


Supporting Families; Charting the LifeCourse  
*Pennsylvania Family Support and Home Visiting Conference*

March 23, 2020



Setting the Stage



# What is the LifeCourse Framework?

- ⊙ A Framework developed to help people, children and families of all abilities
- ⊙ Any age or stage of life develop a vision for a good life



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## What are the LifeCourse Tools?



*How can the LifeCourse tools be useful to you in your work and useful to the families you support?*

### The LifeCourse Tools Are:

- Conversation starters
- Problem solvers
- Help us with visioning about the future
- Empower ownership of the vision
- Can be used by anyone in any setting
- Focused on all stages of the lifespan

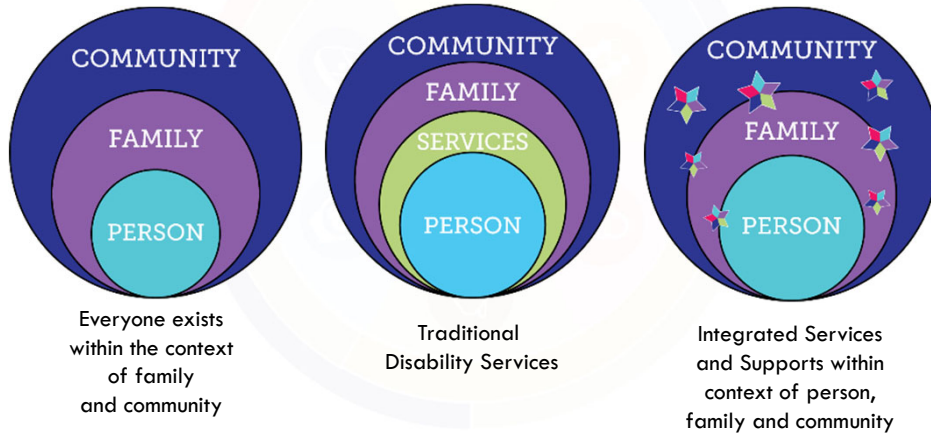
### What the LifeCourse Tools are not:

- Mandatory
- A replacement for other family engagement resources
- A substitution for Person Centered Thinking, MAPS, PATHS, Biographical Timelines or other person focused resources



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# Services and Supports are Evolving



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## 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.



# GUIDING PRINCIPLES FOR THE SUPPORTING FAMILIES LIFECOURSE FRAMEWORK



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



## Expectations (Erik Carter)

- ⊙ Expectations of professionals and parents are the strongest predictor of post-school outcomes
- ⊙ Kids exposed to high expectations
  - ★ 5x more likely to have paid community job in adulthood
  - ★ 15x more likely to have a paid job
- ⊙ Expectations shape experiences
- ⊙ Experiences shape the future



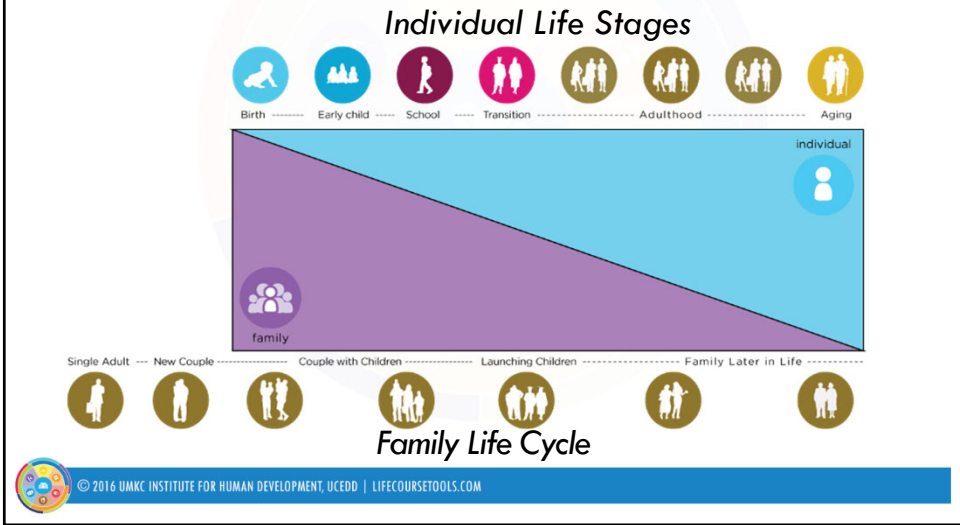
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Person Within Context  
of Family & Community



