



A Good Life

from **OK YLF**



WHAT IS A GOOD LIFE?

05:53



||||| :: vimeo

<http://supportstofamilies.org/what-is-a-good-life/>



Life Course Planning

A Universal Person-Centered Planning Option



Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

About the Community of Practice

The National Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities will help five states develop systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities. The objective of the grant is to develop systems of supports for families throughout the lifespan of their family member.

Facilitating the Community of Practice

Grant partners include

- National Association of State Directors for Developmental Disability Services (NASDDDS)
- University of Missouri-Kansas City – Institute for Human Development (UMKC-IHD)
- Human Services Research Institute (HSRI)
- National Association of Councils on Developmental Disabilities (NACDD)

Goals of the CoP

The goals of the Community of Practice are:

- to create a model framework for supporting families that addresses the needs of families with a family member with I/DD across the lifespan and supports states to develop and sustain exemplary family support practices.
- to develop and facilitate a multi-level Community of Practice designed to build capacity within states and the nation to create policies, practices, and systems to better assist and support families that include a member with I/DD across the lifespan.
- to capture and share lessons learned and products to develop, implement and sustain exemplary practices to support families and systems

The Goal of Supporting Families

The overall goal of supporting families, with all of their complexity, strengths and unique abilities is so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.



from Building a National Agenda for Supporting Families with Member with I/DD 2011

Learn about policies and practices for supporting families, find resources connect with the Community of Practice, and share your ideas about supporting families:



Visit our website at www.supportstofamilies.org



Like us on Facebook at facebook.com/supportstofamilies



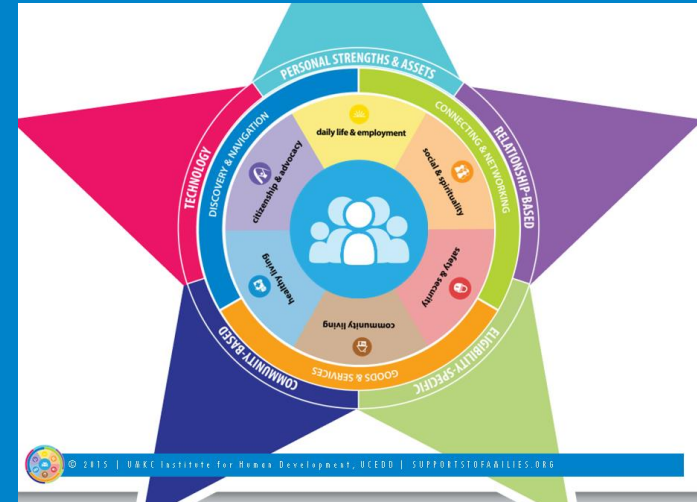
Sign up for our mailing list at www.supportstofamilies.org



Follow us on Twitter at twitter.com/familieswithidd

Project Outcome 1:

Develop State and national consensus on a national framework and agenda for improving support for families with members with I/DD.

