

Charting Your Life Course

Michelle "Sheli' Reynolds, SIB, PhD Snohomish County, WA April 21, 2015

About me...

- Sibling of three brothers, one who is 32 year old with developmental disability
- Director of Individual Advocacy and Family Support, UMKC UCEDD
 - Supported the Self-Advocacy
 Movement for 12 years
 - Director of Mo Family-to-Family Health Info Center
 - Co-Director of National CoP on Supports to Families



About My 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 for over 25 years with evolving and on-going statewide partnership











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 than 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 by



National Partners

















Table Introductions

- Introduce yourself to tablemates
- Share a few sentences describing your first job



Outcomes for Today

- Learn about and apply the LifeCourse framework and tools to assist with **Discovery** and Navigation for information and planning
- Connect and Network with others who are on a similar journey through interactive activities and discussions
- Identify Integrated Supports strategies for enhancing the trajectory towards a good life

DISCOVERY & NAVIGATION

Knowledge & Skills

CONNECTING & NETWORKING

Mental Health & Self-Efficacy

INTEGRATED SUPPORTS
& SERVICES

Day-to-Day & Caregiving/Supports

What is YOUR Vision for a Good LIFE?



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

What DON'T you want for your Focus Person??



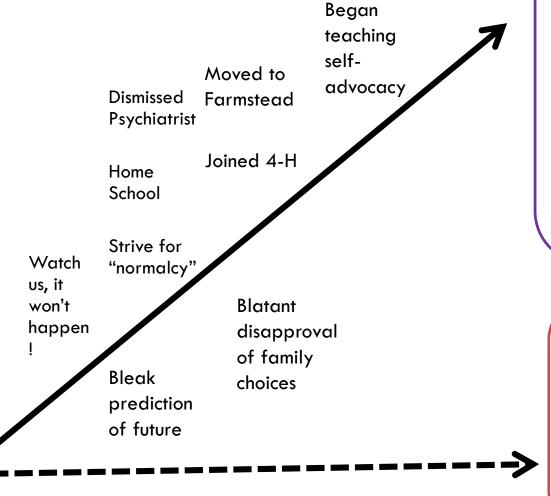
Write down your responses on your worksheet & discuss with your table

How the Story Began: Shaylee

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



Shaping the Rest of the Story: Shaylee



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 choices for her.















TECHNOLOGY BASED

ID tag/jewelry
Cell phone alarm
clock microwave
Timer
computer kindle
or l-pad daily
schedule

PERSONAL STRENGTHS & ASSETS

curious, sense of humor, friendly, loyal, ability to focus, organized, stands firm in her beliefs, compassionate

SHAYLEE'S

INTEGRATED SUPPORTS

RELATIONSHIP BASED

Family, Support group families, neighbors, 4-H club members, Advocates, Librarian, Pastor, Sunday School Teacher and Youth Leaders, Pharmacist, Doctor and Nursing staff, Homeschool families, bowling league members and owners of the lane.

Church/Sunday School/Youth Group, Parks and Recreation, YMCA, Bank, Library, Grocery Store, Pharmacy, Doctor Office, Taxi, Bus or Oats Transportation, Support and Advocate Organizations, Homeschool Support Groups

COMMUNITY-BASED

service coordinators, insurance coverage, diagnosis and testing, age, location, living arrangements, therapies, income/SSI benefits or other financial aid, doctors, nursing, and specialists working as a team WITH her

ELIGIBILITY-SPECIFIC

Mapping Shaylee's Good Life



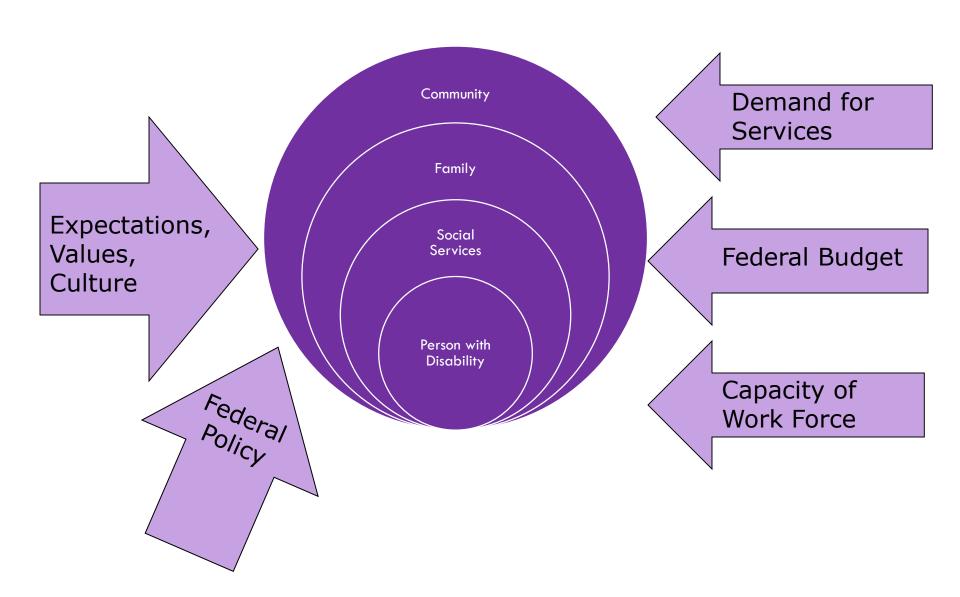
Why is this important Now?