# Life Stages and Individual and Family Cycles



# Impact on All Family Members

**My LifeCourse Portfolio Crystal**

- My address is 1234 Main Street, Apt 502, Denver, CO 80202
- My phone number is 303-555-1234
- My email is crystal@denver.com
- My favorite color is purple
- My favorite food is pizza
- My favorite movie is Frozen
- My favorite book is The Secret Garden
- My favorite animal is a dog
- My favorite season is winter
- My favorite holiday is Christmas
- My favorite sport is ice hockey
- My favorite time of day is the evening
- My favorite time of year is the winter
- My favorite city is Denver
- My favorite state is Colorado
- My favorite country is the United States
- My favorite continent is North America
- My favorite planet is Earth
- My favorite galaxy is the Milky Way
- My favorite universe is the universe

**My LifeCourse Portfolio Lily**

- My dog's name is Max
- My family name is Smith
- My favorite color is pink
- My favorite food is ice cream
- My favorite movie is Disney movies
- My favorite book is fairy tales
- My favorite animal is a cat
- My favorite season is spring
- My favorite holiday is Easter
- My favorite sport is ballet
- My favorite time of day is the morning
- My favorite time of year is the spring
- My favorite city is New York
- My favorite state is New York
- My favorite country is the United States
- My favorite continent is North America
- My favorite planet is Earth
- My favorite galaxy is the Milky Way
- My favorite universe is the universe

**Life Trajectory Worksheet**

Successful Futures Career Development Personal Growth Good Health Financial Independence Clear Goals Active Involvement in Choices Mentally/Emotionally Healthy

Happy Personally Independent Educator Healthy Relationships Diverse Life Experiences Adaptable/Resilient Anticipating Open-minded Healthy

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## 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.*

o -Leonard L. Sweet



# “Good Life for All ”



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

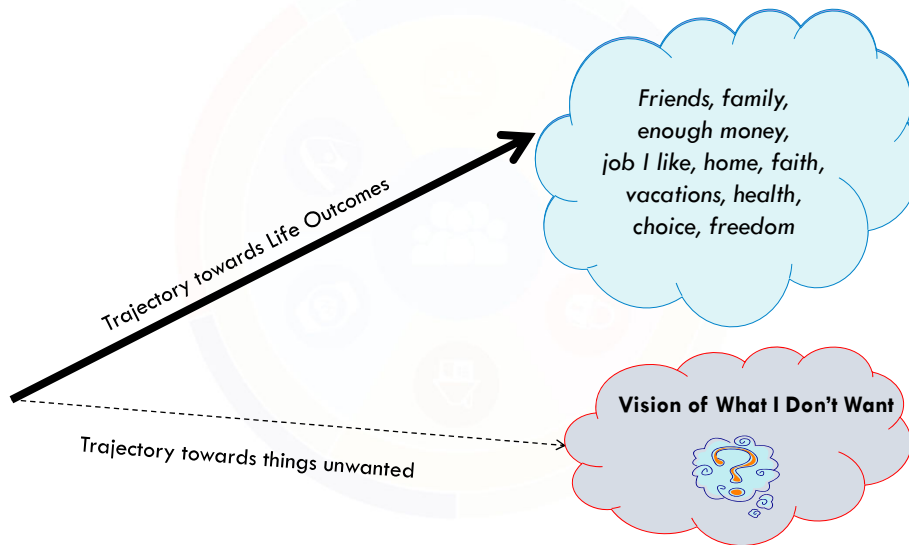


**Families** will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support all individual members to achieve their goals