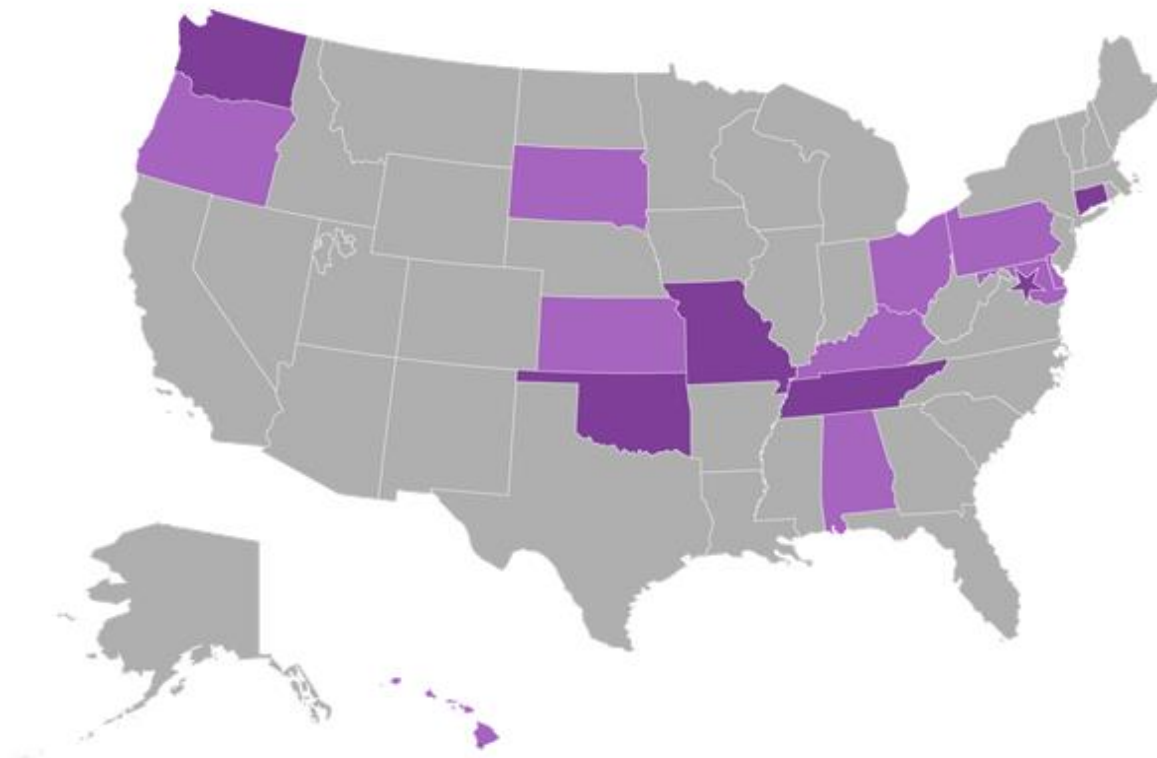




SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES



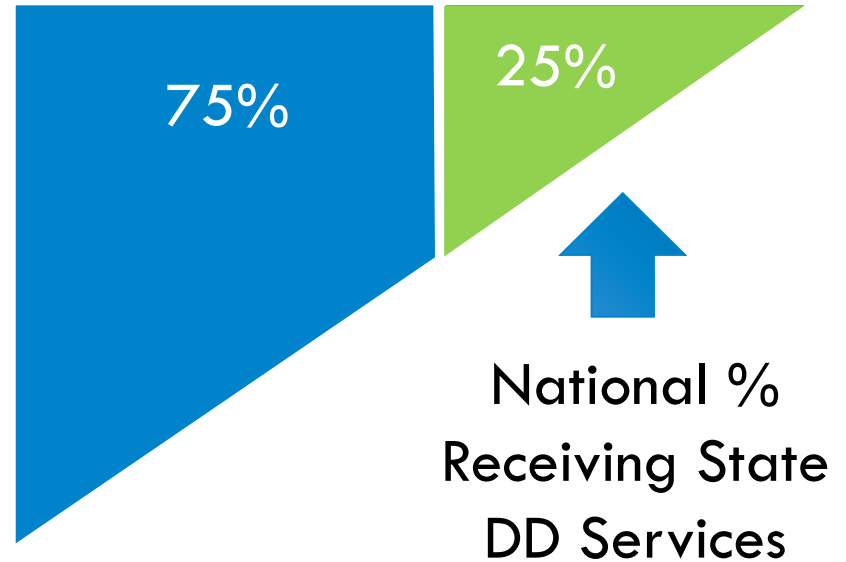
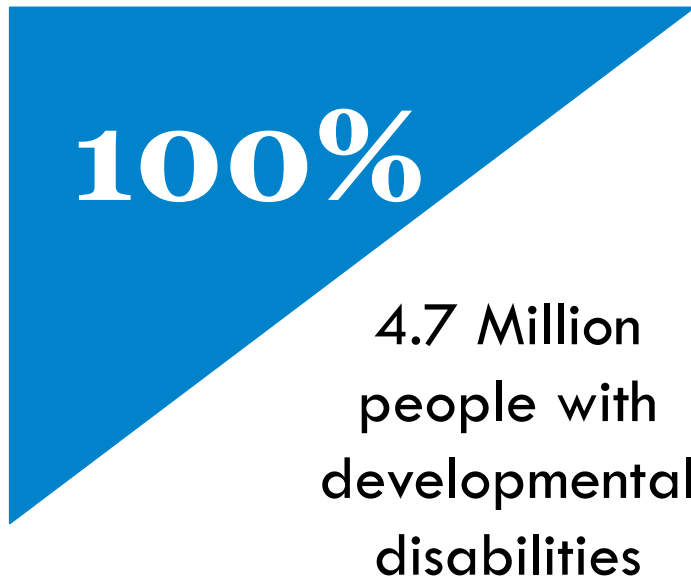
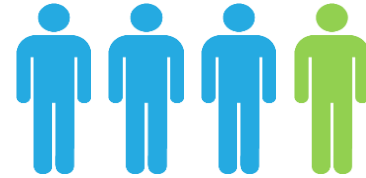
CoP Expansion: 10 New States Starting in July 2016





Setting the Stage: Current Reality

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



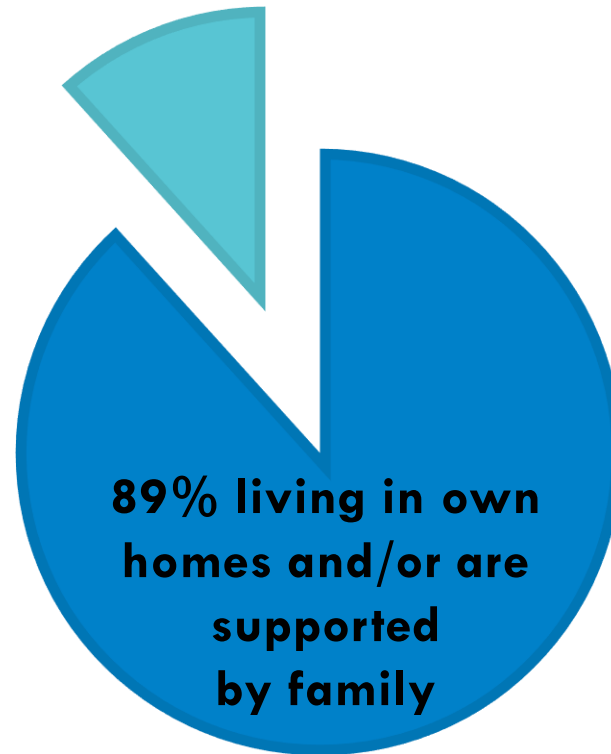
*** Based on national definition of developmental disability with a prevalence rate of 1.58%*



Where do People with I/DD Live?

TOTAL 4.7 MILLION PEOPLE WITH IDD

■ Own or With Family ■ Residential Supports



Anderson, L.L., Larson, S.A., Kardell, Y., Hallas-Muchow, L., Aiken, F., Hewitt, A., Agosta, J., Fay, M.L., & Sowers, M. (2015). Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2013. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