1 in 5 Americans with Disability

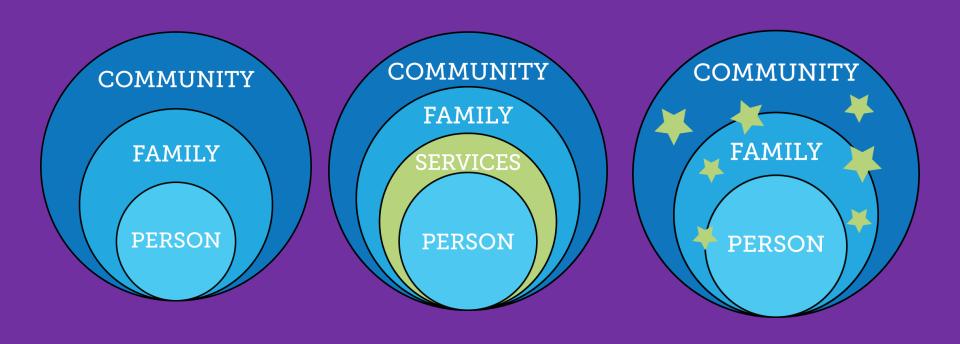
- 9.4 million individuals have difficulties with activities of daily living (eating, bathing, dressing)
 5 million required assistance
- 15.5 million individuals have difficulties with instrumental activities of daily living (housework, phone, meal preparation)
 - 12 million required assistance

(Americans with Disabilities 2010, U.S. Census Bureau)

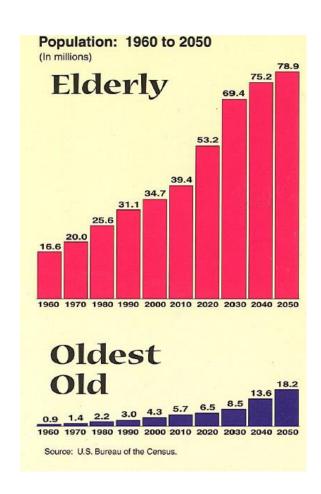
What we know about current realities?



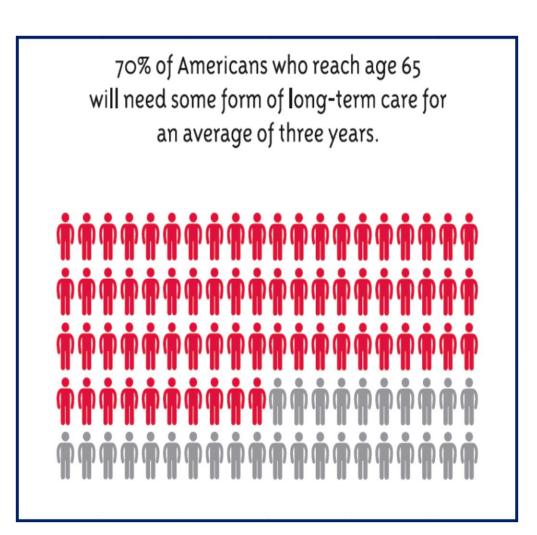
Services and Supports are Evolving



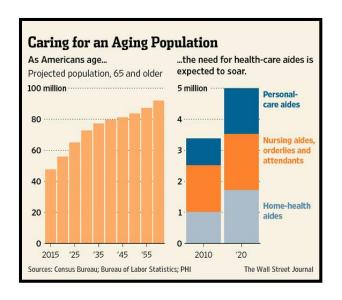
Baby-Boom Generation



National Institute on Aging

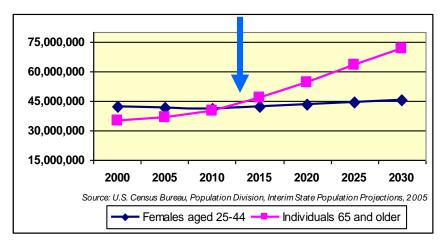


Shortage of Caregivers



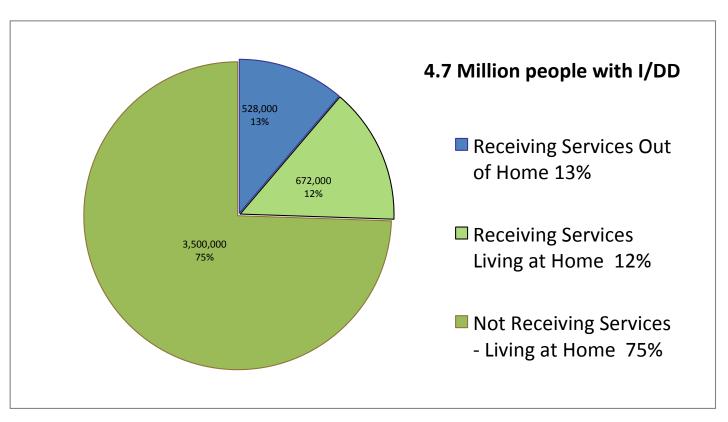
A labor shortage is worsening in one of the nation's fastest-growing occupations—taking care of the elderly and disabled-just as baby boomers head into old age.

Wall Street Journal April 15. 2013



Recognizing Families Role in LTSS

89% of People I/DD are Supported Outside of Formal Residential Supports



Larson, S. A., Lakin, K. C., Anderson, L., Kwak, N., Lee, J. H., & Anderson, D. (2000).

Joining Forces for a New Vision

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

1970s Self-Advocacy and Independent Living Movements (Not 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 Family *

Person with Disability *

2000's Community and Society



Reframing the Conversation at All Levels

GUIDING PRINCIPLES FOR THE FAMILY LIFECOURSE FRAMEWORK



Focus on "ALL"

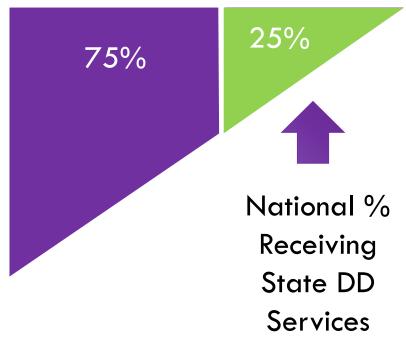
ALL individuals and their families are considered in our values and vision.