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# Trajectory towards Good Life



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### CHARTING the life course

**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.

This is Joshua's "short-term" trajectory within the next 6 - 12 months.  
 Joshua's trajectory was developed by his grandmother (Lisa) after a conversation she had with (her son Larry) Joshua's father, shortly after the family was told that Joshua has characteristics similar to a child with Autism

VISION for a GOOD LIFE

I want Joshua to be able to talk to us

To tell us what he wants without throwing a tantrum

I want Joshua to have friends

I want to hear him call me daddy

What I DON'T Want



I don't want Joshua stigmatized

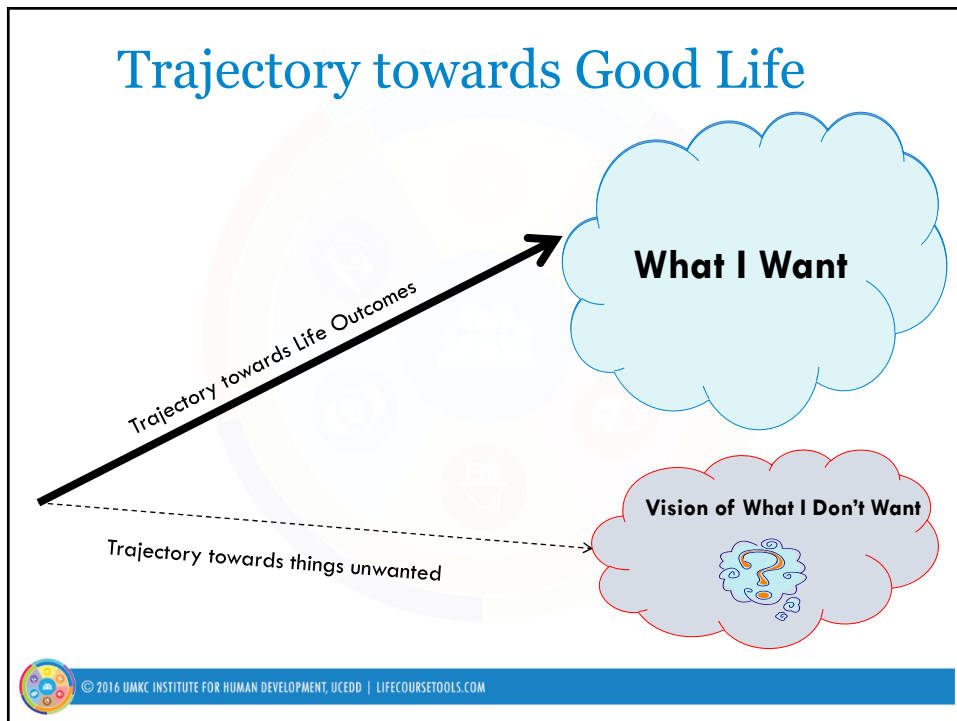
I don't want people treating him differently