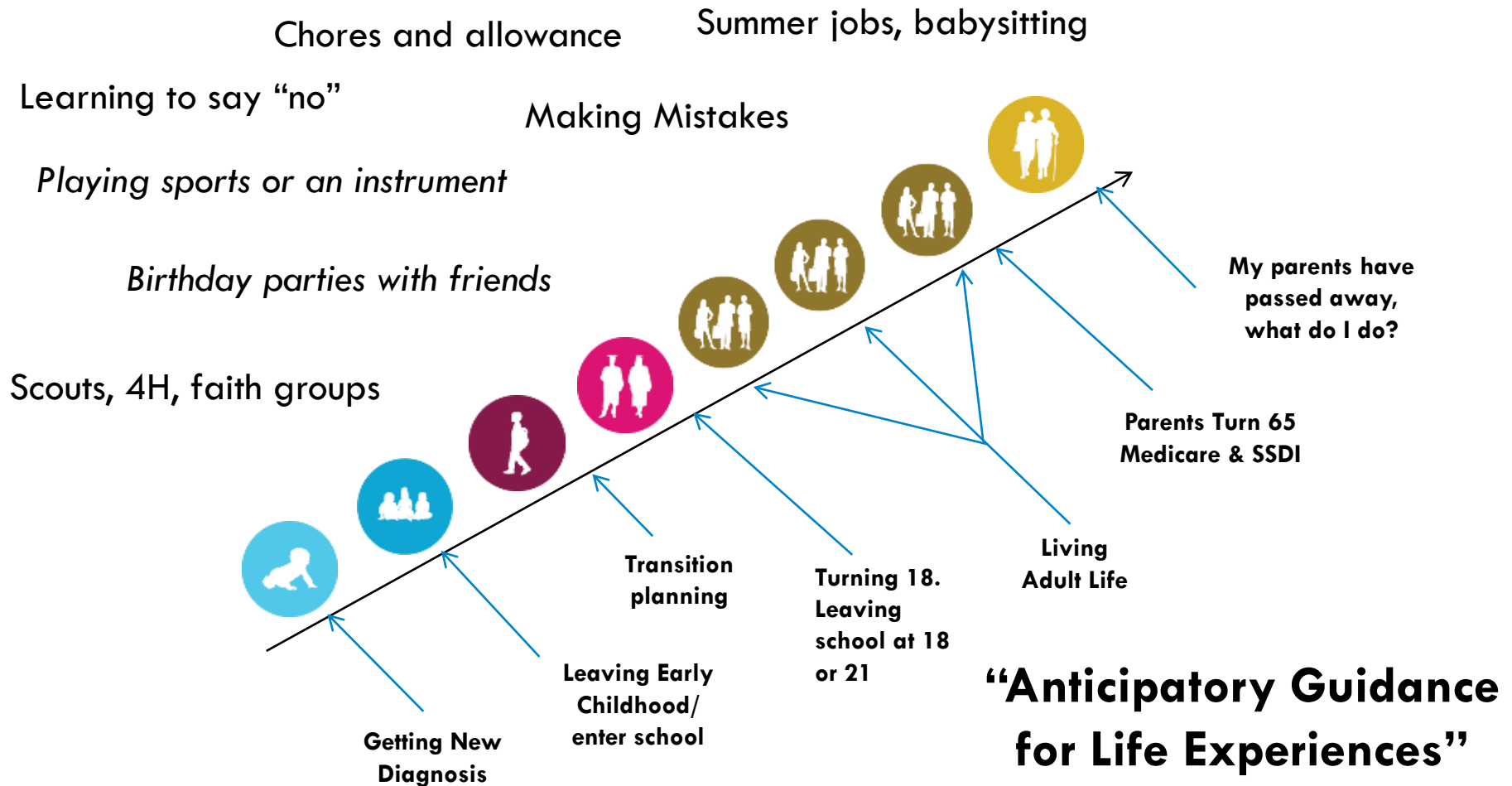




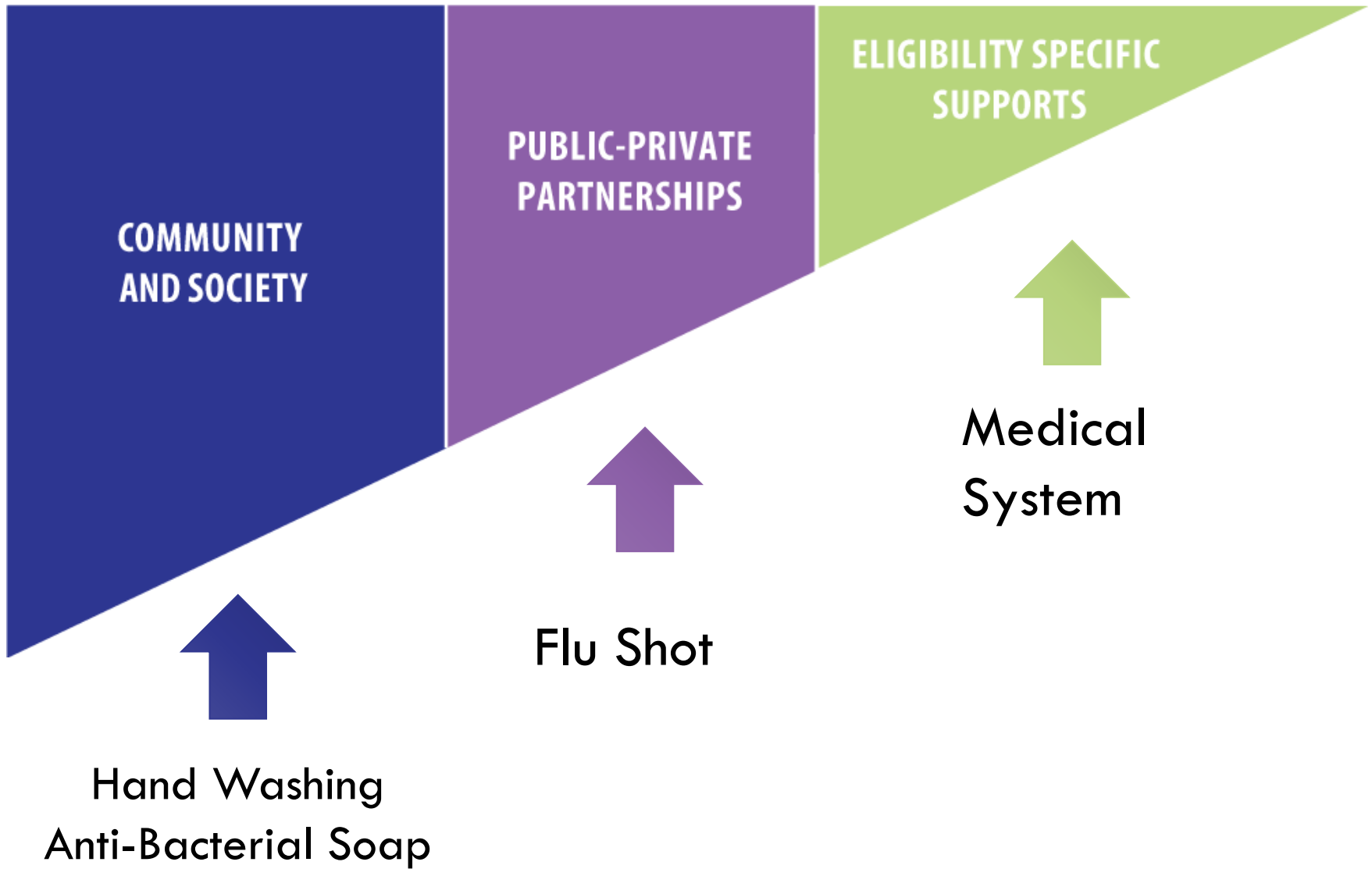
Guiding Principles of the Supporting Families LifeCourse Framework



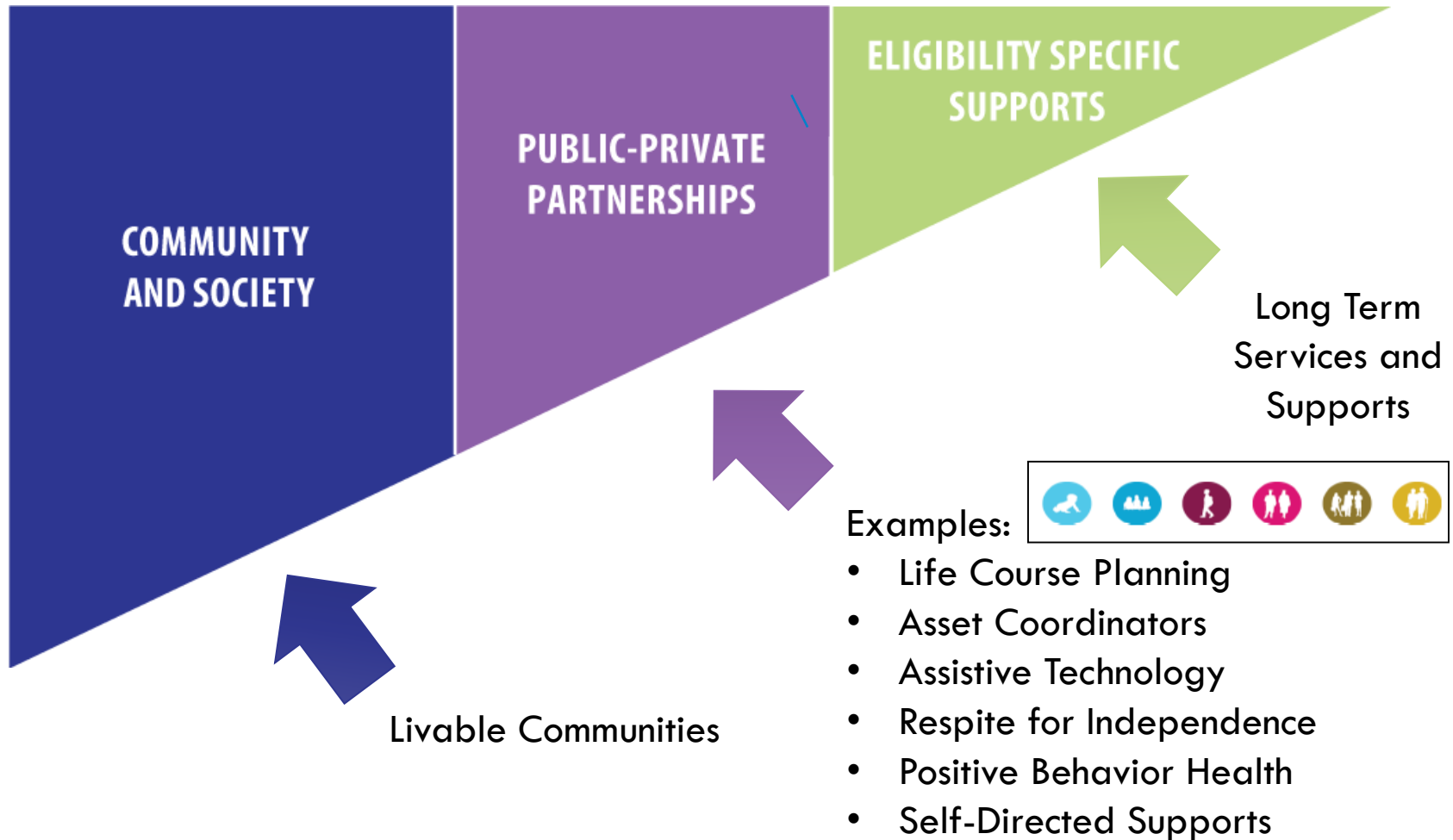
Focusing on Life Experiences and Life Transitions



