE DOMAIN	My Vision for My Family Member's Future	rank	Current Situation/Things to Work On	rank
Daily Life Development	What do I think he/she will do during the day in his/her adult life?		want him to work if he can	
Community Living	Where and with whom do I think my child will live in his/her adult life?		Assisted Living or with mom	
Social & Spirituality	How will my child connect with spiritual and leisure activities; have friends and relationships in his/her adult life?			
Healthy Living	How will my child live a healthy lifestyle and manage health care supports in his/her adult life?			
Safety & Security	How will I ensure the safety of my child from financial, medical, physical or social harm in his/her adult life?		mom handle many caps handle security counseling for emotional	

UCEDD MAY 2014

CHARTING the life course

Life Trajectory Worksheet: Family Bentley 7/8/15

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
Independence
Structure & guidance
understanding of things
(people who work with him how best works for him)
Family
Good

What I DON'T Want
Bullies
Negativity
Live in baby mentality

Being a family unit & showing him that
getting him the help that he needs

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD MAY 2014



Kylie

4 yrs old:

Support Planning

CHARTING the life course

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.

SCANNED
169-1740

Steps To Take:

- Look into ABA therapist for home
- Research social activities to engage w/ other kids more
- Talk to doctor/Therapist about other tools/resources/services that will be beneficial for Jane

Find resources for potty training and introducing new foods

School is linking to ABA Therapist for school
Enjoying school! seems to want to go

* He is using more words to request things, not just echolalia

IEP in place - 1hr of speech therapy, 5 days a week

Byam Preschool w/ Camden Point Elementary

Completed Hippotherapy - posture and task follow through improved

Progress Made:

VISION for a GOOD LIFE

Able to verbally communicate with others, hold a conversation
Have Friendships, improve social skills
Be successful w/ school
Know and use manners

What I DON'T Want

In a segregated classroom
Not able to talk at all, regression in skills
Bullied or taken advantage