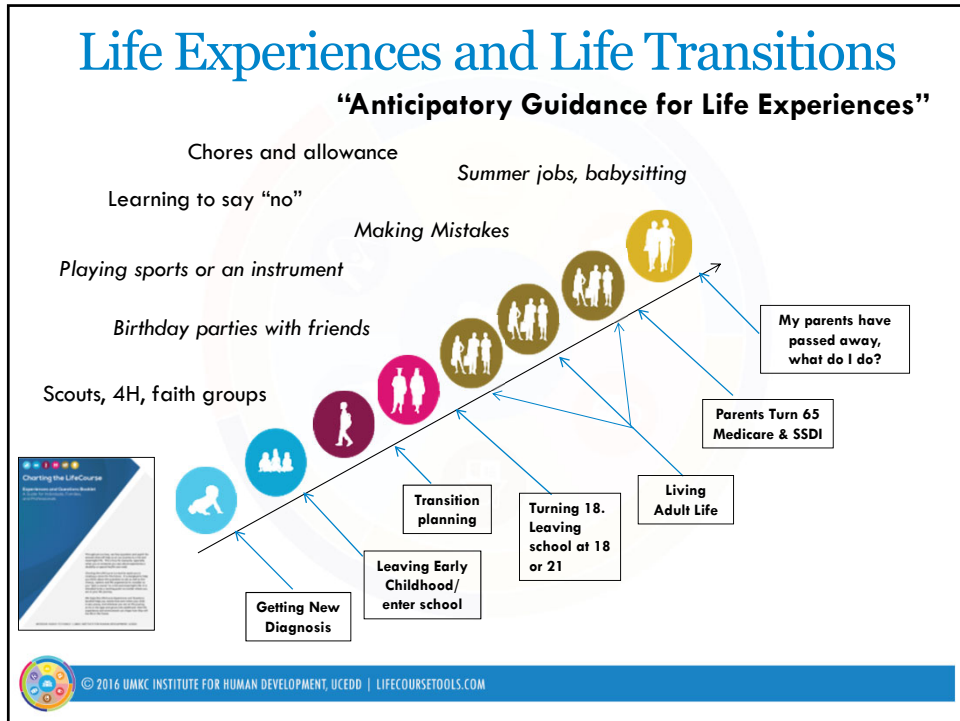
I don't want him excluded from what other kids get to do

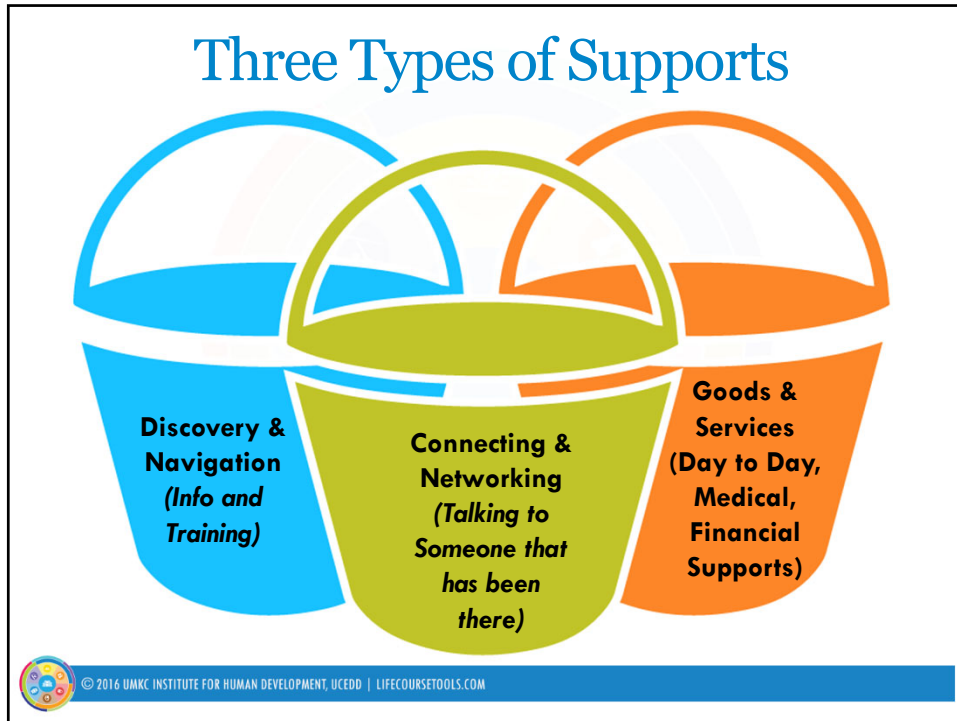
I don't want him labeled

## Joshua 3 years old







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

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## Integrated Star for Problem Solving & Exploring Options