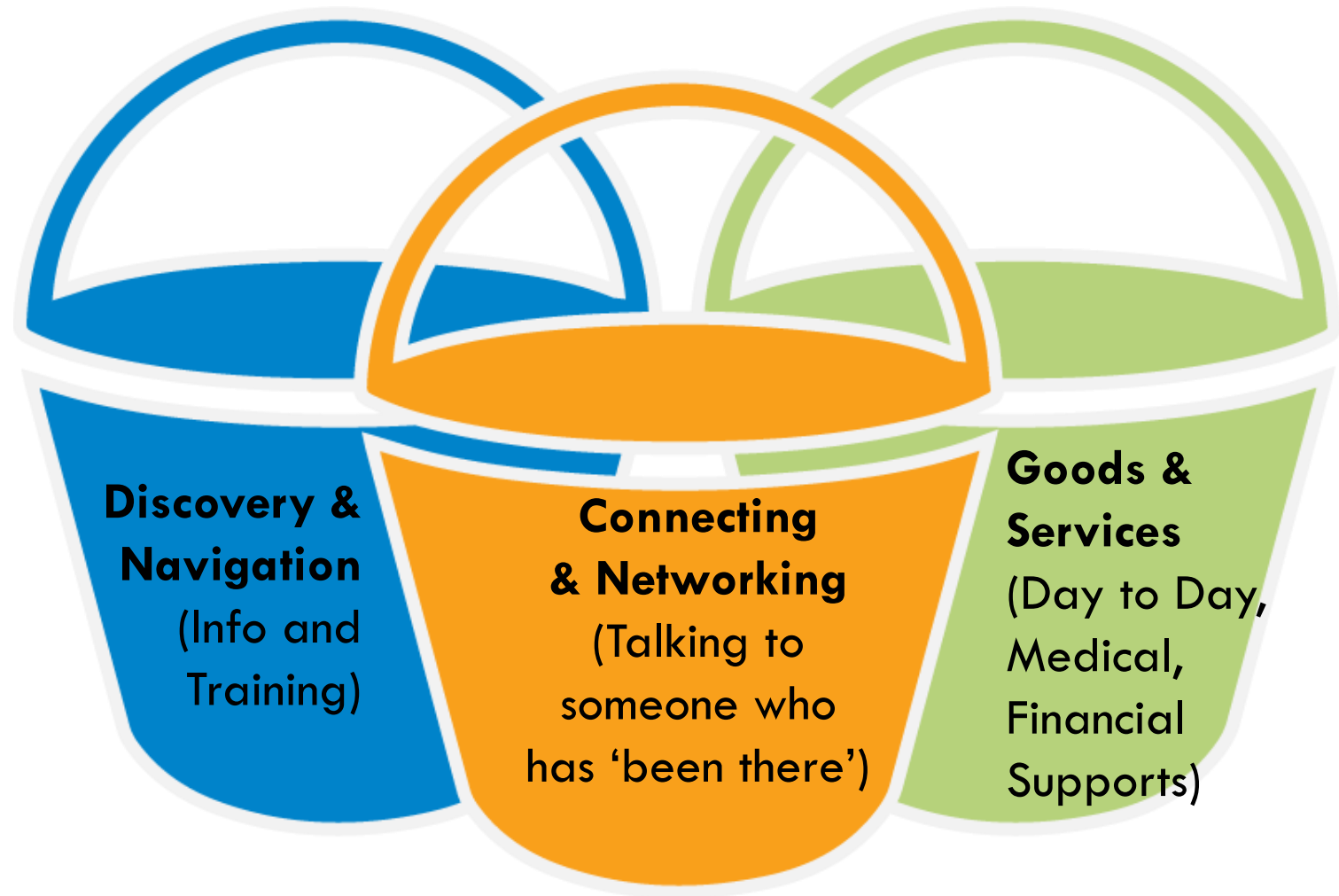
Focus on ALL: Public Health Framework



Construct Universal Strategies for Supporting Individuals with Disabilities and Families Across the LifeCourse



Supporting the Needs of the Person and Their Family







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



_____ 's **ONE-PAGE PROFILE**
 What people like & admire about me (My contributions and talents)

What's Important to ME
 (My conditions, preferences, values)

How to Best Support ME
 (Strategies for working together)

Self Advocacy
Self Determination
Peer Advocacy

Safety 

Relationships 

Quality Life
 Outcomes 



Birth



Early child



School



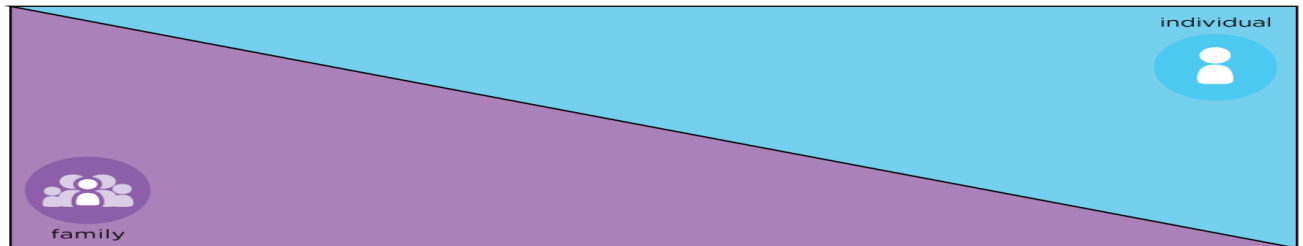
Transition



Adulthood



Aging



Single Adult

New Couple

Couple with Children

Launching Children

Family Later in Life





Focusing on Quality of Life Domains



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



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



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



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)





Focusing on Quality of Life Domains



CHARTING the life course

Tool for Developing a Vision - Family

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, think about a specific vision in each life domain for how their family member will live their life as an adult, and prioritize what they want to work on right now that will help move toward the life vision.

