

Real Life Examples: Life Course Tools in Action


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John's Vision for Good Life: Developed at Annual Person Centered Planning Meeting with Support Coordinator

Vision for a Good Life

- * Visit Mom / spend time as she gets older
- * Making good \$, job I Love
- * Moving forward → , Internet
Being my own guardian - don't want to rush, being in control of \$, not having
- * Living alone - no roommate - ^{lots of} _{grocery staff} _{transportation} _{+ chore}
- * Doing more lawn/snow blowing business
- * Not getting bored - ever!
Getting support on my own terms

What I DON'T Want

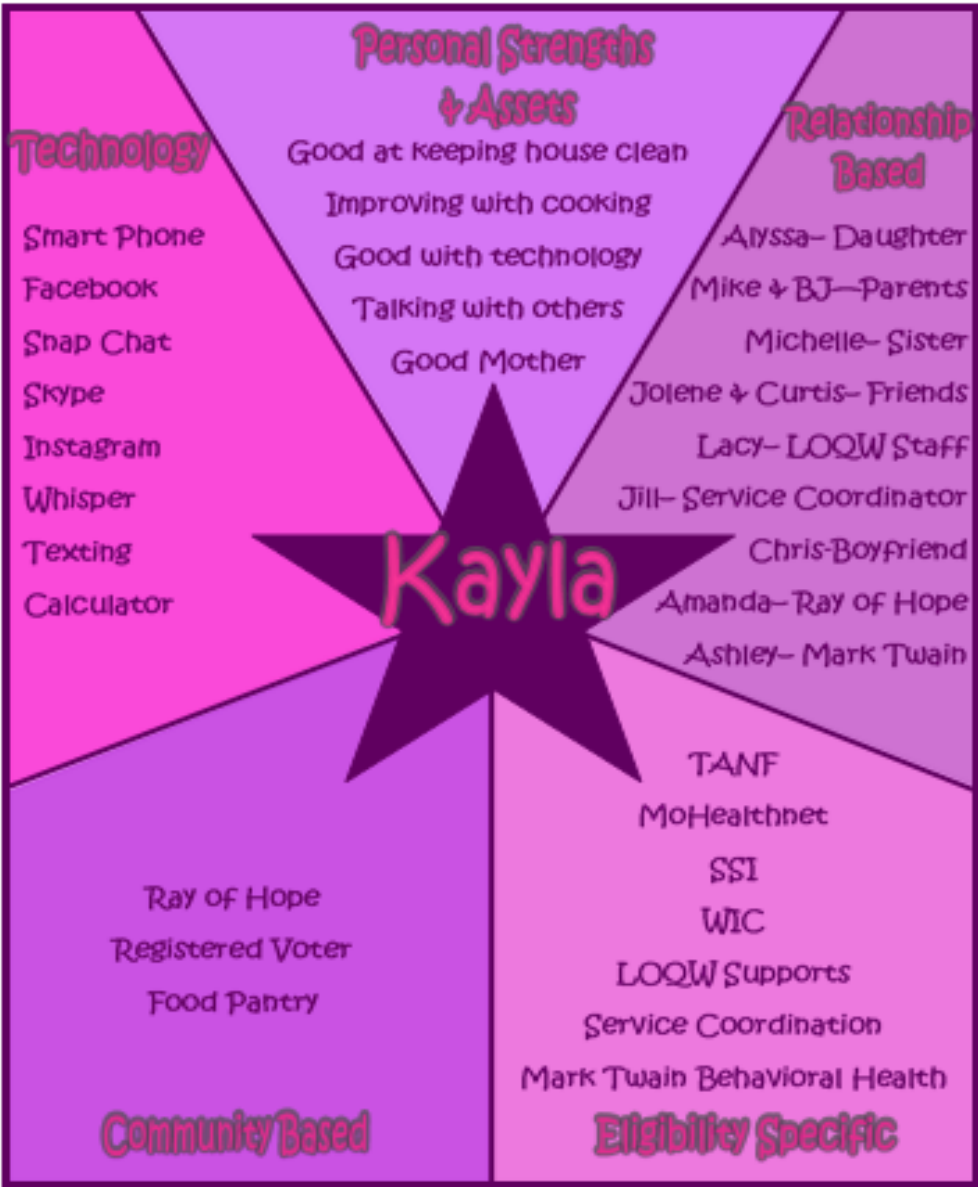
Lose job

Not having reliable transportation
not feeling trapped, restricted, stuck

Not being in placement ^{→ staff} rest of your life.