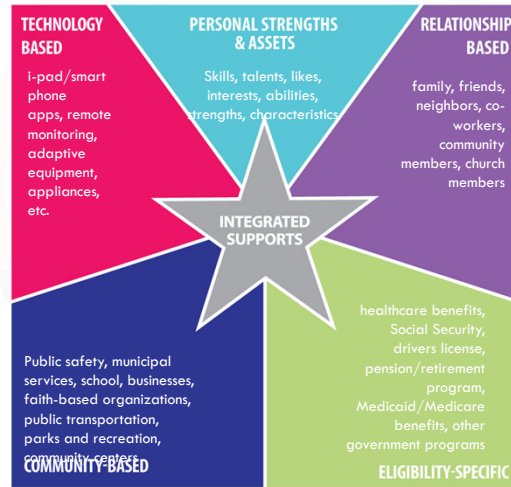
*We all use a variety of  
supports in our daily lives!*

- Relationships
- Technology
- Community
- Personal assets and strengths
- Eligibility based supports and services





# Integrated Supports Star



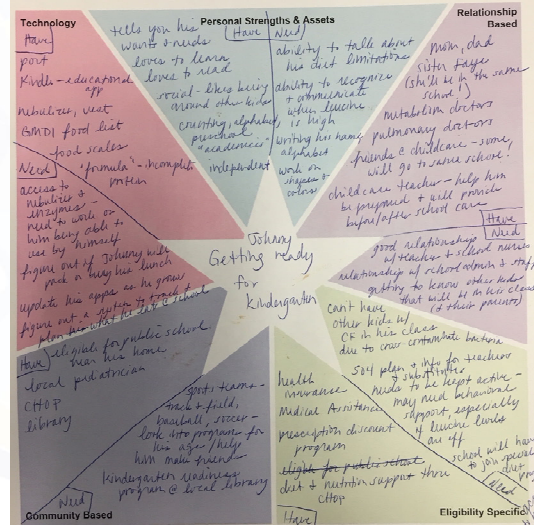
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## Johnny



### 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.



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Access the LifeCourse framework and tools at [lifecoursetools.com](http://lifecoursetools.com)

**pennsylvania** DEPARTMENT OF HUMAN SERVICES  
BUREAU OF EARLY CHILDHOOD, YOUTH & FAMILY SERVICES  
mydcp.org

**PA Family Network**  
Supporting families throughout the lifecycle

Developed by UMKC HD, UCEDD, [lifecoursetools.com](http://lifecoursetools.com) | AUGUST 2016  
DH 1000 1016

## LifeCourse in Action

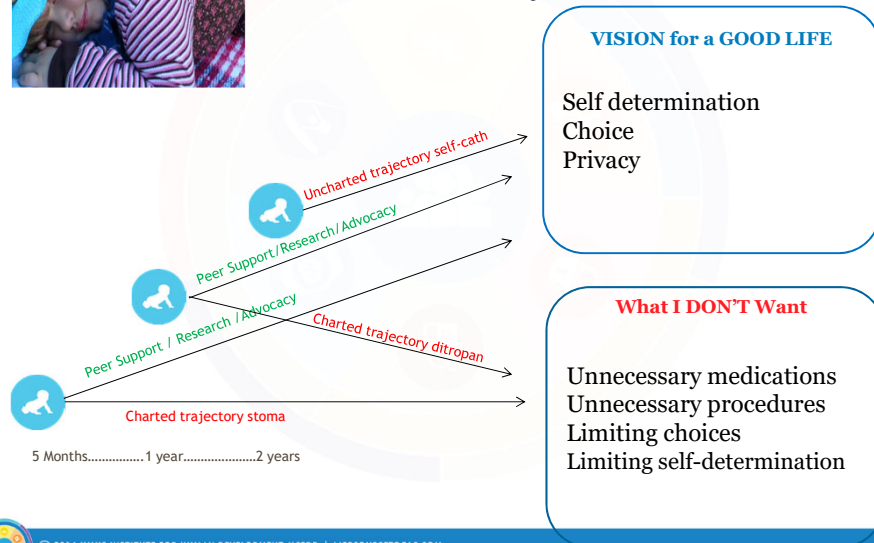
- Prepare for IFSP/IEP meetings
- Problem Solving
- Working on self-directing or self-determination skills
- Exploration & Planning