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?			
Community Living	Where and with whom do I think my family member will live in his/her adult life?			
Social & Spirituality	How will he/she connect with spiritual and leisure activities; have friendships & relationships in his/her adult life?			
Healthy Living	How will he/she live a healthy lifestyle and manage health care supports in his/her adult life?			
Safety & Security	How will I ensure safety from financial, emotional, physical or sexual harm in adult life?			
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?			
Supports for Family	What will our family need to help support him/her to live a quality life as an adult?			
Supports & Services	How will he/she be supported in adult life to lead the kind of life he/she wants as independently as possible?			

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





Life Trajectory Worksheet

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

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



Write current age here

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

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

VISION for a GOOD LIFE
LIST what you want your "good life" to look like ...

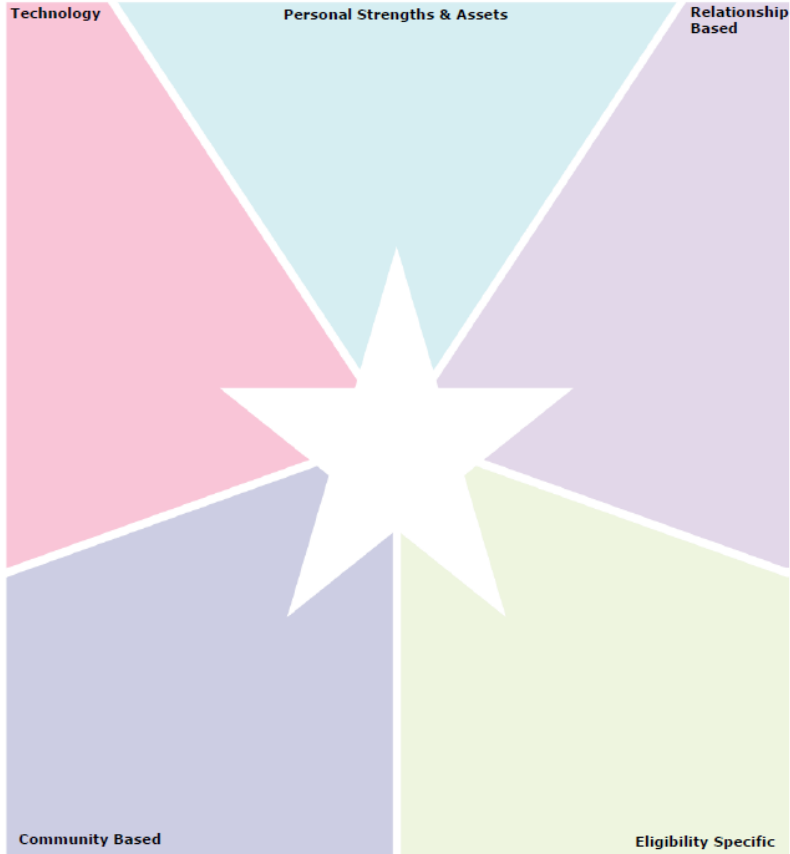
What I DON'T Want
LIST the things you don't want in your life...





Supports and Services Star - Vision for a "good life"

This tool will help families and individuals think about using a combination of different types of supports to plot a trajectory toward an inclusive, quality, community life in partnership with others



_____ Date _____ Provider _____ Date _____
 Person Date Provider Date

_____ Date _____ Other _____ Date _____
 Parent/Guardian Date Other Date

CHARTING the life course



Planning a "Good Life" within my Community – Activities, Supports and Services

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							

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.



Personal Strengths and Assets	Relationship Based Supports	Technology	Community Resources	Eligibility Based Supports
<p>Asset Development: There is growing emphasis on helping people with disabilities and their families to grow personal assets. The assumption is that as individuals with disabilities develop assets, they will be able to move out of poverty and build better a better life.</p> <p>The websites below provides information on how to save and protect money; to increase assets through education and employment and ideas on how to help people with disabilities to use personal strengths to help build a better life.</p> <p>Assets Development</p> <ul style="list-style-type: none"> ABLE Act: The ABLE Act is federal legislation that aims to ease financial strains faced by individuals with disabilities by making tax-free savings accounts available to cover qualified expenses such as education, housing, and transportation. http://www.ablenrc.org/ Assets for Independence Resource Center: AIRC is a one stop resource for information on the Assets for Independence Program and on Individual Development Accounts (IDA). http://idaresources.acf.hhs.gov/ 	<p>Relationship Based Supports: Healthy relationships are a vital component of health and wellbeing. There is compelling evidence that strong relationships contribute to a long, healthy, and happy life. Helping people with disabilities to enhance personal relationships helps ensure a better life.</p> <p>The websites below provide information on how people with disabilities and their families can use expanded and enhanced personal relationships as a source of support for building a better life.</p> <p>Advocacy Groups/Organizations</p> <ul style="list-style-type: none"> ARC CT: http://thearcct.org/ CT Council on Developmental Disabilities: http://www.ct.gov/ctcdd/site/default.asp CT Down Syndrome Congress: http://www.ctdownsyndrome.org/ CT Family Support Council: http://www.ct.gov/dds/cwp/view.asp?q=427738 CT Parent Advocacy Center (CPAC): http://www.cpacinc.org/ CT Cross Disability Alliance: http://ctsilc.org/wp-content/uploads/2007/06/Annou 	<p>Technology: There is a growing movement toward requiring that people with cognitive disabilities have equal access to technology and information. Access to technology is deemed key to helping people with disabilities realize full and equal participation and a better life.</p> <p>The websites below provide information on how people with IDD can use technology to stay safe; to make learning easier; to increase independence, and to live an empowered life.</p> <ul style="list-style-type: none"> CT Tech Act Project: Assessment, Demonstration Sites, Funding Ideas Loan Programs, Training http://cttechact.com/#sthash.pUtpQjHm.dpbs Center on Technology and Disabilities: Assistive and Instructional Technology Supporting People with Learning Disabilities http://www.ctdinstitute.org/ Standard Technology Tools Checklist For Middle and High School http://assistivetech.sf.k12.sd.us/middle_and_high.htm 	<p>Community: The Americans with Disabilities Act (ADA) has helped people with disabilities become more independent and involved in their world. Living, working, learning, and being engaged within a community is an essential way to help people with disabilities live a better life.</p> <p>The websites below provide information on ways to help make communities more accessible for people with IDD and provides information on accessible community-based social activities.</p> <ul style="list-style-type: none"> CT ADA: Knowledge of the ADA can be used to help communities become more accessible. http://www.jud.ct.gov/ADA/default.htm Connect Kids: Special Needs Fun Stuff http://www.ct.gov/kids/cwp/view.asp?a=4072&q=478302 Fun Things to Do in CT http://www.wegoplaces.com/things-to-do-in-connecticut 0-5 (Day Care/Pre-School) Office of Early Childhood (OEC) Childcare and Camp Information http://www.ct.gov/oec/cwp/view.asp?p=a=4542&q=544636 	<p>Help for Those Who Are Eligible: There are many state agency and other federal and state funded organizations that provide support to people in need who are eligible for the services provided. These services are all designed to help people with disabilities live a better life.</p> <p>The websites below are just a few of the organizations providing eligibility-based services. It is important that families are provided information about these supports.</p> <p>General Information</p> <ul style="list-style-type: none"> 211: A one-stop connection to local services, from utility assistance, food, housing, child care, after school programs, elder care, crisis intervention and much more http://www.211ct.org/ Connecticut Association for Human Services: Federal, state and local programs that help people in CT: http://cahs.org/publications/programs-that-help-people/ Connecting Connecticut Resource A Directory for Schools and Community Organizations Serving Families With Children Who Have Disabilities http://www.cpacinc.org/wp-content/uploads/2014/03/Connecting-CT-2012_Mar14_Interactive.pdf CT Department of Social Services: Programs for people with disabilities http://www.ct.gov/dss/cwp/view.asp?a=2345&Q=304922&dssNav=1