Focus on "ALL"



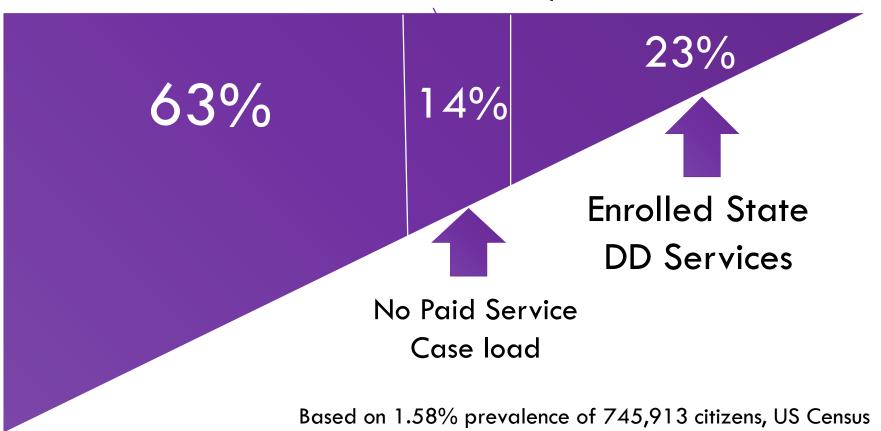
All 4.9 Million people with developmental disabilities



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

Snohomish County with I/DD

11,785 estimated Person with Developmental Disabilities



Based on 1.58% prevalence of 745,913 citizens, US Census

No paid service case load- 1,651

Enrolled in services, 2,726 paid DDA service



All individuals live within the context of a family

Family is defined by the person and Incudes members regardless of where they live

Lifelong Impact of Family on Individual

Biologically: Likes, dislikes, skills, abilities

Socially: Family and friend network, connection with community members

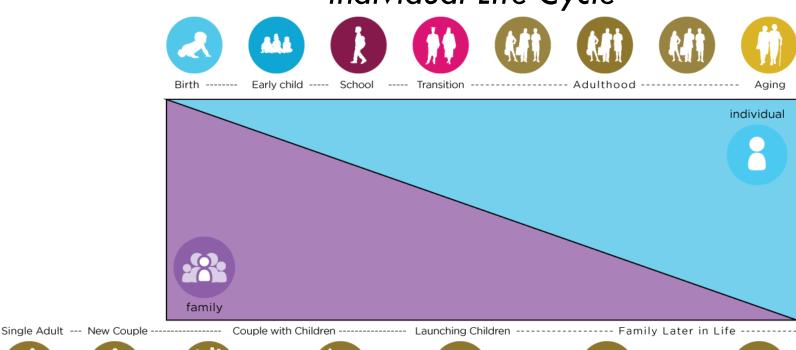
Environmentally:

Neighborhood, socio-economic, education

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

Recognition of Individual and Family Cycles

Individual Life Cycle



Family Life Cycle

Reciprocal Roles of ALL Family Members



Affection & Self-Esteem

Repository of knowledge

Lifetime commitment



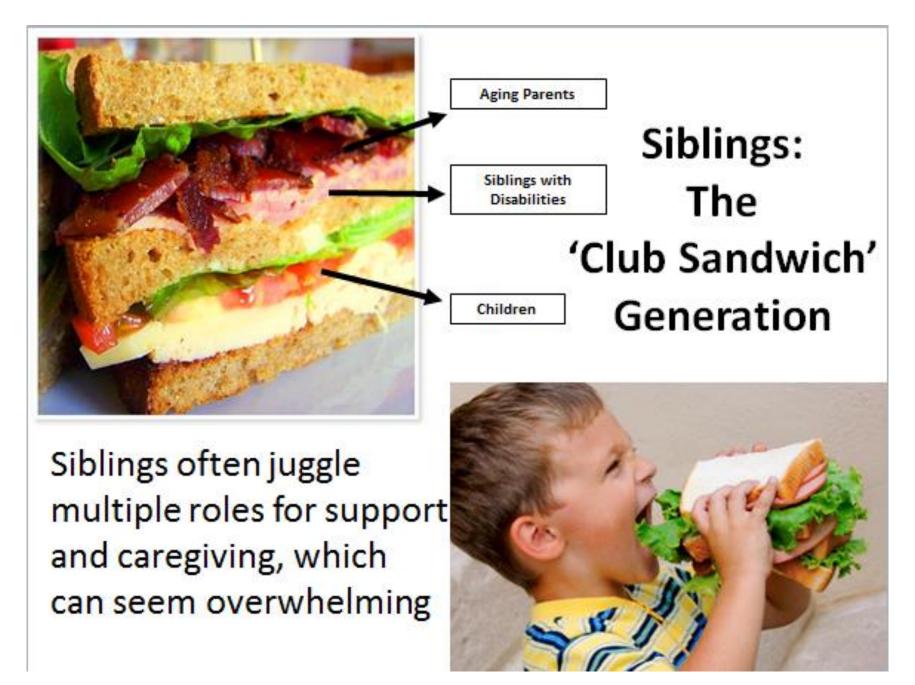
Provider of day-to-day care

Material/Financial

Facilitator of inclusion and membership

Advocate for support

^{*}Adapted from Bigby & Fyffe (2012), Dally (1988), Turnbull et all (2011)



*Borrowed with Permission from Sibling Leadership Network

"Good Life for All"



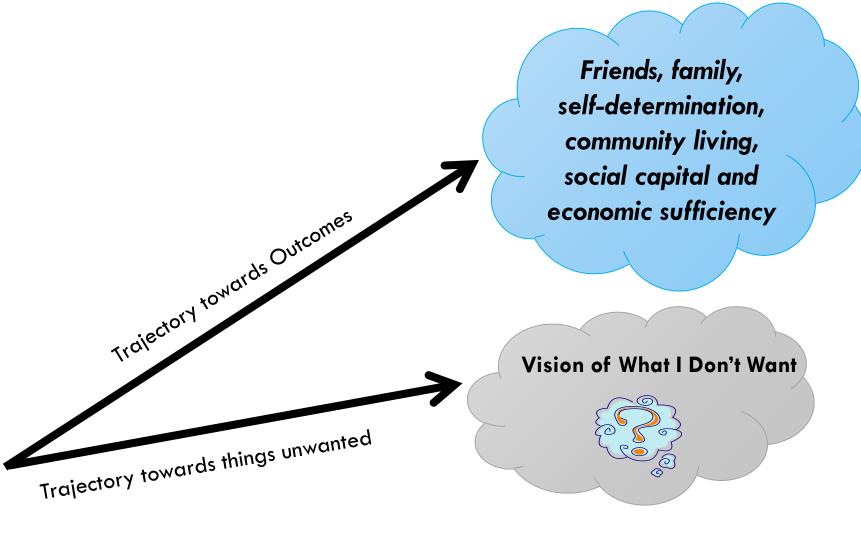
The Individual will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life



