



# *Charting the LifeCourse Path to the Good Life*



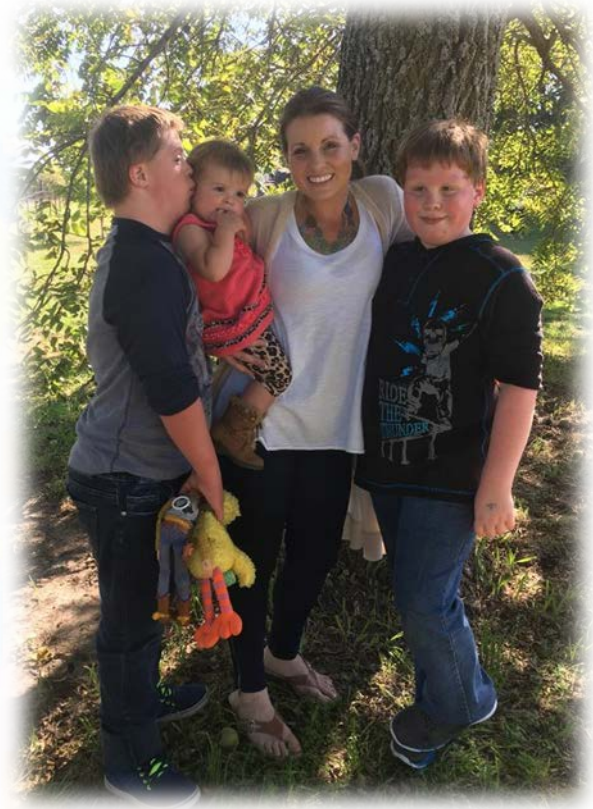
# About Our Organization

- ⊙ Housed at UCEDD/LEND with longstanding focus on Family Support, Self-Advocacy and Self-Determination
- ⊙ State and National Systems and Policy Change
- ⊙ Statewide Family Resource Center, Family-to-Family HIC, for over 25 years, with evolving and on-going statewide partnerships



# About Crystal ...

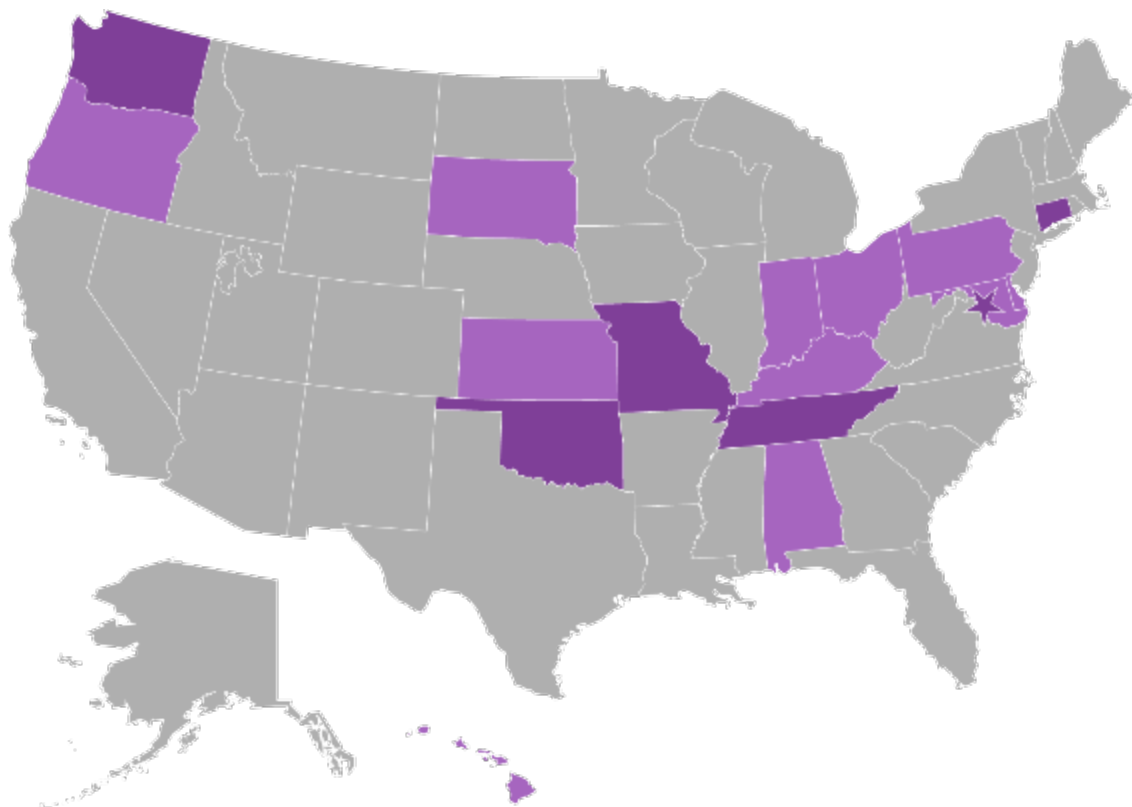
- Mom to Peyton, Conner and Lilly
- Missouri Family to Family  
-Coordinator
- UMKC-IHD  
-Family LifeCourse Specialist
- CtLC Certified Trainer
- AMCHP  
-Family Delegate
- Partners in Policymaking  
Graduate