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## Elizabeth's Health Trajectory As Told by Her Mother



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### 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

CHARTING the life course

OCTOBER 2015

## Elizabeth, age 6

## Elizabeth's Life Trajectory

**Life Trajectory Worksheet**

**Past Life Experiences**  
LIST past life experiences and events that supported your vision for a good life.

Community involvement  
- Ball, Tennis, Dance, skate park, park church, school, skiing  
Media exposure  
- Bathroom giveaway  
- Ability expo  
Public Speaking  
- Fundraiser  
Birthday Parties  
Family Activities  
- Fl, WI, WI  
- Cousins

**Future Life Experiences**  
LIST current/ future life experiences that continue supporting your good life vision.

Go to college  
Get involved in robotics  
Advocacy apps  
Leadership

**What I DON'T Want**  
LIST the things you don't want in your life...

People to think I can't do something just because I use a wheelchair

**VISION for a GOOD LIFE**

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

Be a mom  
Be a scientist  
Live in Wisconsin  
Go to the beach

Write current age in the STAR

★ 5

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

Assumptions of medication  
mobility  
dependence

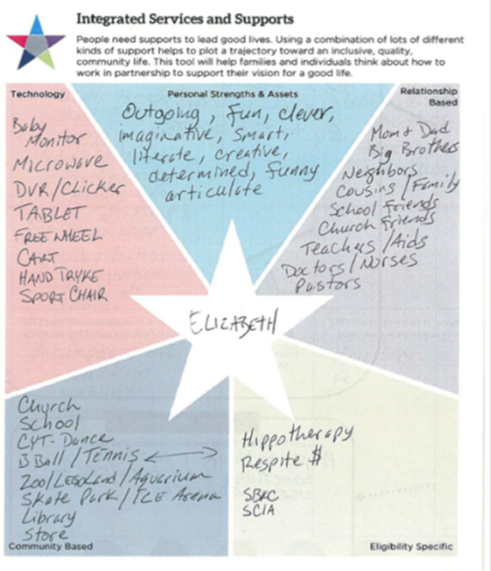
**LIST life experiences to avoid because they push you toward things you don't want.**

Isolation  
Feeling left out

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UGEDD

Oct 2015

August 2015



**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**  
Baby Monitor  
MICROWAVE  
DVR/Clicker  
TABLET  
FREE WHEEL  
CARAT  
HAND TRAY  
SPORT CHAIR

**Personal Strengths & Assets**  
Outgoing, Fun, clever, imaginative, Smart, literate, creative, determined, Funny, articulate

**Relationship Based**  
Mom + Dad  
Big Brothers  
Neighbors  
Cousins / Family  
School Friends  
Church Friends  
Teachers / Aids  
Doctors / Nurses  
Pastors


**Community Based**  
Church  
School  
CYT - Dance  
B Ball / Tennis  
Zoo / Legoland / Aquarium  
Skate Park / Ice Arena  
Library  
Store

**Eligibility Specific**  
Hippotherapy  
Respite \$  
SBXC  
SCA

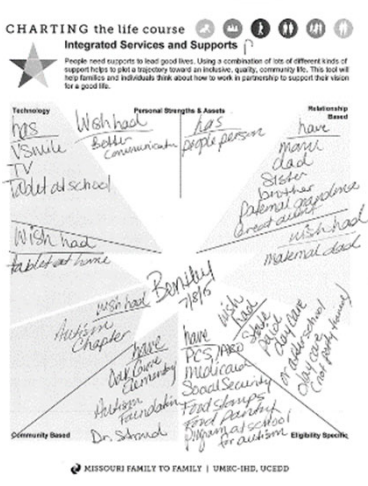
ELIZABETH

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD | OCTOBER 2015

## Elizabeth's Integrated Star: Mapping Supports



## 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**  
nos  
PS/able  
TV  
tablet at school  
wish had tablet at home