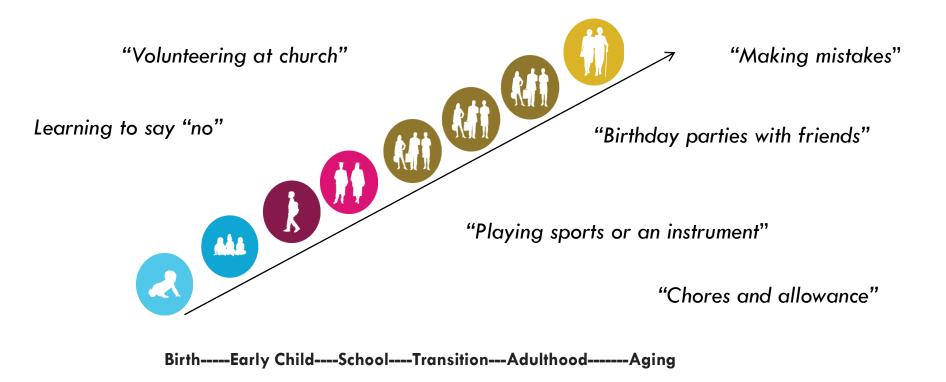
Families will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support all individual members to achieve their goals



Trajectory towards Good Life



Focusing on Life Experiences

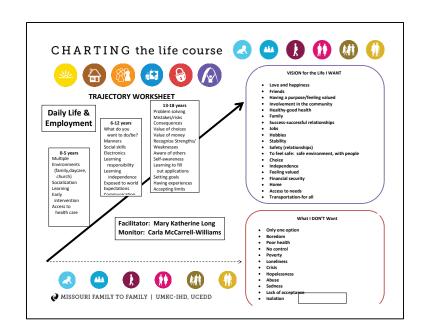


"Anticipatory Guidance for Life Experiences"

Think Across Life Stages and Generations

Age	0-5	6-18	19-64	65
WA Total Population	446,319 (6.4%)	1,150,667 (16.5%)	4,428,326 (63.5%)	948,428 (13.6%)
DD WA (1.58%)	7,096	18,295	70,410	15,080
Snohomish County	47,026 (6.3%)	127,642 (17.1%)	484,443 (64.9%)	87,334 (11.7%)
DD Sno. (1.58%)	747	2,029	7,702	1,388

Applying the Life Stage and Life Experience Concept



What did you do during that life stage? What are you or others in that life stage doing?

Thinking Across all Life Domains



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



Healthy Living (medical, behavioral and mental health, wellness, nutrition)



Community Living (housing, transportation, community access)



Safety and Security (emergencies, legal, wellbeing, guardianship and alternatives



Social and Spirituality (friends, relationships and leisure activities)



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



Understanding Possibilities for Individuals with I/DD Through the Lens of My Life









Community Living Possibilities



Vision for the Future

Innovative

Not Yet Discovered

Islands of Excellence

- Own home
- Shared Living Space
- Co-op
- Environmental Adaptations
- Independent Supported Living

Traditional Options

- Training Centers
- Intermediate Care
- Group Homes



Service & Support Possibilities



Vision for the Future

Innovative

A new possibility

Islands of Excellence

- Remote Monitoring
- Assistive Technology
- Time banks
- Human-service coops
- Self-directed Services
- Respite
- Micro-boards
- Companion Model

Charted

Staff hired by Provider



Daily Life/ Employment Possibilities



Vision for the Future

Innovative

New possibilities, needs discovery

Islands of Excellence

- Micro-enterprise
- College/Tech Schools
- Career
- Military
- Supported Employment
- Volunteerism
- AmeriCorps/VISTA

Charted

- Sheltered Workshops
- Day Habilitation

The road is not always easy.....





What do Persons with Disabilities and Their Families Need to Support their GOOD LIFE?



Three Types of Supports

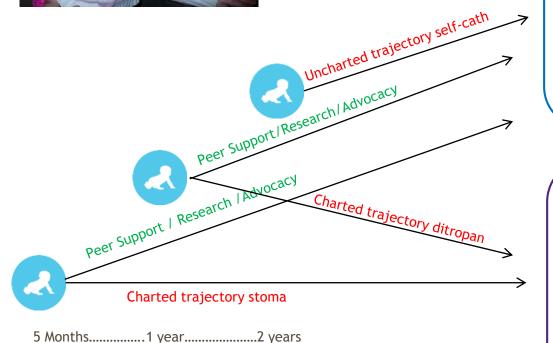
Discovery & Navigation:	Connecting & Networking	Day-to-Day Services
Knowledge & Skills	Mental Health & Self-efficacy	Instrumental Supports
Information on disability Knowledge about best practices and values Skills to navigate and access services Ability to advocate for services and policy change	 Parent-to-Parent Support Self-Advocacy Organizations Family Organizations Sib-shops Support Groups Professional Counseling Non-disability community support 	Self/Family-Directed services Transportation Respite/Childcare Adaptive equipment Home modifications Financial assistance Cash Subsidies Short/Long term planning Caregiver supports a training