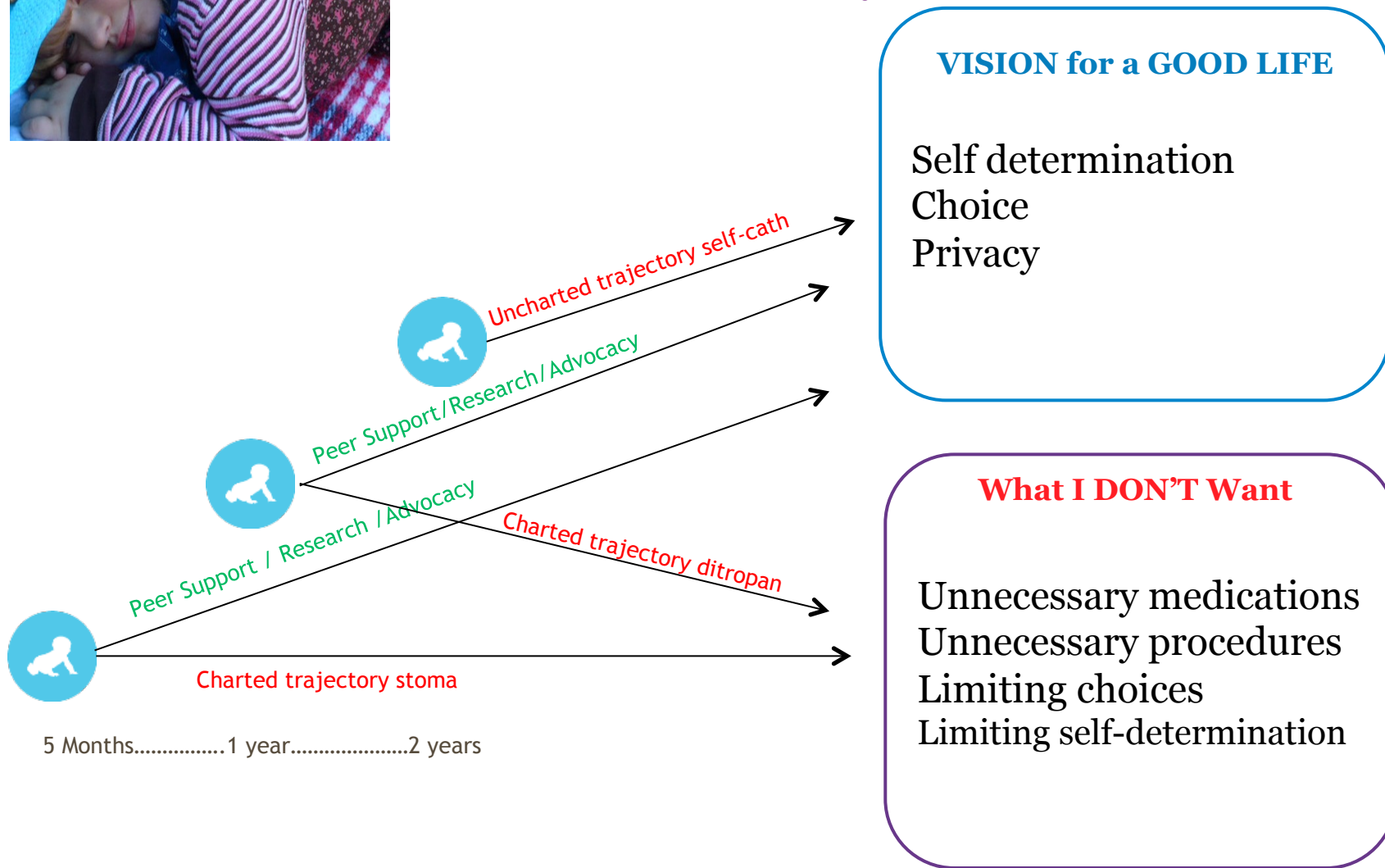
Others making the rules/decisions

Integrated Stars Map Developed During Annual Person Center Planning Meeting with Support Coordinator