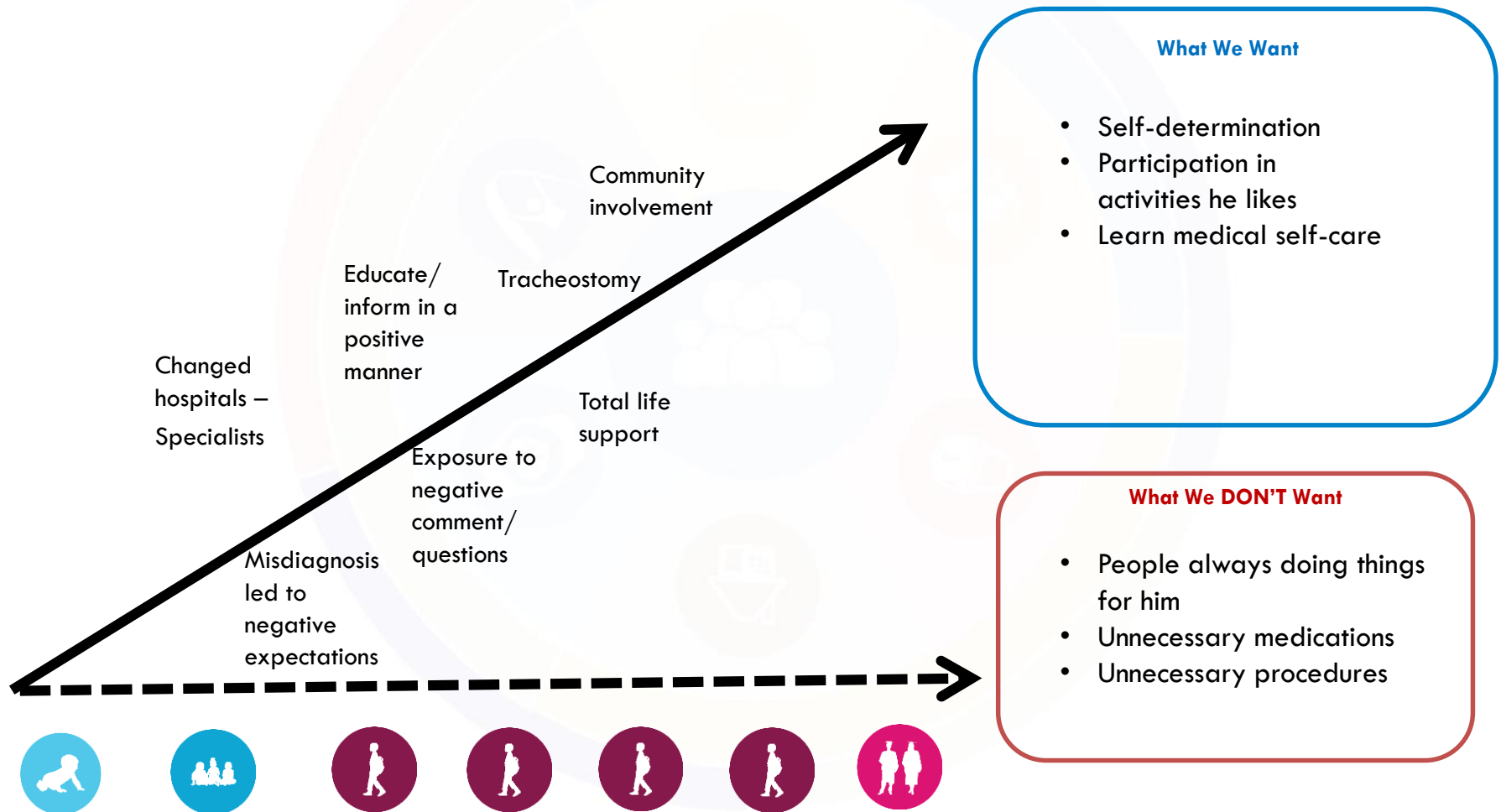
How the Story Began: Izaac

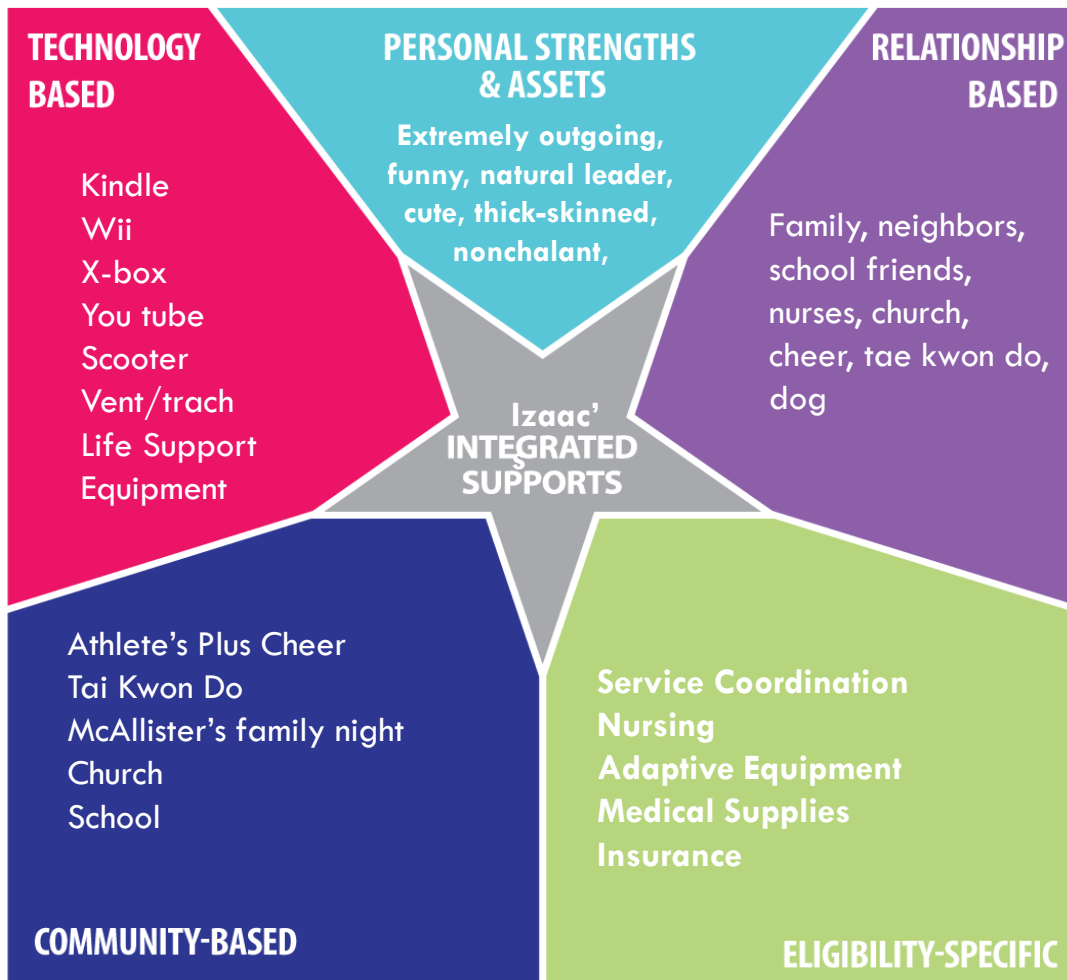


- Achondroplasia
- Severe Sleep Apnea/O₂/Monitors
- Severe pneumonia/coded
- Multiple hospitalizations
- Trach/ventilator
- Delayed walking/talking