Elizabeth's Health Trajectory As Told by Her Mother

VISION for a GOOD LIFE

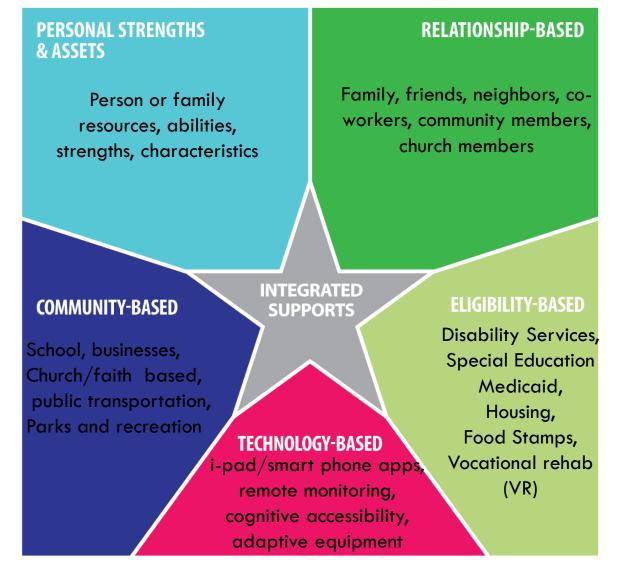
Self determination Choice Privacy



What I DON'T Want

Unnecessary medications
Unnecessary procedures
Limiting choices
Limiting self-determination

Assistance in Developing and Integrating Supports and Services



Opportunities for Self-Advocates and Families to Engage, Lead, and Drive their Own Supports and Impact Policy and Systems Change



Putting the Framework Together!!





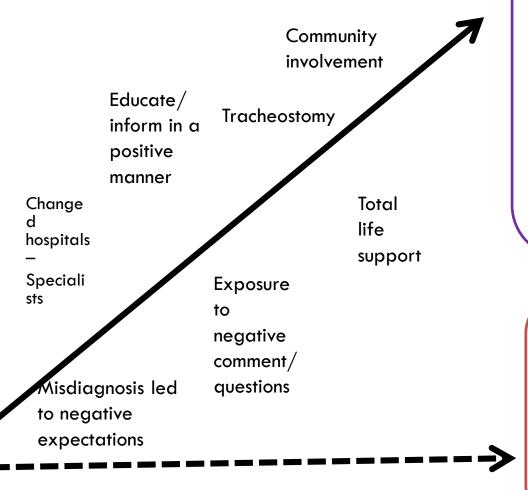
Putting the Family Life Course Framework into Practice

How the Story Began: Izaac



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

Shaping the Rest of the Story: Izaac



What We Want

- Selfdetermination
- Participation in activities he likes
- Learn medical self-care

What We DON'T Want

- People always doing things for him
- Unnecessary medications
- Unnecessary procedures















TECHNOLOGY BASED PERSONAL STRENGTHS
& ASSETS
Extremely outgoing,

funny, natural leader,

cute, thick-skinned,

nonchalant,

RELATIONSHIP BASED

Kindle

Wii

X-box

You tube

Scooter

Vent/trach

Life Support Equipment

Izaac's (INTEGRATED SUPPORTS Family,
neighbors,
school friends,
nurses, church,
cheer, tae
kwon do, dog

Athlete's Plus Cheer
Tai Kwon Do
McAllister's family night
Church
School

Service Coordination
Nursing
Adaptive Equipment
Medical Supplies
Insurance

COMMUNITY-BASED

ELIGIBILITY-SPECIFIC

Izaac's Integrated Services and Supports



Ben's GOOD LIFE



I PITY THE FOOL WHO DOESN'T LIKE



BEN'S ONE PAGE PROFILE!

WHAT PEOPLE LIKE & ADMIRE AROUT 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)
- Mv 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

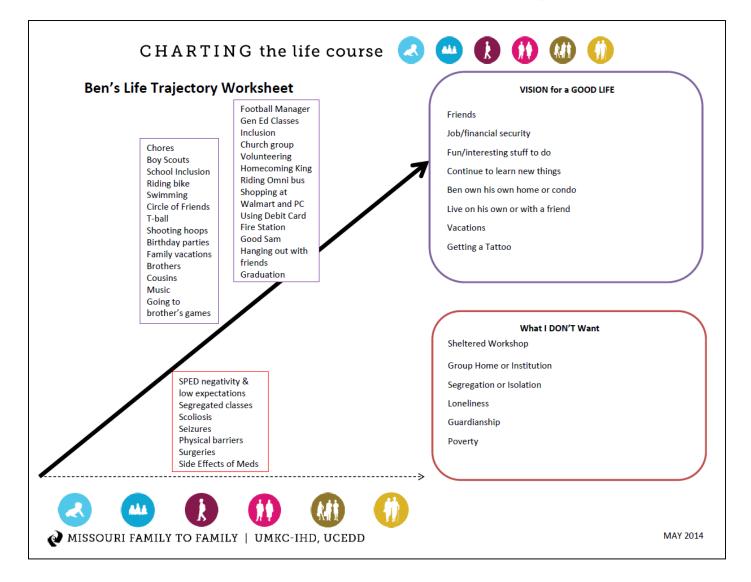
HOW BEST TO SUPPORT ME

- 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

Tools Used for Planning and Day-to-Day Supports Self-Directed Waiver in Missouri

(Ben's One Page Profile)

Ben's Life Trajectory



TECHNOLOGY BASED

I-pad, apps,
Facebook,
Facetime,
Digital watch,
Vibrating
toothbrush,
Glasses

PERSONAL STRENGTHS & ASSETS

Outgoing personality, friendly, Eagle Scout, can ride city bus

INPEGRATED SUPPORTS

RELATIONSHIP BASED

Dad, Mom, Matt,
Zac, Ali, Chad,
Ericka, Sheli,
Firemen friends,
Ange, Pam, Wally,
Josh B., Matt S.,
Mike, Nick,
Scouting friends

PCA –DDD, selfdirected supports
Social Security,
Medicaid, Special
Needs Trust

COMMUNITY-BASED

Power of attorney

Omni bus, Walmart,

library, Price Chopper, Dr. T., St.