MISSOURI  
FAMILY TO FAMILY  
UMKC INSTITUTE FOR HUMAN DEVELOPMENT | UCEDD

**UMKC** INSTITUTE FOR  
HUMAN DEVELOPMENT  
A University Center for Excellence in Developmental Disabilities





# 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.



# Funded in 2012 by



# National Partners

NASDDDS



SIBLING  LEADERSHIP NETWORK

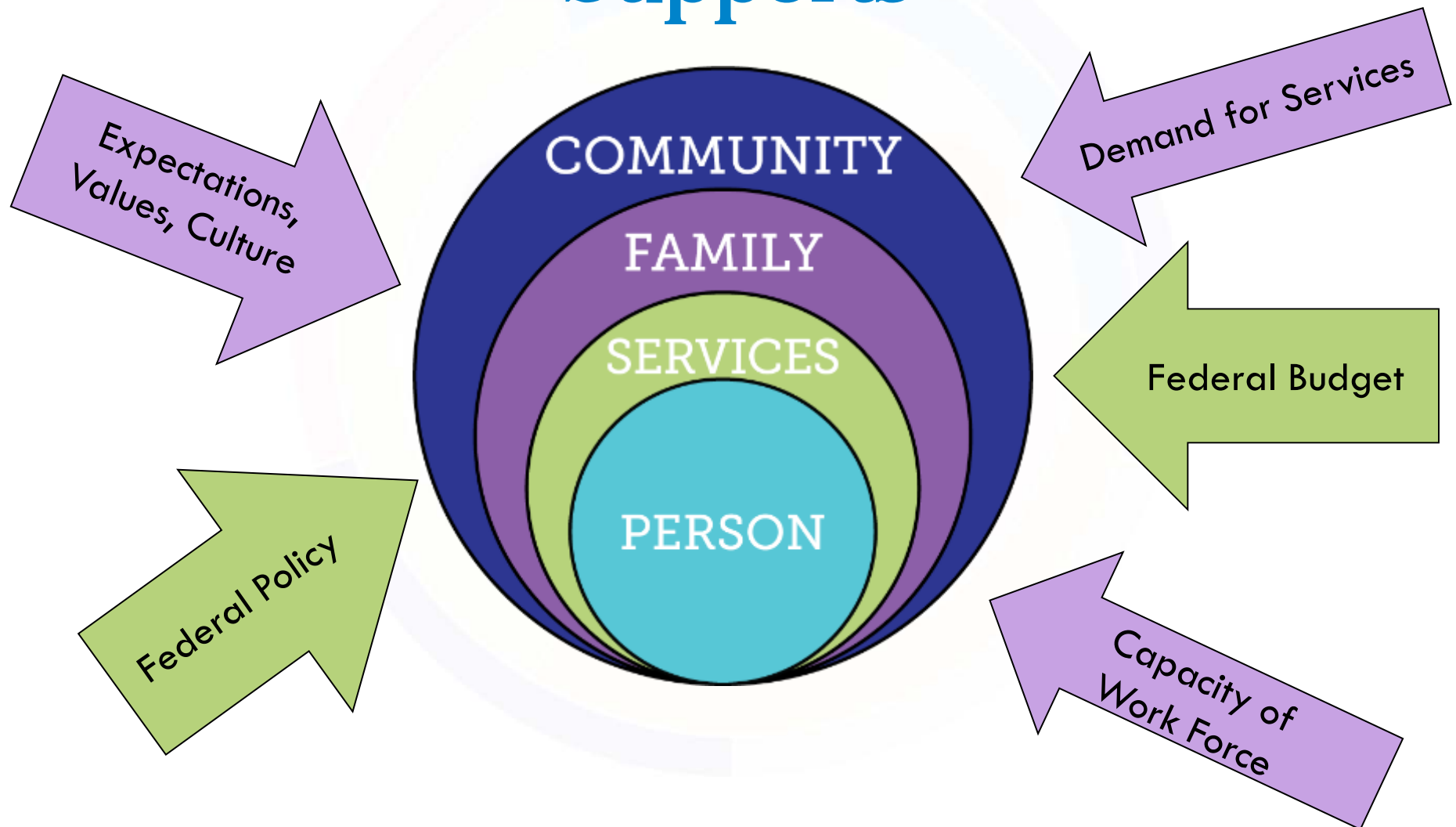




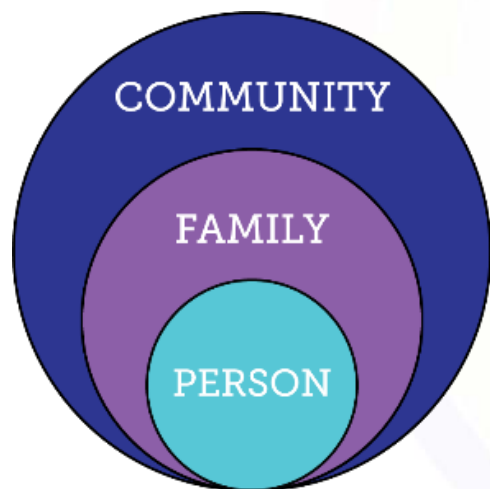
# Setting the Stage



# Current Reality of Services and Supports



# Services and Supports are Evolving



Everyone exists within the context of family and community



Integrated Services and Supports within context of person, family and community enables us to serve The ALL