Izaac's Trajectory





Izaac's Integrated Supports

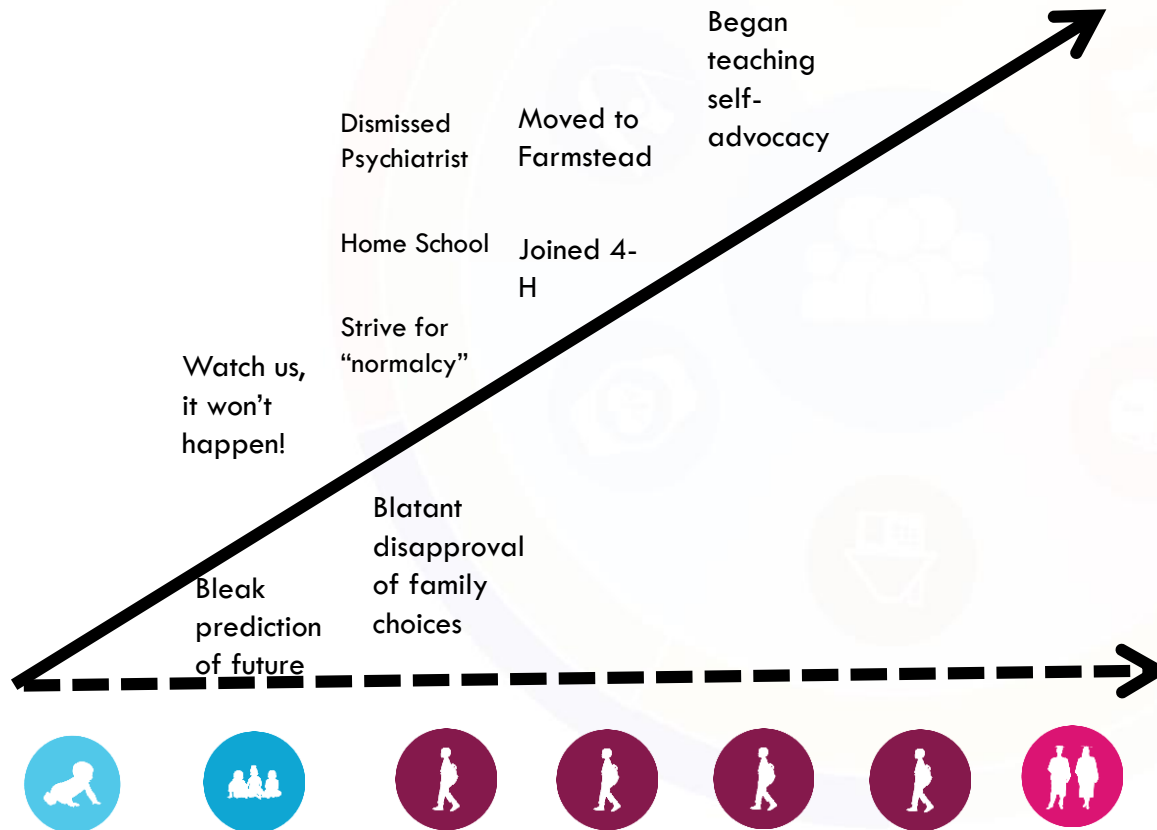


How the Story Began: Shaylee

- Fetal Alcohol Syndrome
- PTSD/Seizures/Learning Delays
- Autism/ADHD/ODD
- Expectancy of Institutionalization
- Foster/Adoptive care