Ann's church, ES Fire Dept, joint

bank account, direct deposit,

24 Hour Fitness,

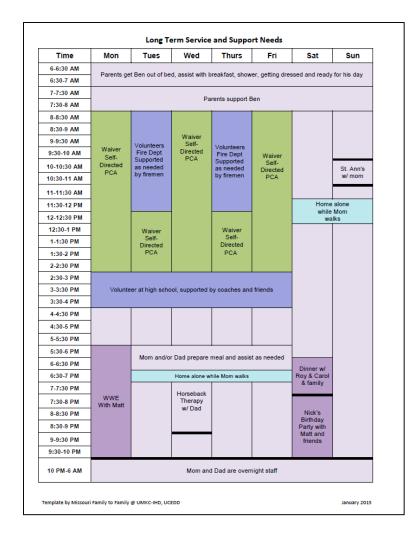
ELIGIBILITY-SPECIFIC

Ben's
Integrated
Services and
Supports

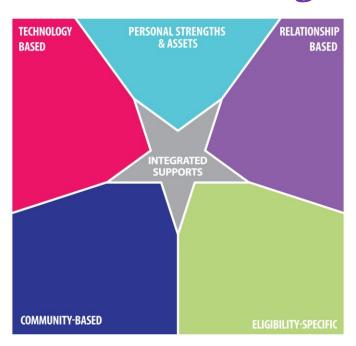


Ben's Integrated Week

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



Adapting, Accommodating and Integrating Supports: Problem Solve Daily Routine



Morning Routine.....Evening Routine



Eric's Focus on Social and Spiritual

PERSONAL STRENGTHS & ASSETS



Happy, Funny and loving
Likes to help people
Likes to try new things
Police cars, tow trucks,
fire engines and racecars
Golf Cart

RELATIONSHIP-BASED

See his girlfriend more Connect with his family Spend more time with friends



COMMUNITY-BASED

Scouts Red Robin Race Tracks INTEGRATED SUPPORTS

.

ELIGIBILITY-BASED

Companion
Supports
day-to-day



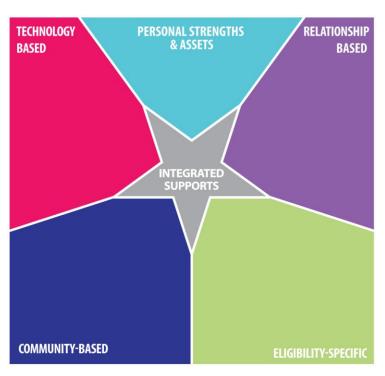
I-pad Smart Phone





Adapting, Accommodating and Integrating Supports: Specific Life Domain





Life Domains

Technology

Personal Strengths & Assets

Relationship Based

Decision Makina

- Smart Phone
- Telephone
- Computer

Money Management

- Online Banking
- Debit Card

Personal Safety

- GPS Enabled Device
- Personal Safety Device
- Remote Monitoring
- Computer or Electronic locks

Decision Making:

 Ability to communicate wants, needs, and wishes (traditional, sign, gesture, communication device)

Money Management:

Understands concept of money

Personal Safety:

- Knows address, phone, other contacts
- Disaster or Emergency Plan
- Ready bag for emergencies

Options & Alternatives To Guardianship

Safety & Security:

Decision Making Supports

- Personal Contract or Agency Agreement
- Power of Attorney -General
- Power of Attorney for Health Care
- Supported (Shared) Decision Making

Money Management

Joint Bank Account

Personal Safety

Close Family & Friends

Decision Making

- Medical Advisors (Doctor, Nurse)
- Clergy or Life Coach
- Financial Advisors
- Educational Advisors (Teacher, Counselor)

Money Management:

- Limited Bank Account
- Direct Deposit
- Automatic Bill Pay

Personal Safety

- Neighbors
- Police
- **Emergency Medical Responders**

Community Based

Decision Making

- Service Coordinator
- Plenary or Limited Guardianship

Money Management

- Representative Payee for SSI, SSDI, VA or other
- Supplemental Special Needs Trust

Personal Safety

- Personal Care Attendant/Direct Care Worker
- Adult Protective Services

Eligibility Specific

Safety and Security: Alternatives Guardianship

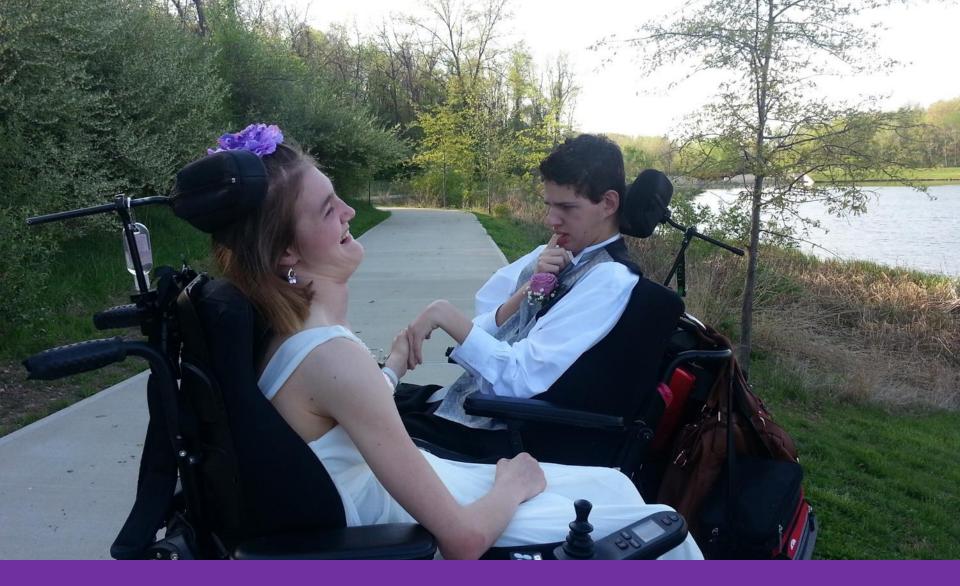


Case Scenarios for Applying LifeCourse Framework and Tools

Your Turn to Try!!!