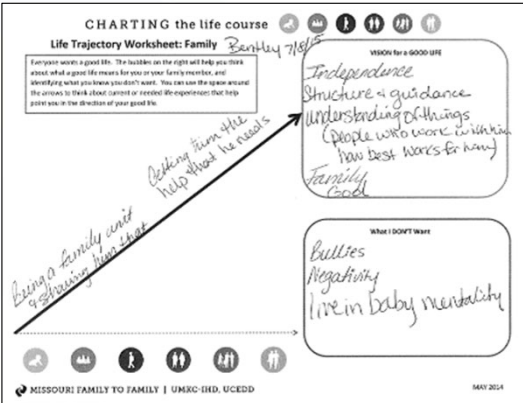
**Personal Strengths & Assets**  
wish had better communication skills  
have people person  
mom + dad  
sister  
brother  
paternal grandparents  
great aunts  
wish had maternal dad

**Relationship Based**  
wish had Bentley help  
have  
mom + dad  
sister  
brother  
paternal grandparents  
great aunts  
wish had maternal dad

**Community Based**  
wish had Bentley help  
have  
mom + dad  
sister  
brother  
paternal grandparents  
great aunts  
wish had maternal dad

**Eligibility Specific**  
have  
mom + dad  
sister  
brother  
paternal grandparents  
great aunts  
wish had maternal dad

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD



**CHARTING the life course**  
**Life Trajectory Worksheet: Family Bentley 7/8/16**  
Everyone wants a good life. The bubble 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 steer 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 ways for him)  
Family  
Good

**What I DON'T WANT**  
Bulles  
Negativity  
live in baby mentality

Being a family unit  
a supporting team that  
helping him with  
help that he needs

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

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**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.

**Steps To Take:**  
 Look into ABA therapist for home  
 Research social activities to engage w/ other kids more  
 Talk to doctor/therapist about other foods/resources/services that will be beneficial for diet  
 Find resources for potty training and introducing new foods  
 School is linking to ABA therapist for school  
 Enjoying school! seems to want to go  
 \* it is using more words to request things, not just echolalia  
 IEP in place - 1hr of speech therapy, 50 mins a week  
 Raiser Prechool 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