Shaylee's Trajectory



What We Want

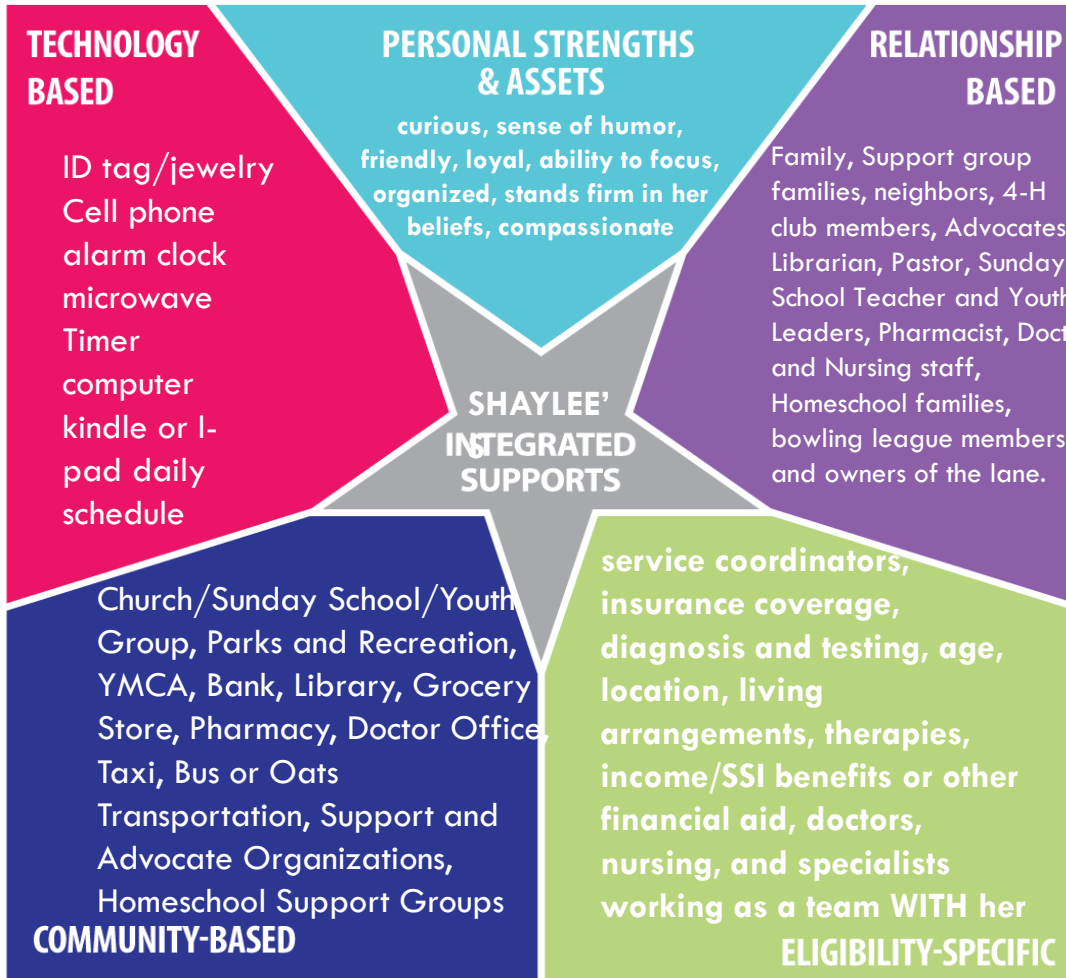
- Live independently
- Work with animals
- Healthy self care
- Self-regulate behaviors
- Control over finances
- Access to transportation
- Strong supports in place as needed

What We DON'T Want

- Over-medicated
- Taken advantage of
- Institution or group home
- Others make all decisions or choices for her.