Traditional Disability Services wrap supports around a person



# 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*





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





# Guiding Principles of the Supporting Families LifeCourse Framework

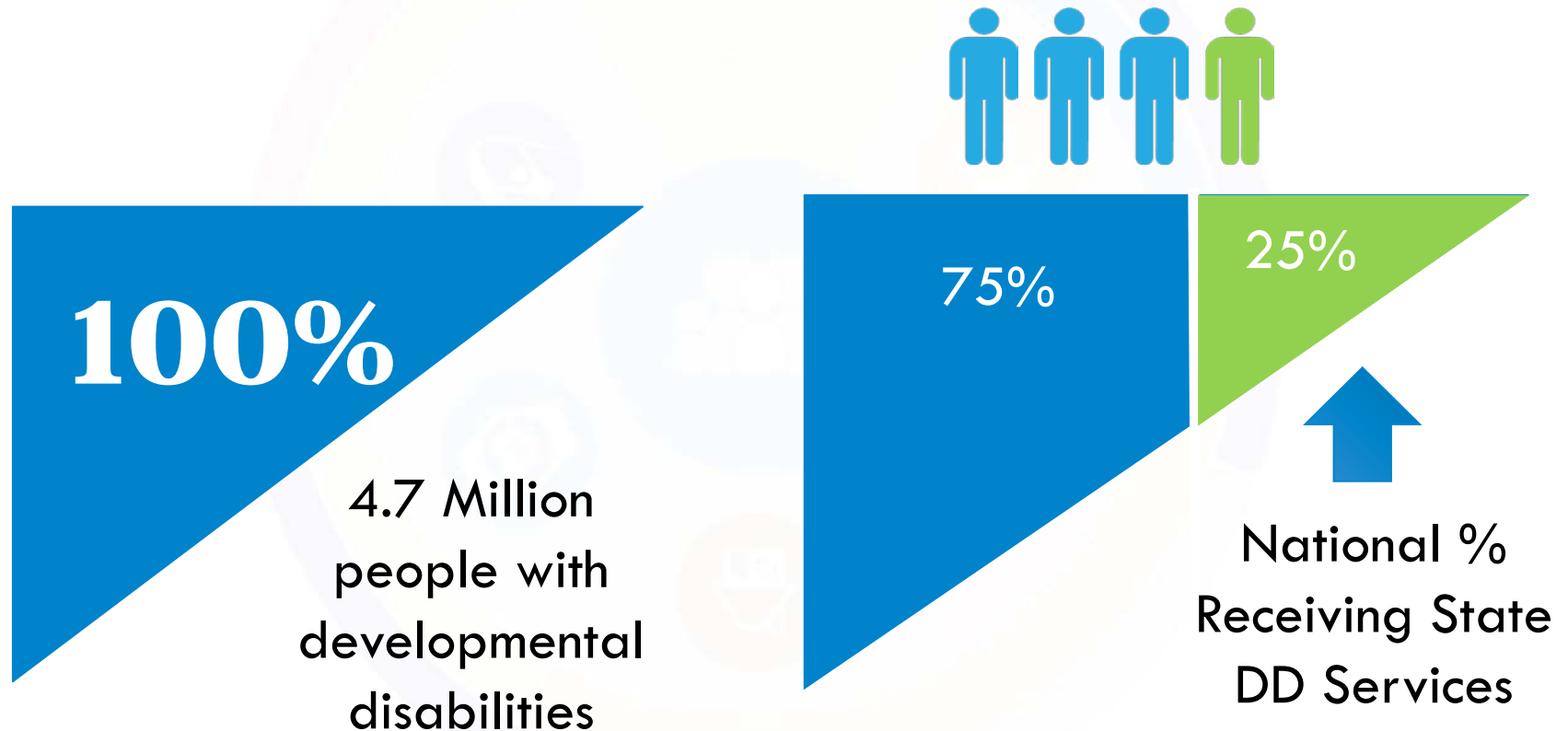




# ALL People



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

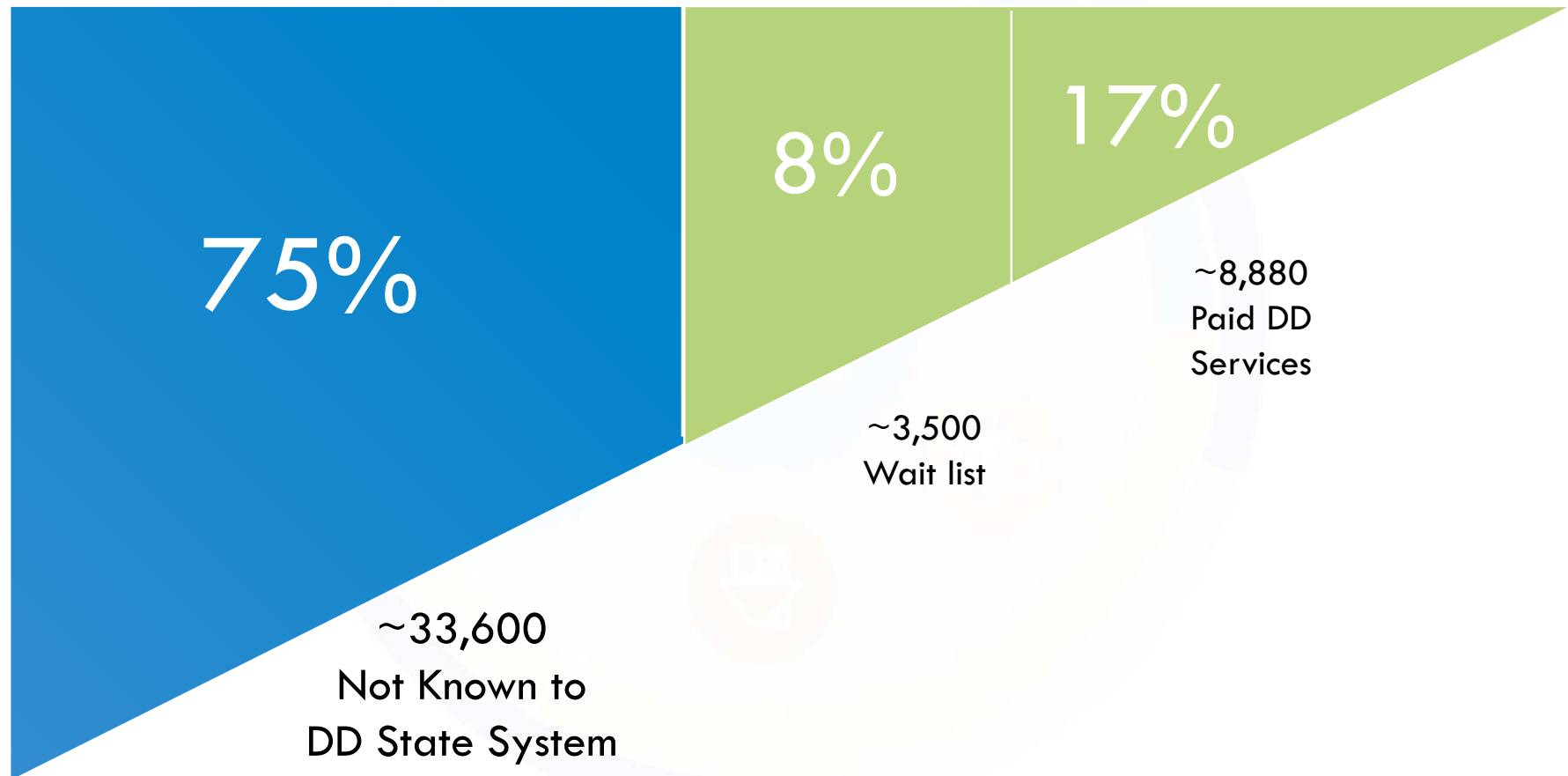


**\*\* Based on national definition of developmental disability with a prevalence rate of 1.49%**



# Kansans Living With DD

45,978 estimated people in Kansas living with Developmental Disabilities\*



\*Based on 1.58% prevalence of 2.92 million citizens, US Census (2015)





# Person Within Context of Family and 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



# Lifelong Impact of Family on Individual

**Biologically:**  
Likes,  
dislikes, skills,  
abilities



**Socially: Family & friend  
network, community**



**Environmentally:**  
Neighborhood,  
socio-economic,  
education

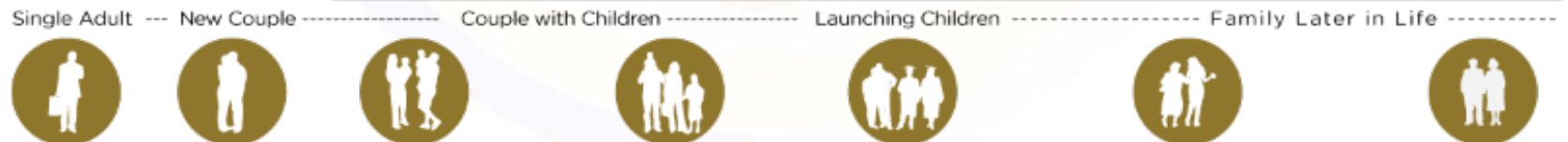


**Policy: Dreams,  
Aspirations,  
House rules,  
cultural rules, expectations**



# Life Stages and Individual and Family Cycles

## *Individual Life Stages*



## *Family Life Cycle*





# 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)*





Aging Parents

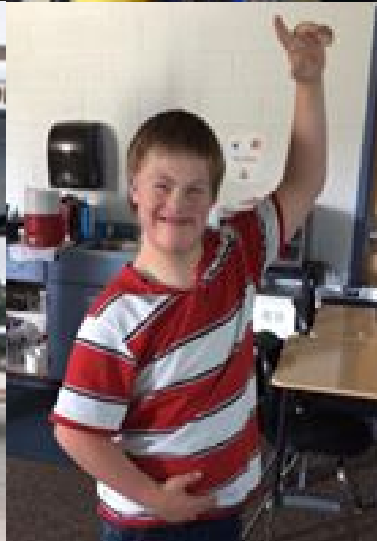
Siblings with  
Disabilities

Children

# Siblings: The 'Club Sandwich' Generation

Siblings often juggle multiple roles for support and caregiving, which can seem overwhelming