Meet Ben



He will help
us put the
Life Course
Planning
Tools
into action

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

Ben's One Page Profile



Ben's Life Trajectory

Life Trajectory Worksheet

Past Life Experiences

Chores; boy scouts;
 School inclusion/circle
 of friends;
 Birthday parties;
 Riding bike;
 Family vacations;
 Church youth group;
 Debit card;
 Football manager;
 Homecoming king;
 Volunteering
 High School diploma

LIST past life experiences that pushed the
 arrow 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;



Write current
 age here
25

Future Life Experiences

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

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

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

Sitting at home
 watching TV all day;
 Rely on paid supports;
 Gain weight;
 Eat unhealthy foods or
 drink too much Pepsi
 (caffeine);

VISION for a GOOD LIFE

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

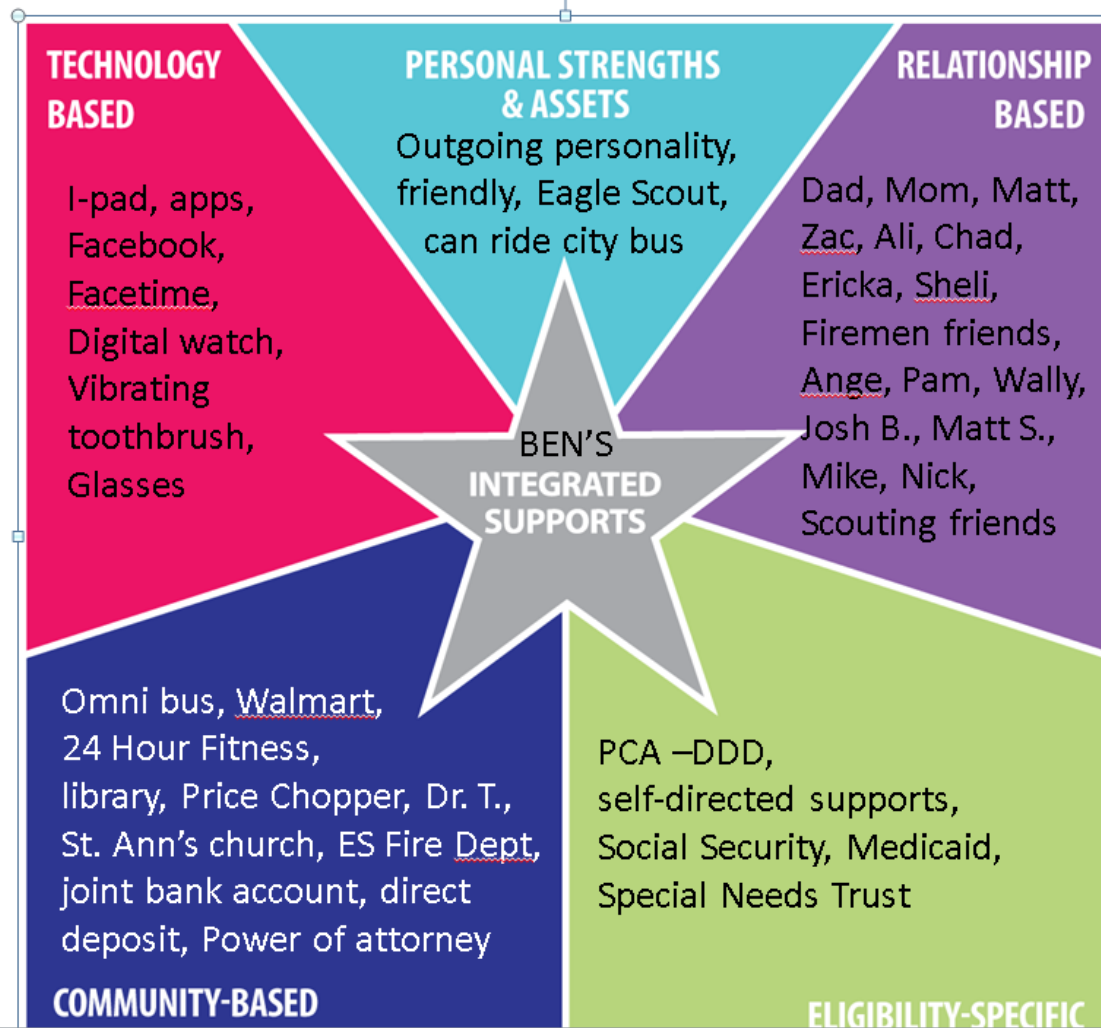
Family and friends
 Girlfriend
 Vacations
 Concerts; WWE; Nascar
 Tattoos
 Money; job or my own business
 Volunteer at fire station
 Being Tiger football manager
 Church
 Healthy & fit
 Good food; Pepsi
 Basketball
 Royals baseball
 Staying active

What I DON'T Want

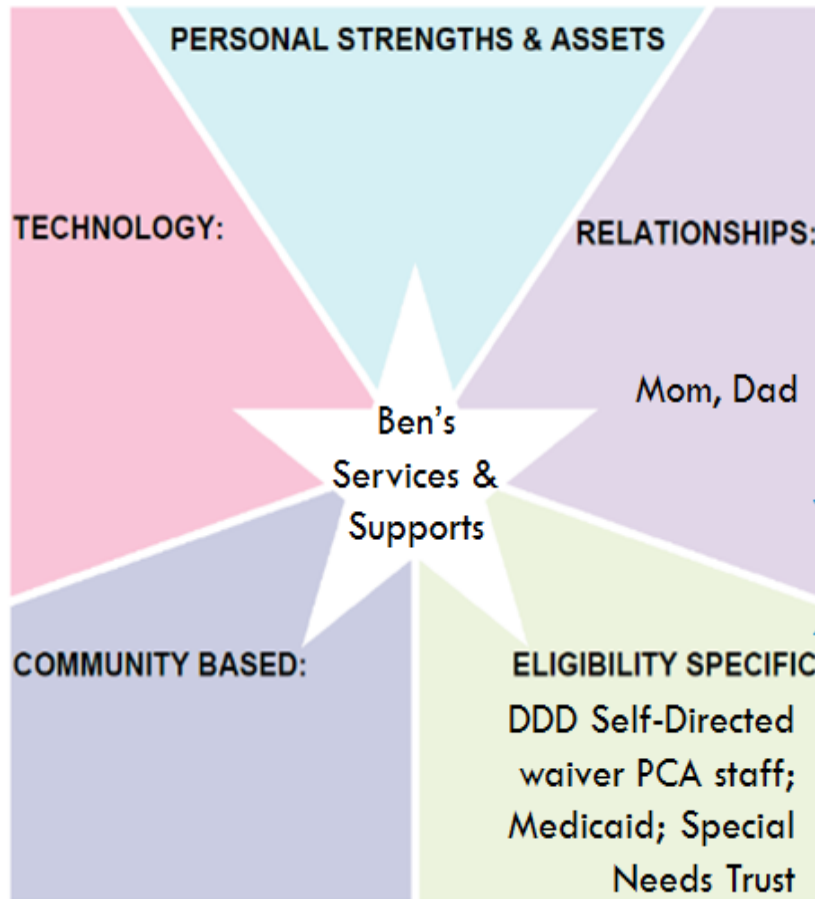
Poor health, heart disease, diabetes;
 Poverty/no money;
 Guardianship; institution/group home;
 Segregation/isolation; being lonely
 Being treated differently;