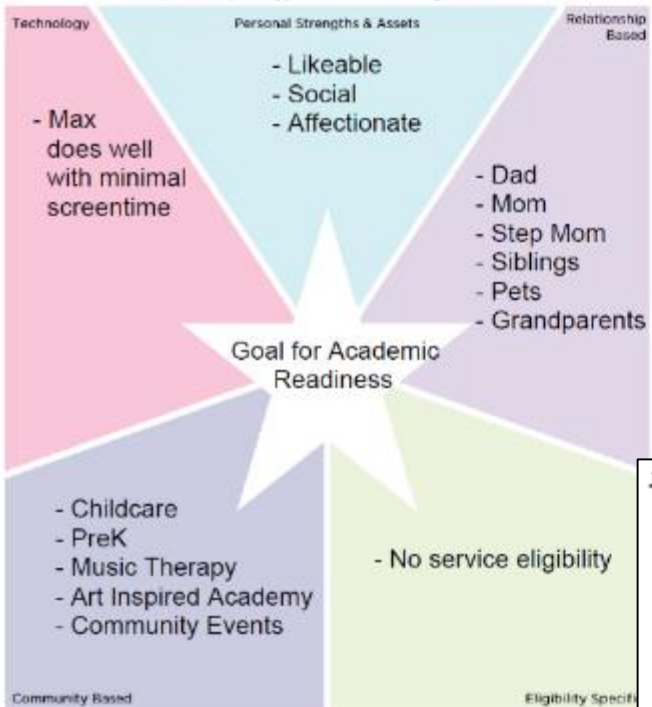
Shaylee's Integrated Supports





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.



DEVELOPED BY MISSOURI FAMILY TO FAMILY | UMKC-DID, UCEDD | OCTOBER 2018



TURNING ABILITIES INTO OPPORTUNITIES
SAFFORD COUNTY SPANISH BOARD FOR
PEOPLE WITH DEVELOPMENTAL DISABILITIES

MAX'S ONE-PAGE SCHOOL PROFILE

What people like & admire about me

- Funny
- Cute
- Little
- Complimentary
- Affectionate
- Energetic



What's Important to ME

How to Best Support ME

Journey through School

Past Life Experiences

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

- Separated parents improved relationship
- Appropriate sleep
- Universal expectations
- Time with family
- Appropriate time with family

LIST past life experiences that created the arrow toward things you

- Inappropriate amount of screen time
- Mixed signals
- Lower expectations due to birth order (the baby)
- Lack of consistency
- Poor communication with PreK



Write current age in the STAR

Future Life Experiences

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

- Starting school when Max is ready
- Supporting and teaching self control
- Consistent Parenting
- Good Communication

LIST life experiences to avoid because they push you toward things you

- Pushing Max to do things that he isn't ready for
- Encouraging an inflated sense of self
- "babying" him
- Mixed expectations, inconsistency

VISION for a GOOD LIFE

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

- School success
- Friends
- Happiness
- Appropriate behavior and social functioning
- Positive relationships
- Consistent expectations

What I DON'T Want

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

- Aggression
- Different conflicting expectations
- Behavioral struggles (particularly in school)



Max's School Portfolio

Sean TCM only

Personal Strengths & Assets

Sean is easy to wake up in the morning. Although he doesn't pick out his clothes he does share when he doesn't want wear something that has been picked out for him by his mom. Sean enjoys school, which is a great asset to his education. He gets good grades (All A's & B's) and in the last couple of years has figured out that he thrives more in the regular classroom than in the resource room with other with special needs. Sean's handwriting is improving, he excels in science, and has gained several new friendships this year.

One of Sean's favorite times of school is Advisory Time which he is able to finish homework, play games, hang out in the gym, and partake in his favorite sports.

Relationship Based

Sean likes his teachers, especially Mrs. Skaggs because she likes him & his love for science.

Some of his friends are Michael, Jackson, Cameron, Colby, James & Oakley

Sean's immediate family also helps him with excelling in school and contributes to his love of education