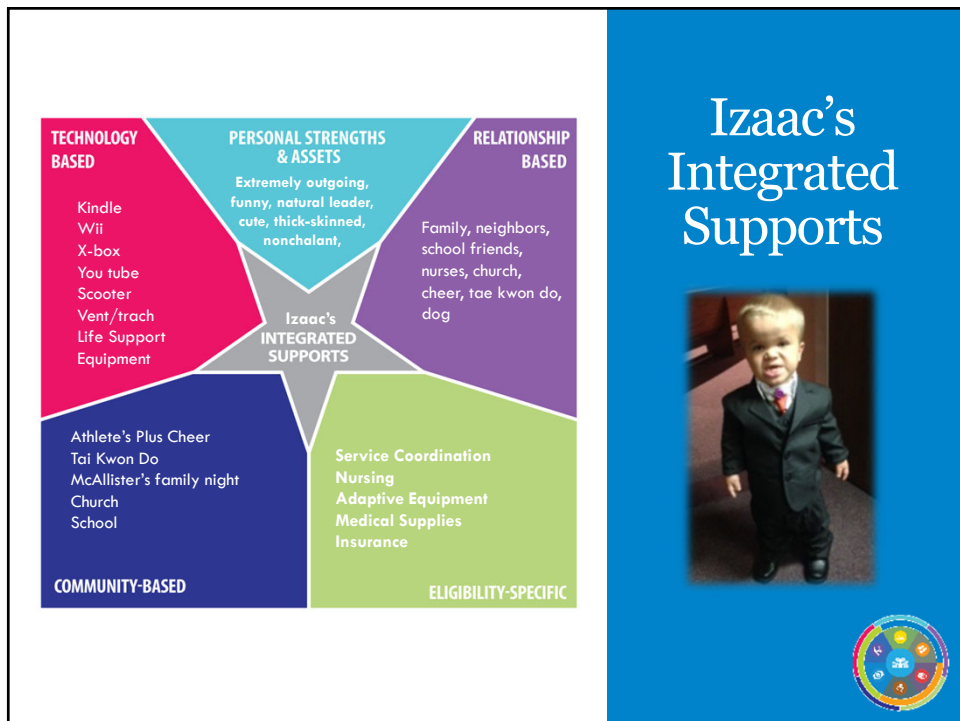
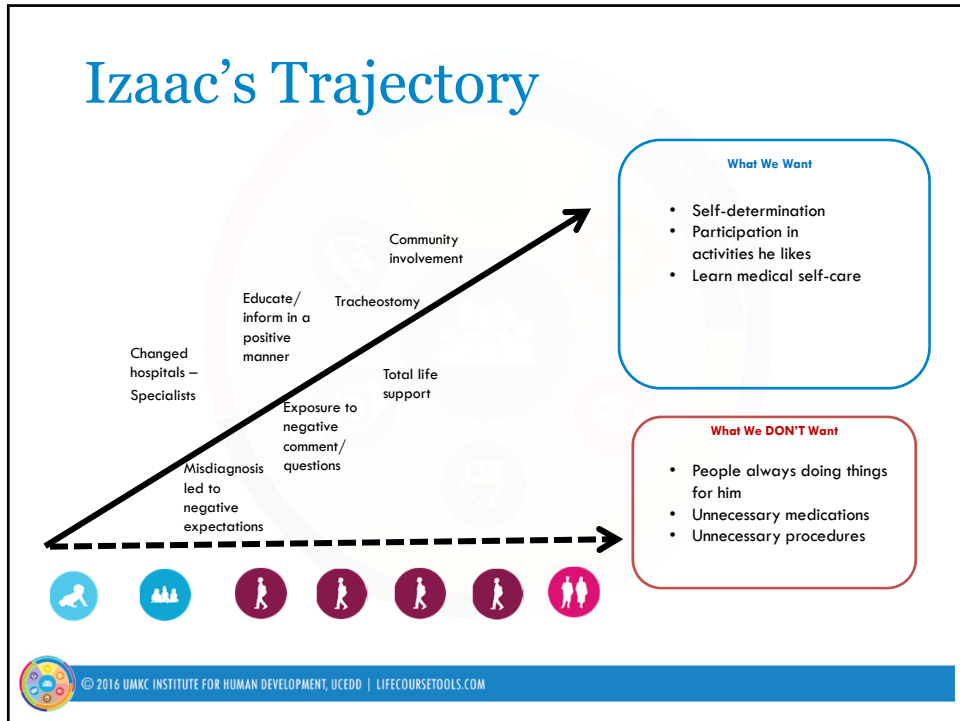
**What I DON'T Want**  
 In a segregated classroom  
 Not able to talk at all, regression in skills  
 Bullied or taken advantage

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

**How the Story Began: Izaac**



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



# Izaac's Integrated Supports

# LifeCourse Tools

# LifeCourse Educational Materials



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

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## 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 vital contact with the state developmental disability systems a more person- and family-centered experience. Staff from the state Intellectual and Developmental Disabilities (IDD) 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 IDD and their families and to serve as a no wrong door to other supports.



**MISSOURI**  
Missouri Department of  
Developmental  
Disabilities

**TENNESSEE**  
Tennessee Department of  
Intellectual &  
Developmental Disabilities

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

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(888) 407-5039

**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](http://supportstofamilies.org).



HOSTED BY



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-920620A. IJED is dedicated to ensuring that individuals with developmental disabilities and their families are able to fully participate 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](http://supportstofamilies.org)  
[lifecoursetools.com](http://lifecoursetools.com)  
[mofamilytofamily.org](http://mofamilytofamily.org)





THANK  
YOU!

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