Elizabeth's Health Trajectory As Told by Her Mother



Ben's "Self-Directed" GOOD LIFE



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

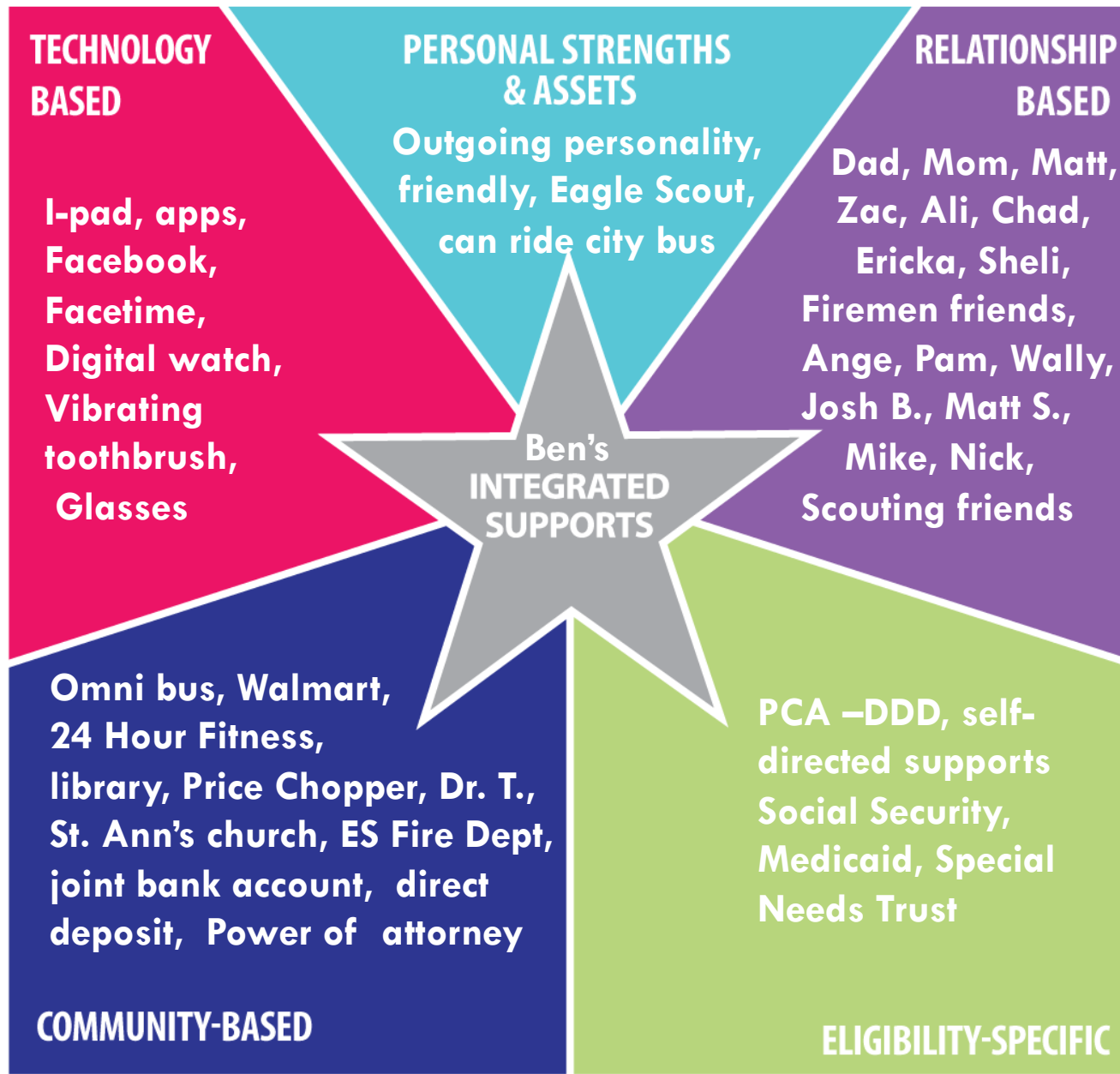
HOW BEST TO SUPPORT ME

- 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

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

*(Ben's One
Page Profile)*

Ben's
Integrated
Services
and
Supports
Star



Ben's Integrated Week

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								
1:30-2 PM								
2-2:30 PM								
2:30-3 PM								
3-3:30 PM								
3:30-4 PM								
4-4:30 PM	Mom and Dad provide all support, including meals, transportation and support for activities, etc.							
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	Mom and Dad are overnight staff							