Good Life, Vision, Trajectory,  
Life Stages and Experiences



# What is YOUR Vision for a Good LIFE?

**Vision of What  
I Want for a Quality of Life**



# Vision for a Good Life

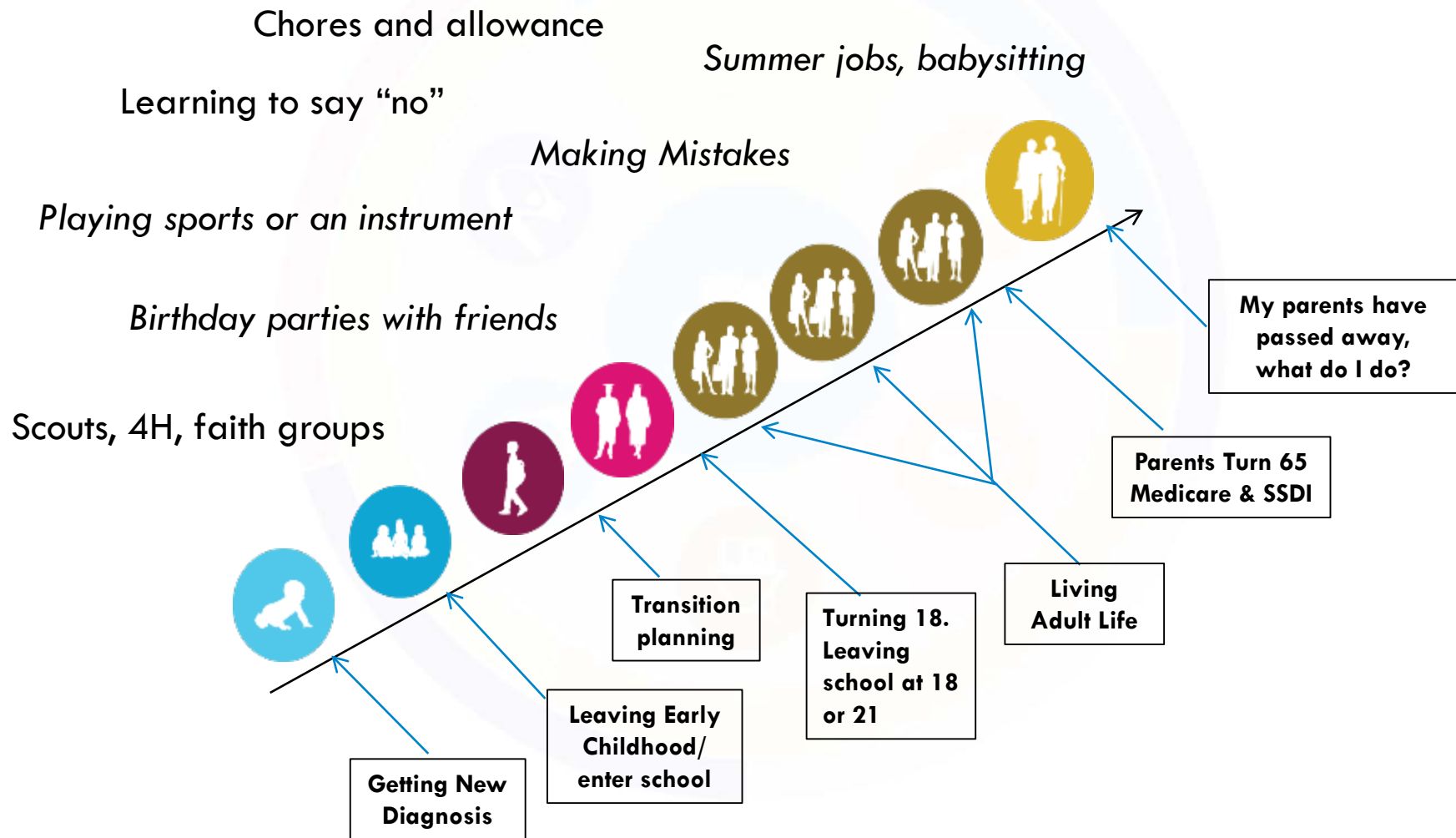


*The future is not something we enter.  
The future is something that we create.  
And creating that future requires us to  
make choices and decisions that begin  
with a dream.*