Ben's Integrated Services and Supports Star



Before Life Course Planning



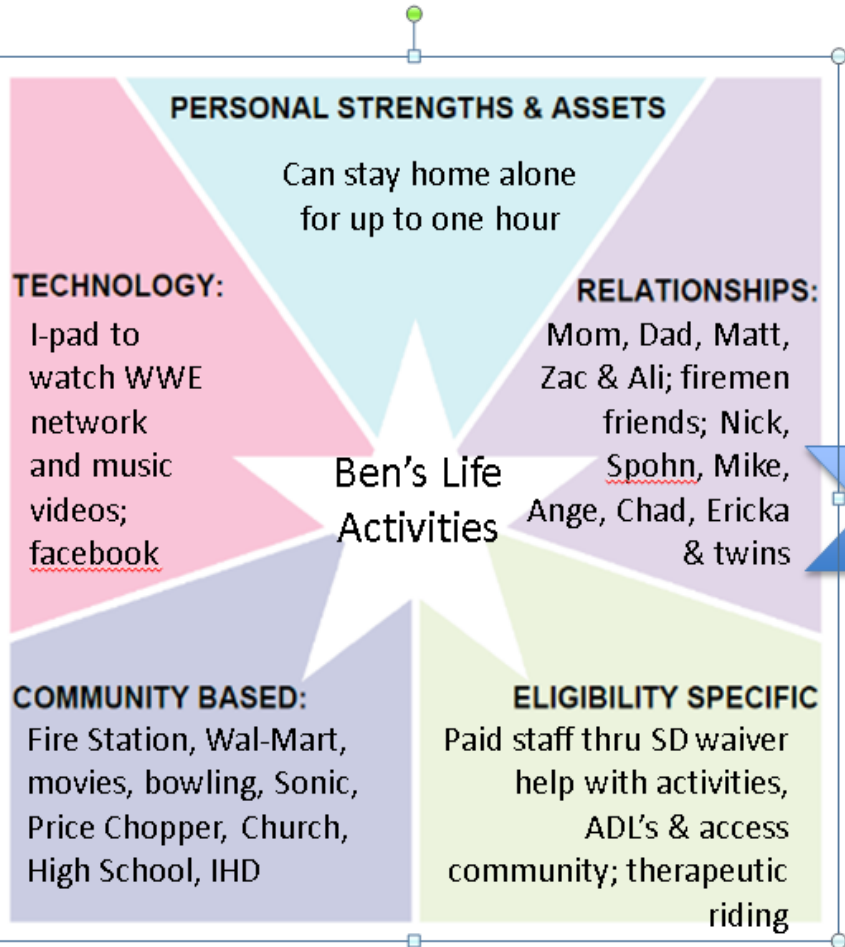
Long Term Service and Support Needs

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							
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-HHS, UCCDD

December 2011

Ben's Current Life



CHARTING the life course

Integrated STAR Activities

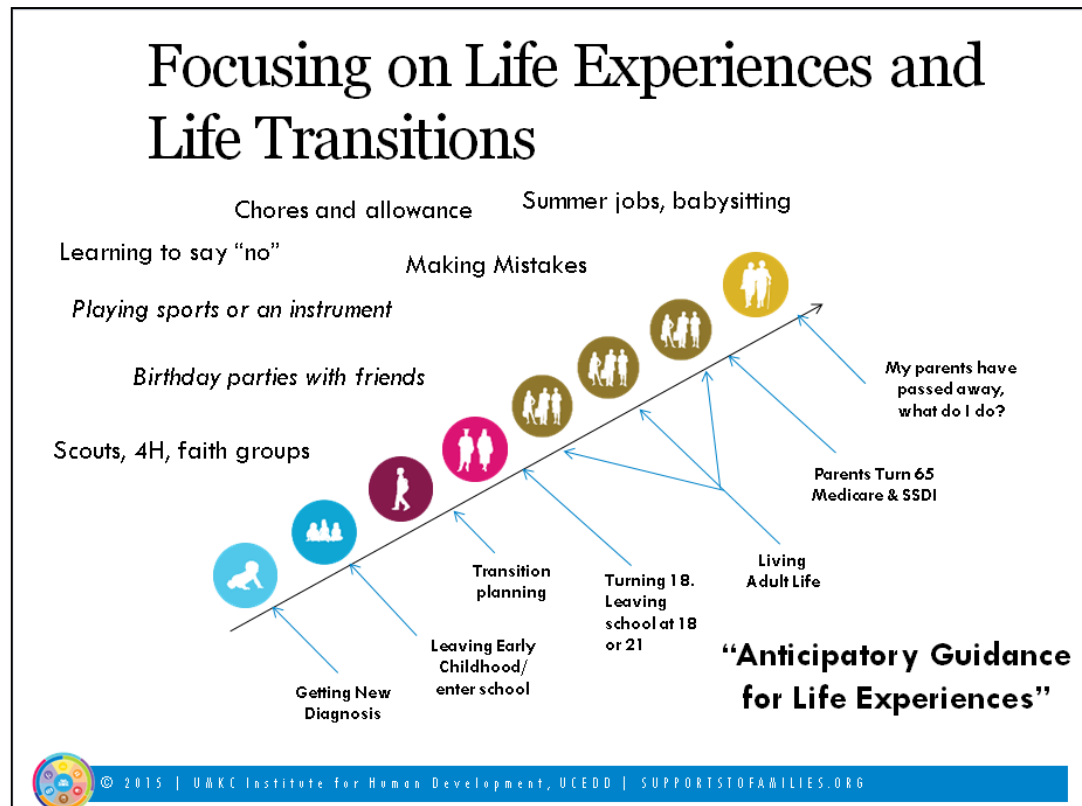
TIME	MON	TUES	WED	THURS	FRI	SAT	SUN
6-6:30 AM	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast		Spend
6:30-7 AM	I-pad while	I-pad while	I-pad while	I-pad while	I-pad		Night with
7-7:30 AM	Mom walks	Mom walks	Mom walks	Mom walks	Mom walks		Matt
7:30-8 AM							
8-8:30 AM		Volunteer		Volunteer	Workout		
8:30-9 AM		Fire Station		Fire Station	@ Gym		
9-9:30 AM	Go for walk	8-Noon	Buy food	8-Noon	Get ready		
9:30-10 AM			& take to		& go to IHD		
10-10:30 AM	Workout		Good Sam.		Volunteer		Church @
10:30-11 AM	@ Gym		Center		At IHD		St Ann's
11-11:30 AM	Watch TV		Watch TV		with PCA		
11:30-12 PM			Lunch with				
12-12:30 PM	Lunch with	Lunch with	PCA help	Lunch with	Lunch @		
12:30-1 PM	PCA help	Firemen @	Workout	PCA help	Crown Ctr		
1-1:30 PM	Library	El Maguey	@ Gym	Wal-Mart			
1:30-2 PM		Watch TV		With PCA			
2-2:30 PM	Watch TV	& chill until	Sonic drink	Watch TV	Get ready		
2:30-3 PM	& chill	football	Chill time	& chill	for game		
3-3:30 PM	Football	Football	Football	Football	ESHS		
3:30-4 PM	Practice	Practice	Practice	Practice	Tigers		
4-4:30 PM					Football		
4:30-5 PM					Game		
5-5:30 PM						Dinner with	
5:30-6 PM		Go visit				Matt (twin)	
6-6:30 PM		Twins, Chad	McDonalds				Watch
6:30-7 PM		& Ericka in				Music	PayPerView
7-7:30 PM		Lawson				Concert	with
7:30-8 PM	I-pad when	I-pad while	Northland	I-pad while		with Matt	Firemen
8-8:30 PM	Mom walks	Mom walks	Therapeutic	Mom walks			friends
8:30-9 PM			Horseback				
9-9:30 PM			Riding				
9:30-10 PM							
10 PM-6 AM						Spend night with Matt at his apartment	