- 1. Identify a note taker and then read the "case scenario" out loud to your table
- 2. On the Good Life Trajectory worksheet:
 - Fill out what you believe is the persons Good Life and What Wouldn't be a Good Life
 - Star the persons age and list a few life experiences for that stage
- 3. Fill out the Integrated Star worksheet to assist the person to identify, develop or adapt the supports he/she needs to achieve the Good Life

Add the 3 scenerios



Applying the Framework to Transformational Change

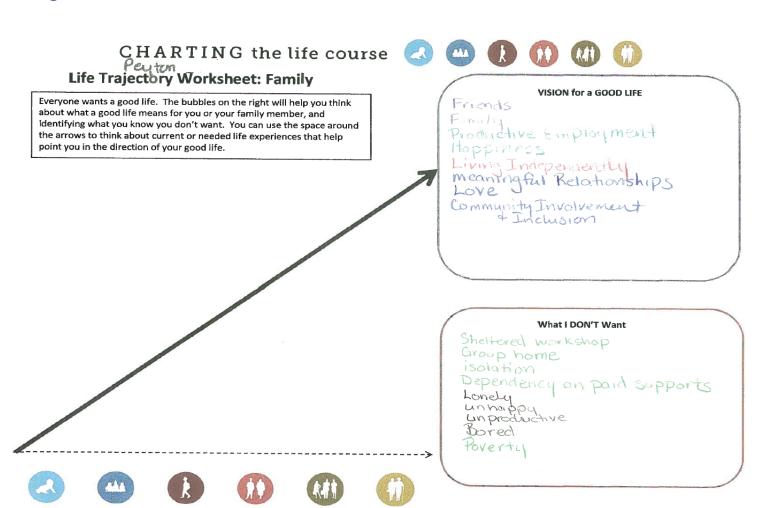
"Creating Space for innovation in Washington"



Peyton's Integrated School Story

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

Peyton's Good "School" Life



B / A V 204 %

Peyton's Integrated Good Life

CHARTING the life course





















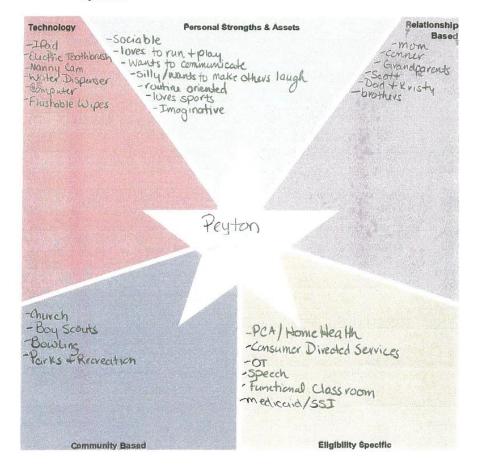






Integrated Services and Supports

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.



Long Term Support Needs

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TIME	MON	TUES	WED	THURS	FRI	SAT	SUN
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10 PM-6 AM		Salah Hari					Andreas Services

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

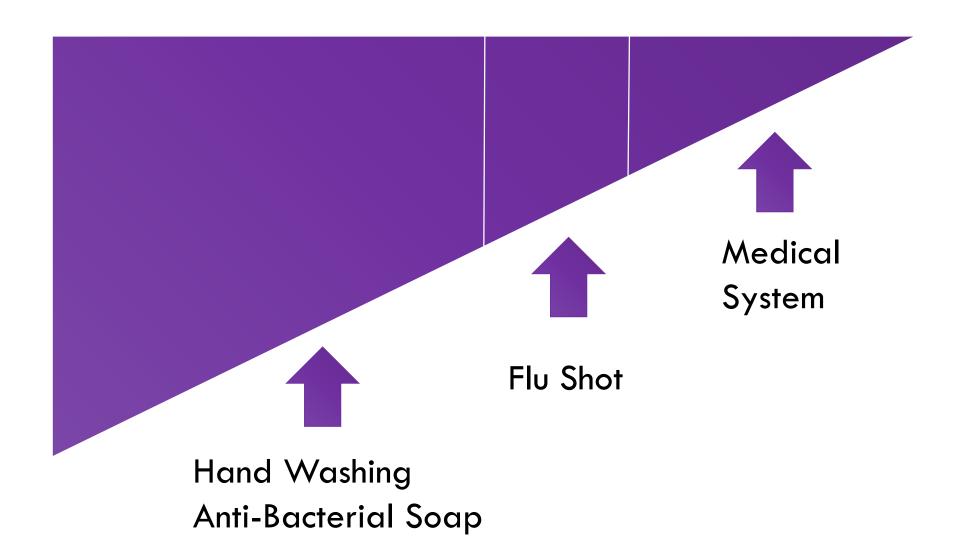
TRANSFORMATION CHANGE

Fundamental reordering of thinking, beliefs, culture, relationships, and behavior

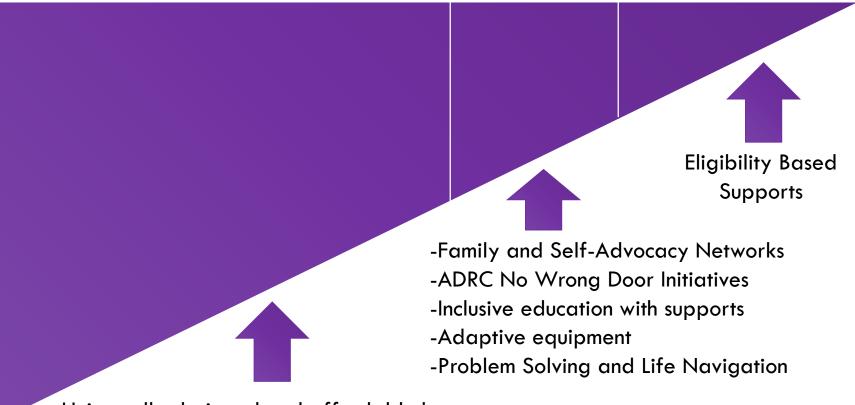
Turns assumptions inside out and disrupts familiar rituals and structures

Rejects command and control relationships in favor of co-creative partnerships

ALL: Public Health Framework



Developing Innovative Strategies for Transformation within and outside DD



- -Universally designed and affordable homes
- -Grocery carts for older kids
- -EMT and Police knowledgeable and supportive
- -Strong families and friends to share lives with
- -Inclusive and accepting spiritual and recreational opportunities