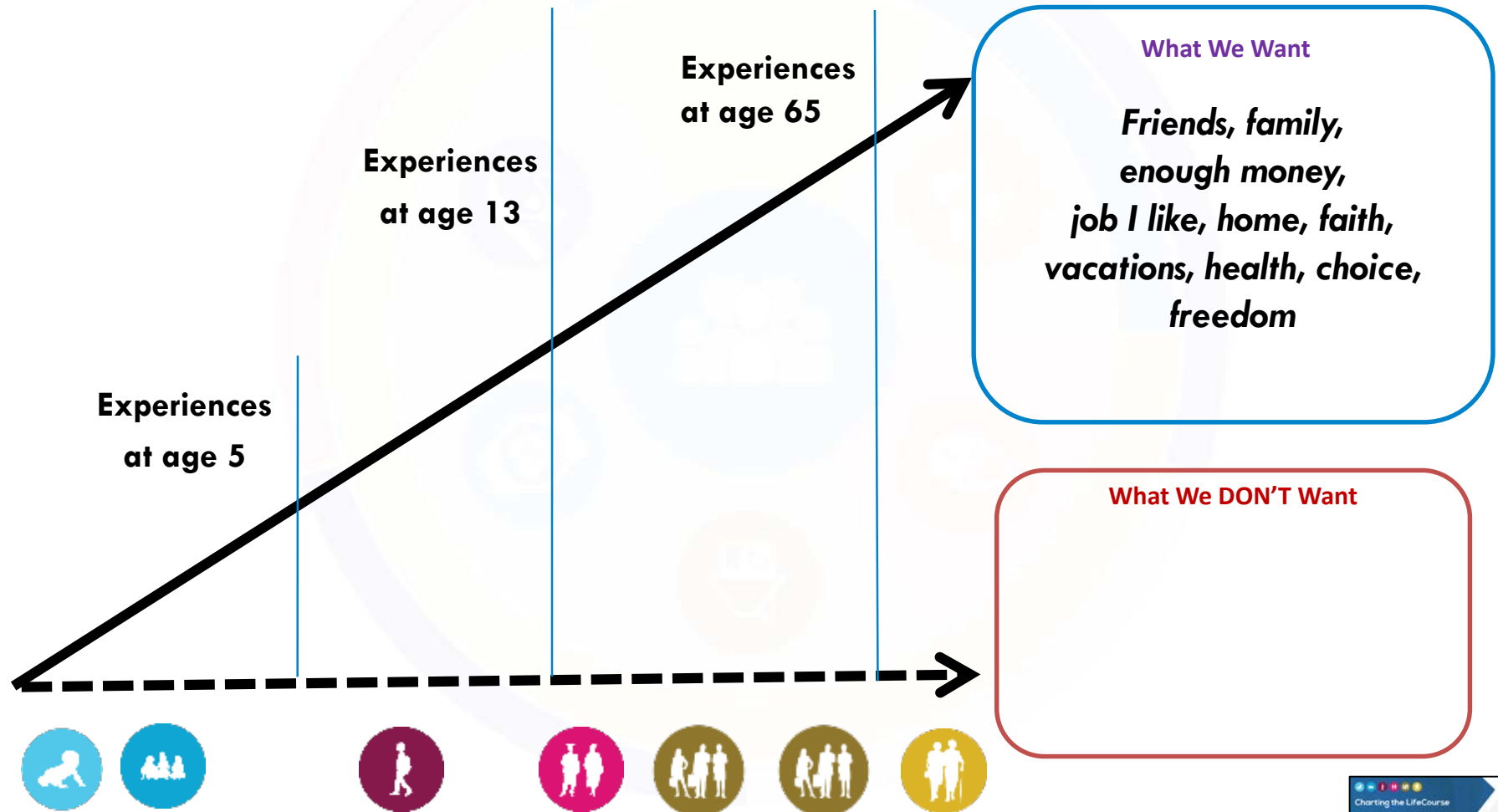
*-Leonard L. Sweet*



# Life Experiences and Life Transitions



# Life Experiences = Life Outcomes



# 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





# 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 )

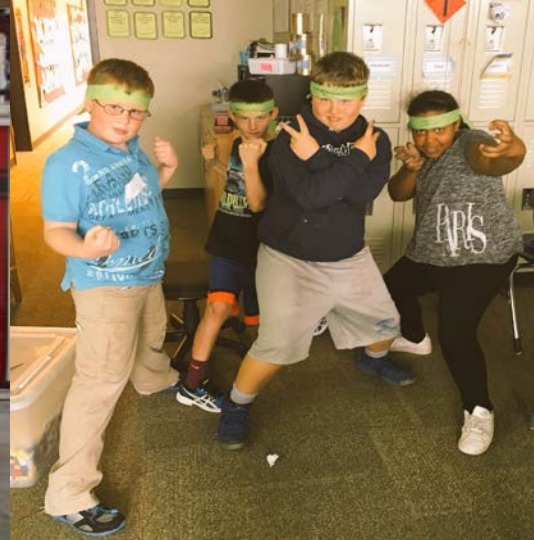


**Social and Spirituality**  
(friends, relationships, leisure activities, personal networks, faith community)



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

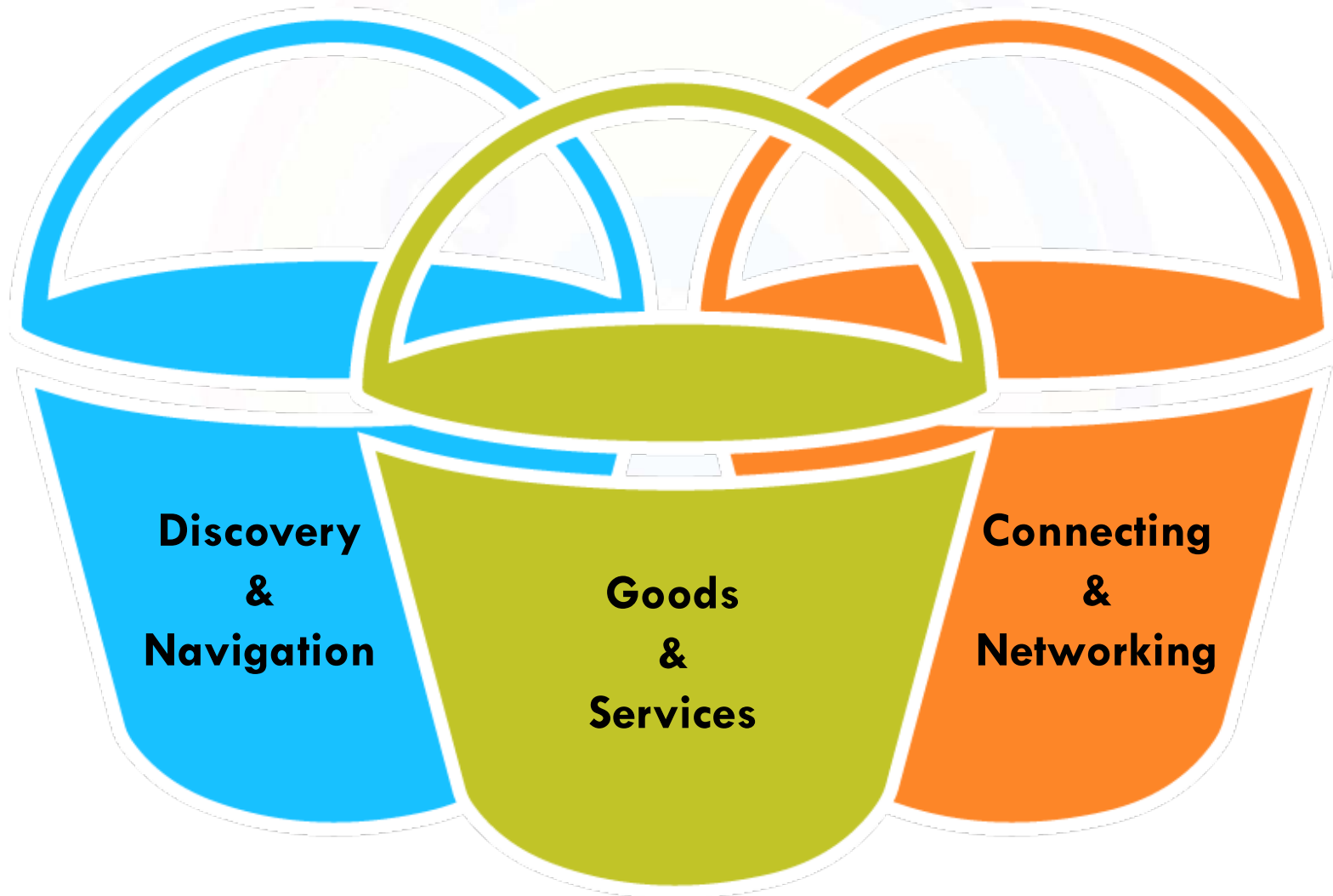




# Integrated Star for Problem Solving & Exploring Options



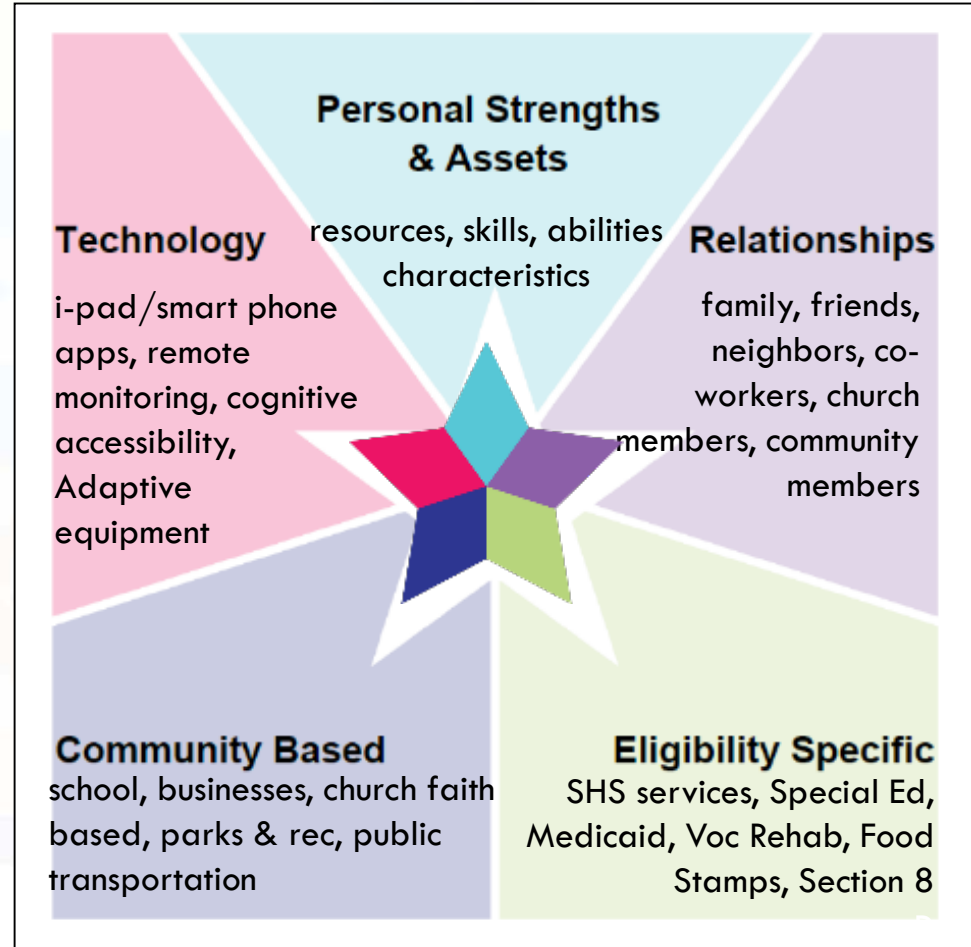
# Three Types of Supports



# LifeCourse Integrated Supports STAR



100%





Brighter Futures, Positive Trajectories  
and Transformational Family Change



# Before Charting the LifeCourse

## CHARTING the LifeCourse

### Integrated Supports



Technology

TV  
Microwave  
Internet  
Computer

Personal Strengths & Assets

Car  
Resilient

Relationships

Gma > 2 hrs away  
Gpa

Gma > 6 hrs. away  
Gpa

1 mom w/ another  
child w/ special  
needs

Bell  
Family

Bureau of Special  
Healthcare Needs  
Special  
Education

Medicaid  
SSI  
Food Stamps  
Section 8  
Pell Grants  
Special Olympics

Sometimes Church  
Movies  
School

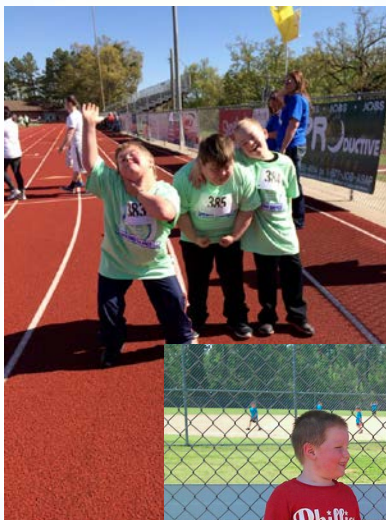
Community Based

Eligibility Specific

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

Developed by the UMKC Institute for Human Development, UCEDD. More tools and materials at [lifecoursetools.com](http://lifecoursetools.com)