School Technology

Digital Clock
Chrome Book
School Bell
Locker Combination Lock

Home Technology

I-Pad
Clock
Game systems

Short term goal

An AWESOME science project

My 6th
Grade Year

Long term goal

Science teacher focusing on fossils

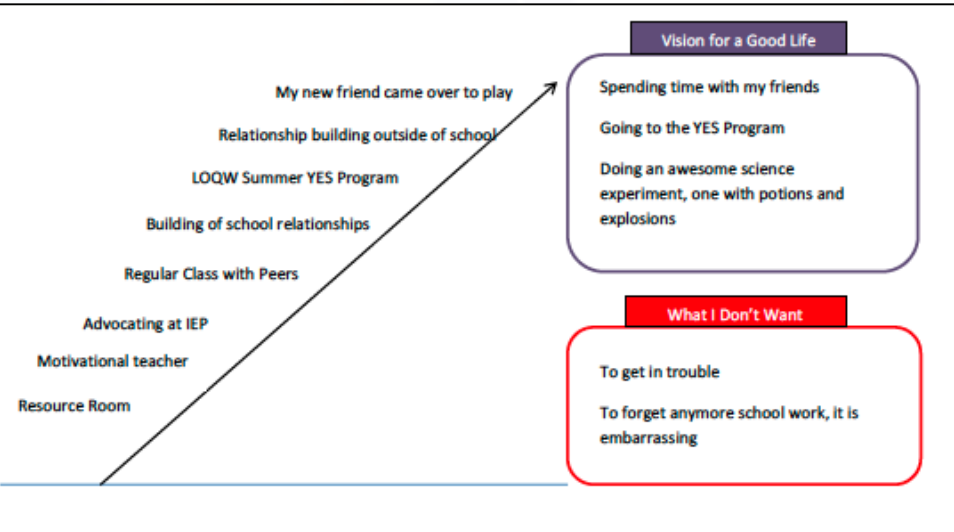
Community Based

Mom drives to and from school

LOQW Summer YES Program- helped maintain safety skills and opportunities for future employment. Sean is greatly looking forward to being able to participate in this program again.

Eligibility Specific

IEP guided education
Floating paraprofessional
Speech Therapy
Service Coordination





HS Football Coach



NASCAR

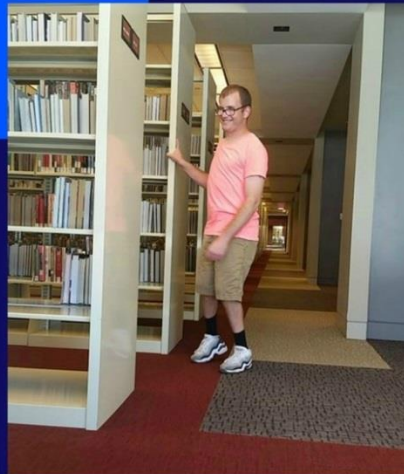


Eagle Scout Leader

Going to country music concerts



Going to the Library and other places around town.



What is important to me?

The Good Life



By: Ben St John

Ben's Cognitively Accessible Tools



What is important to me?



Graduating with my High School class and getting my diploma!

Hanging out with my friends and having things in common with others.



Working at the Fire Station and being an important part of my community.

Spending time with my family



Ben's Good Life



What bothers me?



Not having money or forgetting my wallet



Izzi on my bed!

Being sick or having a family member in the Hospital.



Being treated differently than others.



Feeling lost or confused



What is NOT a Good Life For Ben



LifeCourse Tools

LifeCourse Educational Materials



[Lifecoursetools.com](http://lifecoursetools.com)





INNOVATIONS IN SUPPORTING FAMILIES COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE WEBINAR SERIES

FOCUSING ON THE FRONT DOOR OF LONG-TERM SERVICES TO ENHANCE SUPPORTS TO FAMILIES

Reaching out to find information or to get necessary services and supports can be a hard first step for many families. Two of the Community of Practice states, Missouri and Tennessee, have been working to make this initial contact with the state developmental disability systems a more person- and family-centered experience. Staff from the state Intellectual and Developmental Disabilities (I/DD) agencies will provide an overview of the changes they are making to the front door of services to better meet the needs of persons with I/DD and their families and to serve as a no wrong door to other supports.



PRESENTERS

Key staff from the state I/DD agencies in



MISSOURI
DMH Division of
Developmental
Disabilities



TENNESSEE
Department of
Intellectual &
Developmental Disabilities

LOG IN AT

<https://nasddds.adobeconnect.com/familynetworks/>

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MARCH 26, 2015

2PM Eastern / 1PM Central / 12PM Mountain / 11AM Pacific / 10AM Alaska / 9AM Hawaii

Webinar will last approximately one hour and a half.

This webinar is part of a series focused on innovative strategies to enhance the systems that support families of individuals with intellectual & developmental disabilities.

For more details about the series, please visit supportstofamilies.org.

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Human Services
Research Institute

The Innovations Webinar Series is brought to you by the National Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities. This project is funded by the Administration on Intellectual & Developmental Disabilities, grant number ACF 90DN0298. AIDD is dedicated to ensuring that individuals with developmental disabilities and their families are able to fully participate in and contribute to all aspects of community life in the United States and its territories.

Ways to Learn More: -Webinars -CoP Listserv -Website Links

supportstofamilies.org

lifecoursetools.org

mofamilytofamily.org





THANK
YOU!!!

Jane St John
stjohnj@umkc.edu