Vision for Integrated Systems & Communities for Good Lives

Pediatrician, Families and Friends, Faithbased

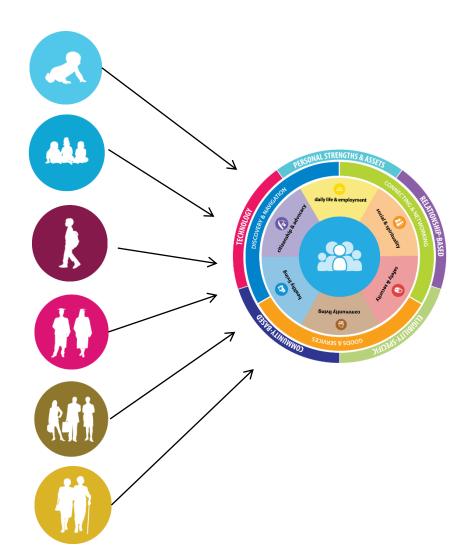
IDEA Part C, Parents as Teachers, Health, Headstart

School, Special Education, Health,
Recreation

Vocational Rehab, Health Employment, College, Military

Disability Services, Health, Housing, College, Careers

Retirement, Aging System, Health

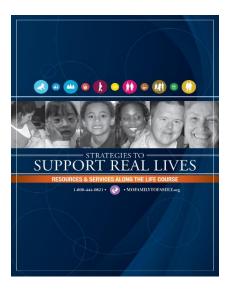




Putting Framework Into Action

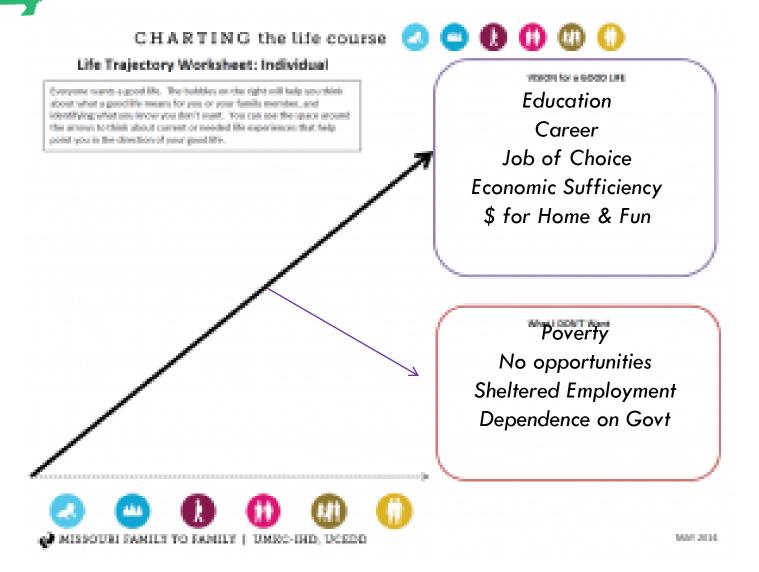
Statewide Systems Partnering to Disseminate a Consistent Message

- Early Childhood and Part C
- School Districts, Special Education
- PNS Show Me Career Employment Grant State
- Division of Developmental Disability
- Special Health Care Needs
- Missouri Family to Family Health Info Center





Trajectory Towards Employment



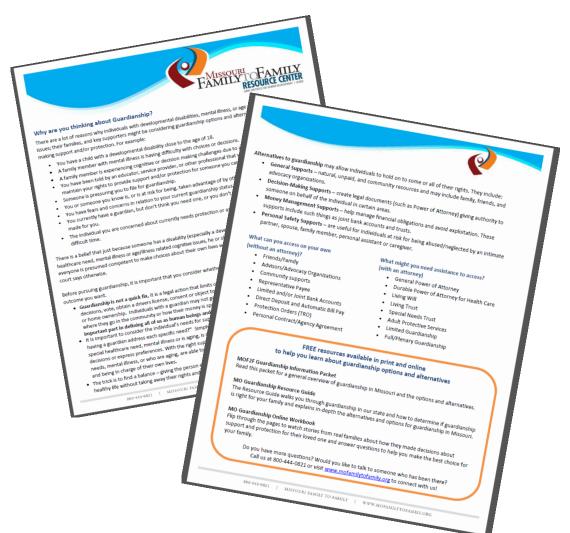


Developed Youth Transition Packet

- Identified the Need to get information into the hands of self-advocates and families transitioning from High School
- Committee of people who have experience at Transition Age developing a draft packet
- Using LifeCourse network and Show Me Career group for further review and suggestions



Partnering in Communities on Transitioning to Adulthood



- Show Me Pilot Community organizations all recognized the impact of the scary letter from schools
- Partnered with F2F to use Alternative to Guardianship materials
- Getting the right materials into the hands of the people on the front line who could get them to families



Hosted Youth Leadership Academy and LifeCourse

Different Marketing Strategies

Materials focused less on "employment" and more on adult life outcomes

Included family members and other supporters to attend with you

Use LifeCourse Framework for Content

Adapted the tools and activities to be youth-focused, interactive and fun Developed concrete "take home" tools with vision and plans

YOUTH LEADERSHIP ACADEMY

School won't last forever... What will a good life look like for you as an adult?

Bring a supporter (like your mom or dad, a teacher or friend) to this two-day retreat to plan your vision for a good life after high schoo!!

This is an interactive event full of fun and games. Sign up today!





















WILL HAY wmhays@loqw.co 573-735-4282.ext.10











What's next in Snohomish County and Washington??

Specific Next Steps and Recommendations

Level I: What changes are you going to make in your **own life or job**, based on what you heard today?

Level II: What are some specific **organizational recommendations**, for where you work or where you receive supports? (Please name organization)

Level III: What are some specific **systems or policy** recommendations that must occur to achieve a "Good Life" for all in Snohomish County or Washington?

Our Good Life



Life isn't about how to survive the storm, but how to dance in the rain.

-unknown



Questions, Reflections and Discussion

Contact Information

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