MAY 2016



# Before Charting the LifeCourse

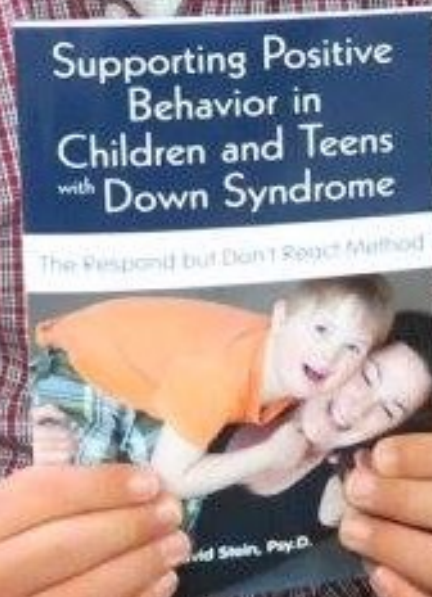


**FEAR**



# Peyton's Plan for Inclusion in School

Using the  
LifeCourse Tools to  
Transform the Way  
the School Thinks  
about Inclusion for  
Peyton



# Transformational Changes in Thinking

**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 that goal.

**Life Trajectory Worksheet**

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

- Being included in areas that work for me
- Being given time to warm up to people/situations
- Trying different ways to help me learn
- People having patience giving me time to communicate in my own way
- Riding the Reg. Ed. bus with my brother and now on my own
- Participating in gen. ed. classes and after school programs
- Giving me choices so I can feel successful and a part of a team
- Immediate consequences/rewards for my actions
- Giving me choice over things in my life
- Learning how to take care of my own needs

**Future Life Experiences**  
LIST current/ future life experiences that will continue supporting you.

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

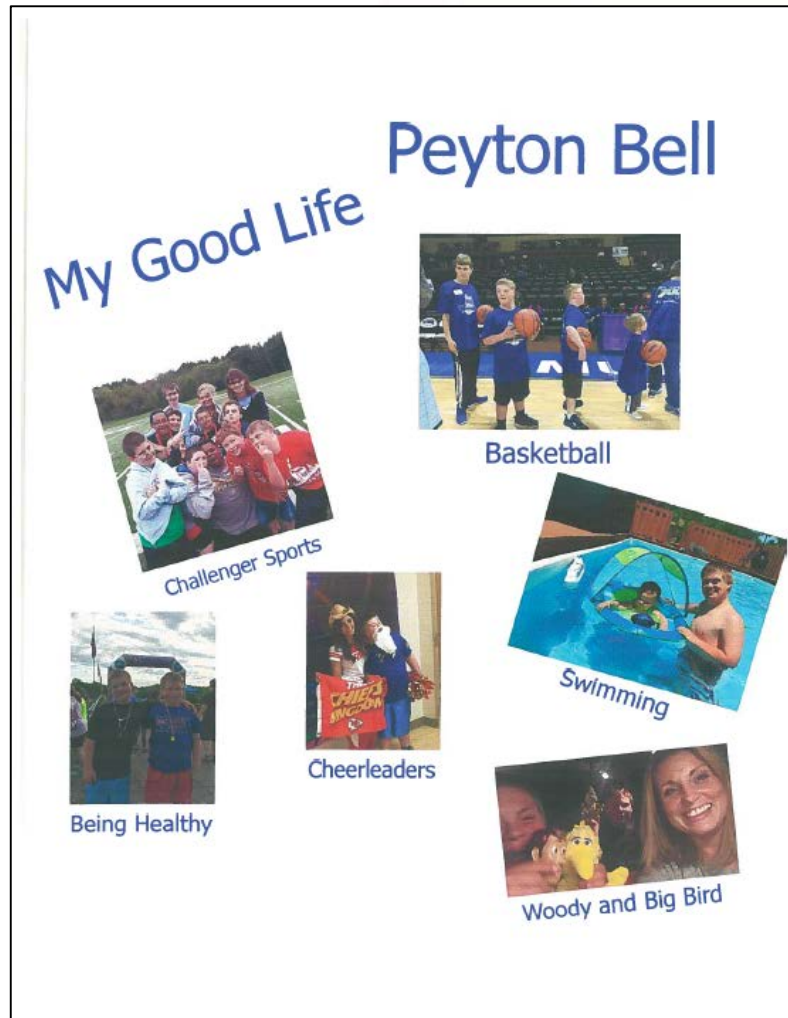
- Unfulfilling/underpaid employment/sheltered workshop
- Group home/no choice in living
- Predetermined schedule/ no choice
- Unhealthy/illness
- Dependence on paid support
- Poverty
- Loneliness
- Boredom
- Being controlled/choices made for me