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



Key Recommendations

- **Support a lifespan approach**





Key Recommendations

- Support use of Life Course common language and images

Focusing on Quality of Life Domains



CHARTING the life course

Tool for Developing a Vision - Family

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 caregiver in between, think about a specific vision in each life domain for how their family member will live their life as an adult, and prioritize what they want to work on right now that will help move toward the life vision.

LIFE DOMAIN	My Vision for My Family Member's Future	priority	Current Situation/Things to Work On
Daily Life Environment What do I think my family member will do during the day as a future adult?			
Community Living Where and with whom do I think my family member will live as a future adult?			
Social & Spirituality How will the life connect with spiritual and leisure activities, like friendships & relationships as a future adult?			
Healthy Living How will the life live a healthy lifestyle and manage health care needs as a future adult?			
Safety & Security How will I ensure safety from intentional, physical or sexual harm as an adult?			
Citizenship & Advocacy How can I make sure the life has self-determination and the control of their own life as a future adult?			
Supports for Family What will our family need to help support the life to live a quality life as an adult?			
Supports & Services How will the life be supported as an adult to lead the best of the life's events as independently as possible?			

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

**DISCOVERY
AND NAVIGATION**
Knowledge & Skills

**211
Choices**
Medical Homes
Behavioral Health Homes
DDS Help Line





Key Recommendations

- **Support strategies that support family-to-family and peer mentoring connections**



**CONNECTING
AND NETWORKING**
Mental Health
& Self-Efficacy

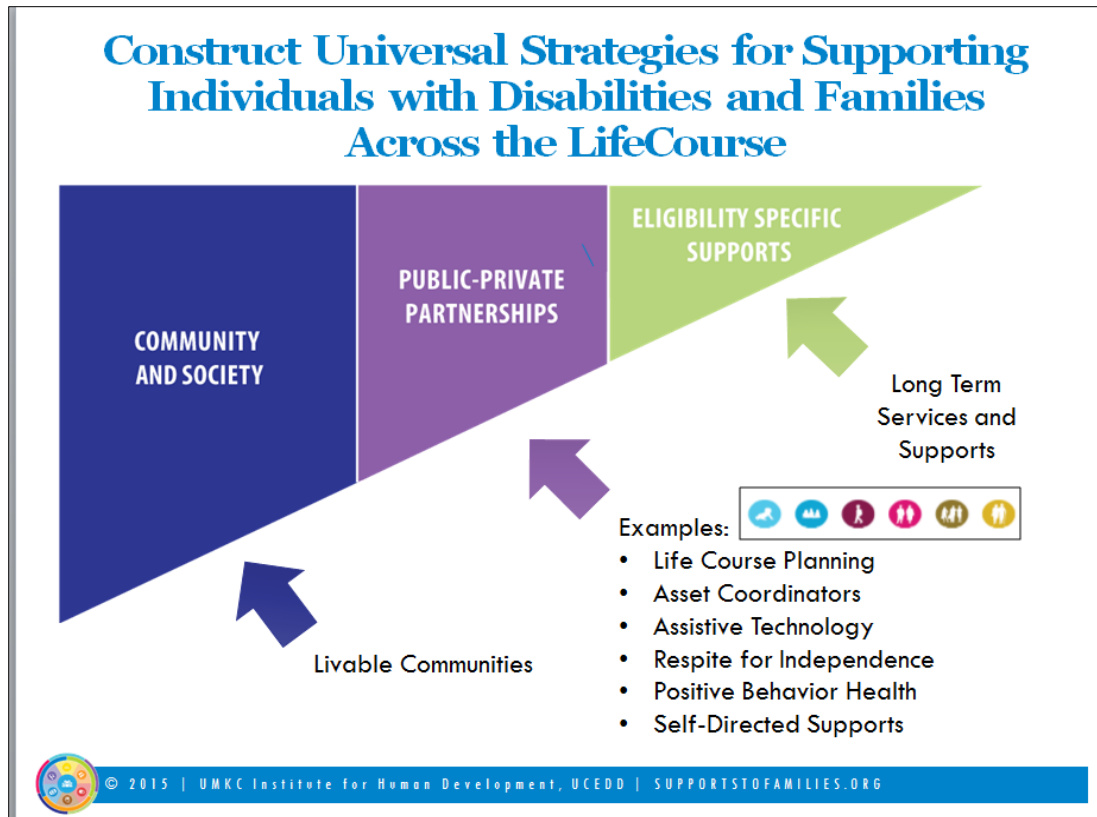
Family Groups
Advocacy Groups
Community Collaboratives
**Family Engagement &
Training Activities**
Roommate Services





Key Recommendations

- Support strategies that focus on the ALL





Key Recommendations

- Support strategies that help families build a strong foundation of support



GOODS AND SERVICES
Day-to-Day
& Caregiving/Supports



Examples:



- Life Course Planning
- Asset Coordinators
- Assistive Technology
- Respite for Independence
- Positive Behavior Health
- Self-Directed Supports



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



Partnering with People with Disabilities and their Families so they can Engage, Lead, and Drive Policy and Systems Change



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