**Payton**  
18-19 school years  
Write current age here  
**13**

**Missouri**



# Transformational Changes in Thinking



# A GOOD *LIFE*!!!



# A GOOD ***LIFE!!!***

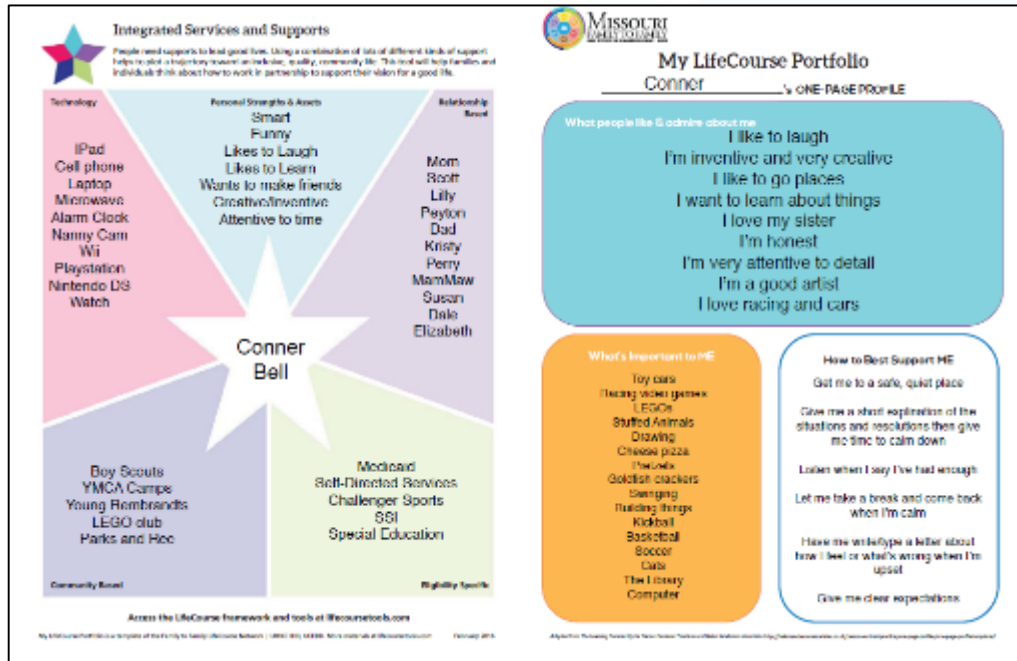




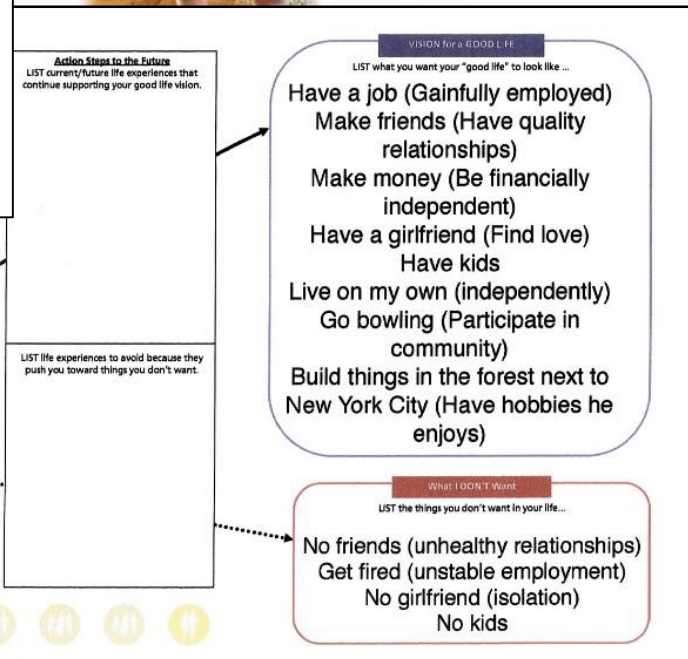
# The Gift of Self-Advocacy



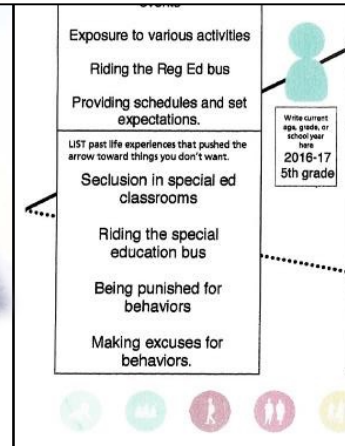
# Conner's Journey



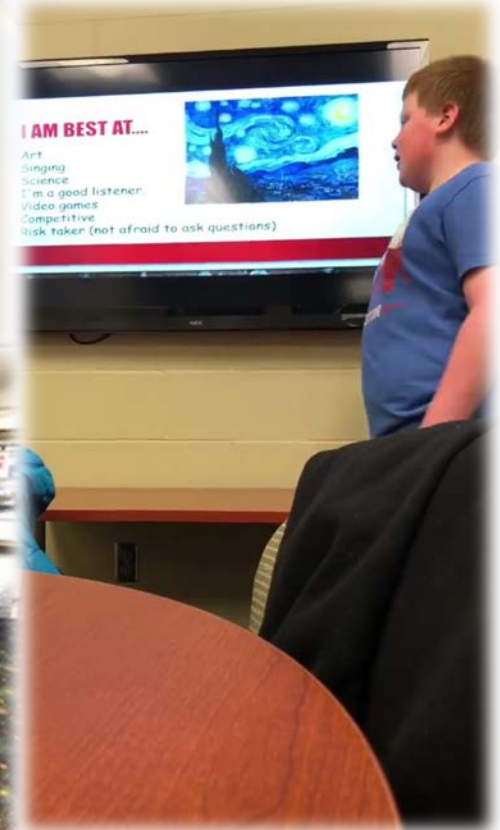
## Discovery



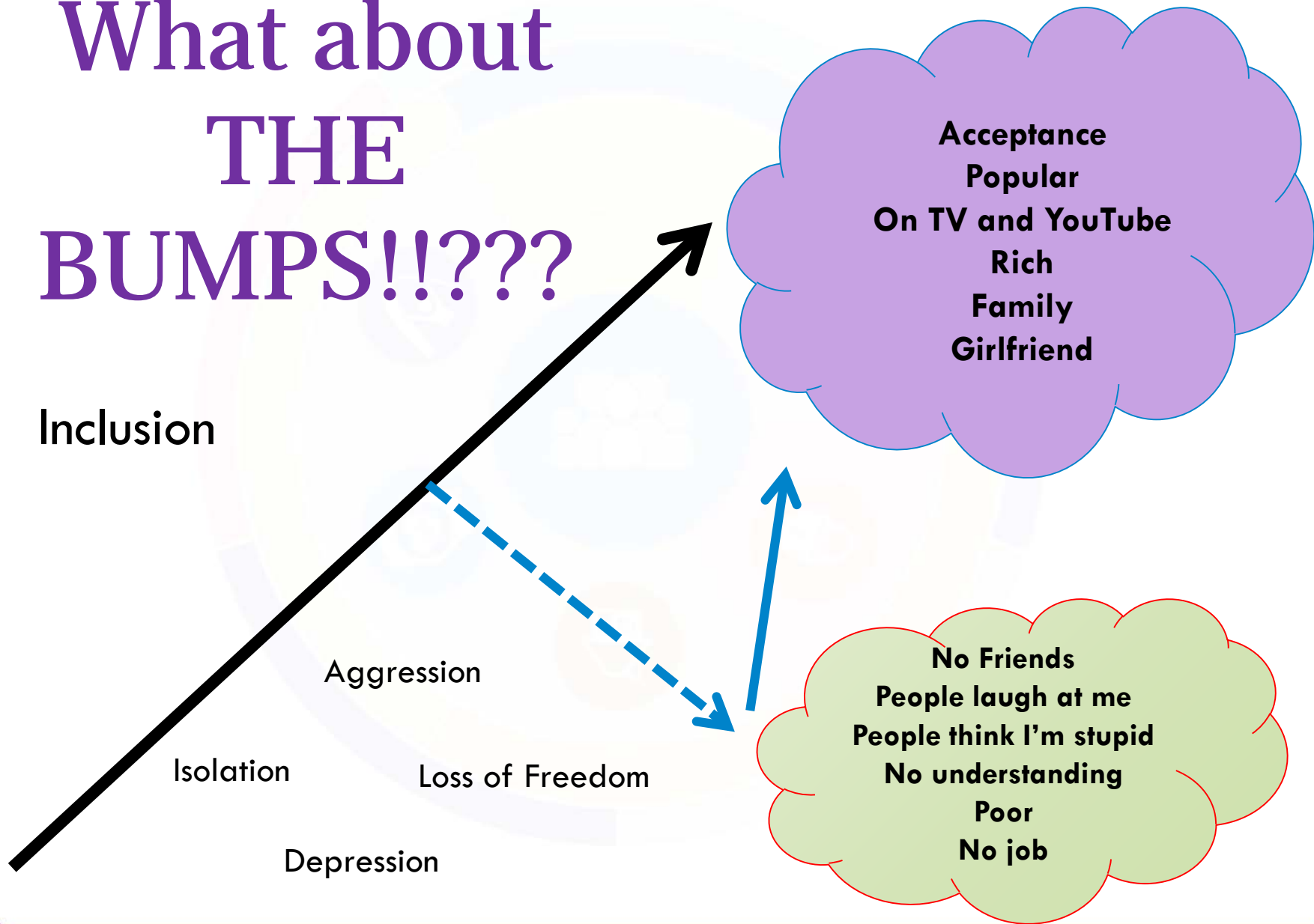
## Self-Advocacy




# A GOOD *LIFE!!!*



# What about THE BUMPS!!???



# Everyone has a different path

**CHARTING the life course**  **Integrated Services and Supports**

People need supports to lead good lives. Using a combine 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.

**Technology**

- Genuinely nice
- Very clear
- Good w/ kids - good at babysitting
- Has a job!!
- Funny
- Will help anybody

**Personal Strengths & Assets**

- Very talkative
- John Fletcher
- Phone
- Facebook
- Messenger
- SnapChat
- YouTube Chat
- Has to pay friend gas to get to work → depends on others to get to work or doctor
- Doctor
- Uncle D's (job)
- No Medicaid
- Used to mow lawns for extra money in his neighborhood.
- Community Based
- Support Coordination
- Eligibility Specific

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

Name: Daniel Kirk  
Today's date: 11/30/2018

**Life Trajectory Worksheet: In 6 years.**

I will be a train conductor at a major railroad

\* I will develop a resume and practice interview skills during the final year of my certification program.

\* I will apply after Propel to a 2-year BNSF certification NAR program to be a train conductor.

\* I will contact Vocational Rehab for possible skills building workshops or courses to enroll in BNSF.

\* I will volunteer at Union Station model railroad every other week.

\* I will explore volunteer opportunities at Union Station and the community in the next month.

**What I WANT**

- Inclusion – I want to be valued on my job
- Diversity – a job that is open to diversity to foster a healthy environment
- Acceptance – a job that embraces me and my knowledge and skills

**Conditions (MUST have):** Accommodations and supports I need to do my job

**Preferences (would LIKE to have):** I would like to have an employment counselor

**Support Needs (things that will help you be successful):** At least 2 hours a week job shadow onsite support and computer access, family and friends

**What I DON'T Want**


- To be disrespected
- To be taken for granted
- To be underestimated
- Underpaid
- Discriminated against

**Barriers to quality employment**

- \*Negativity and low expectations
- \*Being at a job that isn't inclusive
- \*Not believing in my abilities
- \*Taking away or limiting my rights

**UP possible steps and people that can help you to achieve "What I Want" ABOVE the line**

**DOWN possible steps and people that can help you to AVOID because they might result in things you don't want**

**CHARTING the LifeCourse** 

**Integrated 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.

**Personal Strengths & Assets**

- I have choices and responsibilities at home and at college.
- I am able to communicate my needs.
- I am a hard worker.
- I am resource oriented.
- I am imaginative, loving, loyal and compassionate.
- I'm a quick learner.
- I have a great memory for facts.

**Relationships**

- Personal contact with ECHO.
- Share decisions with my family.
- Developing a group of friends in college.
- Close family and a small network of friends.
- Work with my family, neighbors and friends to do odd jobs for our HOA.

**DAVID KIRK**

**ACR Challenges**

- Member at Union Station Ohio Railroad
- Go to Mid-Carroll Library
- Go to Kansas City Zoo
- Go to Worlds of Fun
- Special Olympics: Bowling
- The White Pines 10th Voice Choir
- Volunteer at Harvesters
- Attend Church games
- Service Coordinator M&O – Janet Thomas
- Atkins Autism Social Group
- Joshua Neurological Center Social Skills Class
- Vocational Rehabilitation or Independent Living Center
- Special Needs Trust
- Career Center in my area for job interview and skills assessment
- Autism Society of the Westland

**Community Based**

**Eligibility Specific**

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Developed by the UMKC Institute for Human Development, UCEDD. More facts and information at [lifecoursetools.com](http://lifecoursetools.com) MAY 2018





# Impacting ALL



# Impact on All Family Members



## My LifeCourse Portfolio

Lilly's

ONE-PAGE PROFILE

### Integrated Services and Supports

People need supports to lead good lives. Using a combination of lots of different kinds of supports is the best way to get a trajectory closer to feeling, quality, community. As the tool helps families and individuals think about how to work in partnership to support their goals for a good life.



### Life Trajectory Worksheet

**Real Life Experiences**  
LST and life experiences are events that supported your vision for a good life. Acknowledging and responding to my own, others', and society's role in this.

**Future Life Experiences**  
LST can help future life experiences that continue supporting your good life vision. -Wishes to the family to maintain current member -Positive strategies for the car, not

#### VISION for a GOOD LIFE

LST: what you want your "good life" to look like...

- Happy
- Financially Independent
- Educated
- Friends
- Healthy Relationships
- Positive Life Experiences
- Balanced/Adaptable
- Accepting/Open-minded
- Independent
- Healthy

#### What I DON'T Want

LST: the things you don't want in your life...

- Lonely
- In Poverty
- Financially dependent on government/parents

#### VISION for a GOOD LIFE

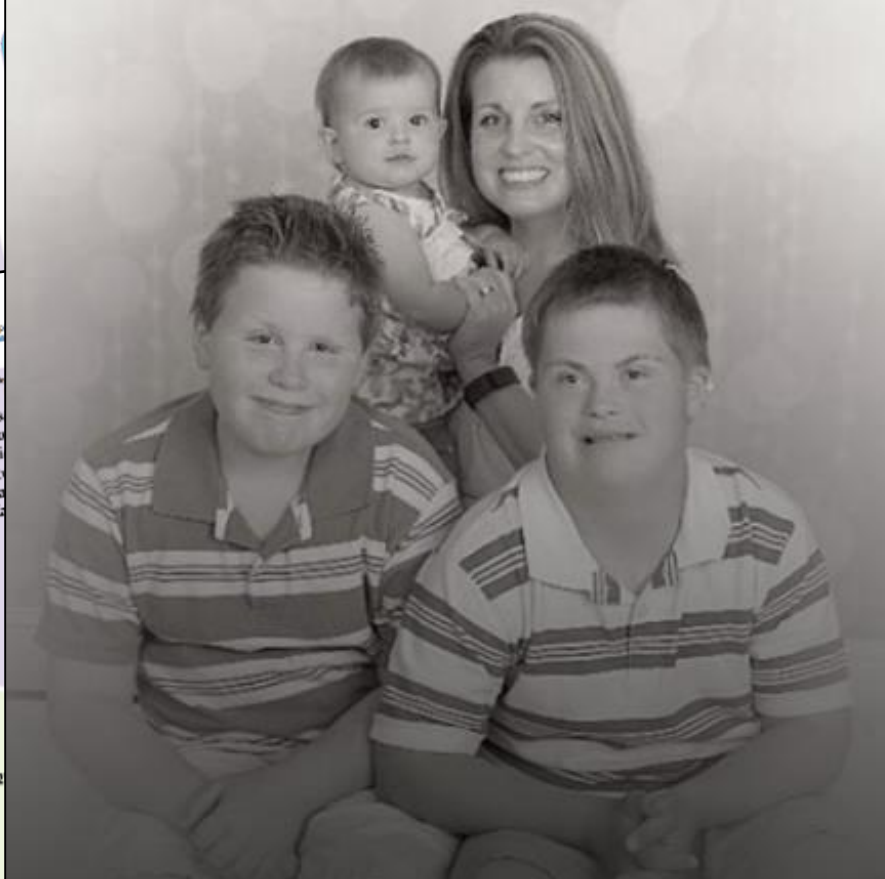
LST: what you want your "good life" to look like...

- Successful/Fulfilling Career
- Financially Stable
- Travel
- Happy
- Good Health/Fit
- Respected
- Independent
- Valued
- Close Friends
- Active Retirement/My Choice
- Affordable/Adequate Healthcare

#### What I DON'T Want

LST: the things you don't want in your life...

- Unhealthy/Fat
- Living like a failure
- Living from day to day/no vision
- Living with family making an impact
- Poverty
- Dependent



### Integrated Services and Supports

People need supports to lead good lives. Using a combination of lots of different kinds of supports is the best way to get a trajectory closer to feeling, quality, community. As the tool helps families and individuals think about how to work in partnership to support their goals for a good life.



Across the LifeCourse framework and levels of representation

# A GOOD *LIFE!!!*



# Thank You!



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