Template by Missouri Family to Family @ UMKC-IHD, UCEDD
December 2014

Long Term Service and Support Needs														
Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun							
6-6:30 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day													
6:30-7 AM														
7-7:30 AM								Parents support Ben						
7:30-8 AM														
8-8:30 AM	Waiver Self-Directed PCA	Volunteers Fire Dept Supported as needed by firemen	Waiver Self-Directed PCA	Volunteers Fire Dept Supported as needed by firemen	Waiver Self-Directed PCA	St. Ann's w/ mom								
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	Home alone while Mom walks		Home alone while Mom walks											
1:30-2 PM														
2-2:30 PM	Home alone while Mom walks		Home alone while Mom walks											
2:30-3 PM														
3-3:30 PM	Volunteer at high school, supported by coaches and friends													
3:30-4 PM	Mom and/or Dad prepare meal and assist as needed													
4-4:30 PM														
4:30-5 PM														
5-5:30 PM														
5:30-6 PM														
6-6:30 PM														
6:30-7 PM								Home alone while Mom walks				Dinner w/ Roy & Carol & family		
7-7:30 PM														
7:30-8 PM								WWE With Matt		Horseback Therapy w/ Dad		Nick's Birthday Party with Matt and friends		
8-8:30 PM														
8:30-9 PM														
9-9:30 PM														
9:30-10 PM														
10 PM-6 AM	Mom and Dad are overnight staff													

Template by Missouri Family to Family @ UMKC-IHD, UCEDD
January 2015

Peyton's Integrated School Story

How the Story Began: Peyton

Family wants Peyton to attend the neighborhood school with his brother and his school age peers

School believes that Peyton will be best supported in a next year in a segregated setting, in a different building which does not have students his age

During the IEP meeting, the school and parent became grid-locked on a what more inclusive day could look like for Peyton (he was not included in homeroom, lunch, specials or other general education class)

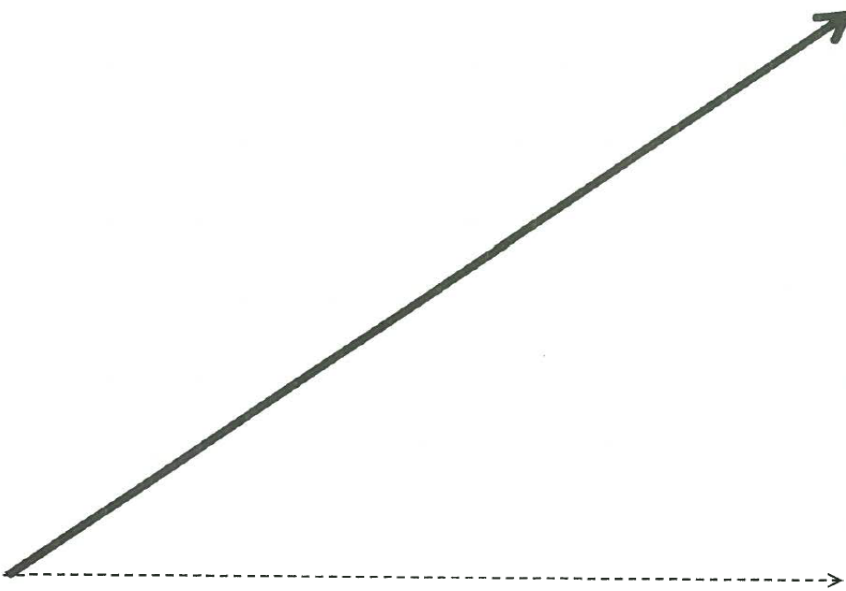
Two weeks later, Mom brought Peyton's trajectory, integrated star and weekly schedule to the follow-up IEP. The school better understood what she wanted and have made more concrete strides at meeting his inclusion needs.

Peyton's Good "School" Life

CHARTING the life course Peyton Life Trajectory Worksheet: Family



Everyone wants a good life. The bubbles on the right will help you think about what a good life means for you or your family member, and identifying what you know you don't want. You can use the space around the arrows to think about current or needed life experiences that help point you in the direction of your good life.



VISION for a GOOD LIFE

Friends
 Family
 Productive Employment
 Happiness
 Living Independently
 meaningful Relationships
 Love
 Community Involvement
 + Inclusion

What I DON'T Want

Sheltered workshop
 Group home
 isolation
 Dependency on paid supports
 lonely
 unhappy
 unproductive
 Bored
 Poverty



Peyton's Integrated Good Life

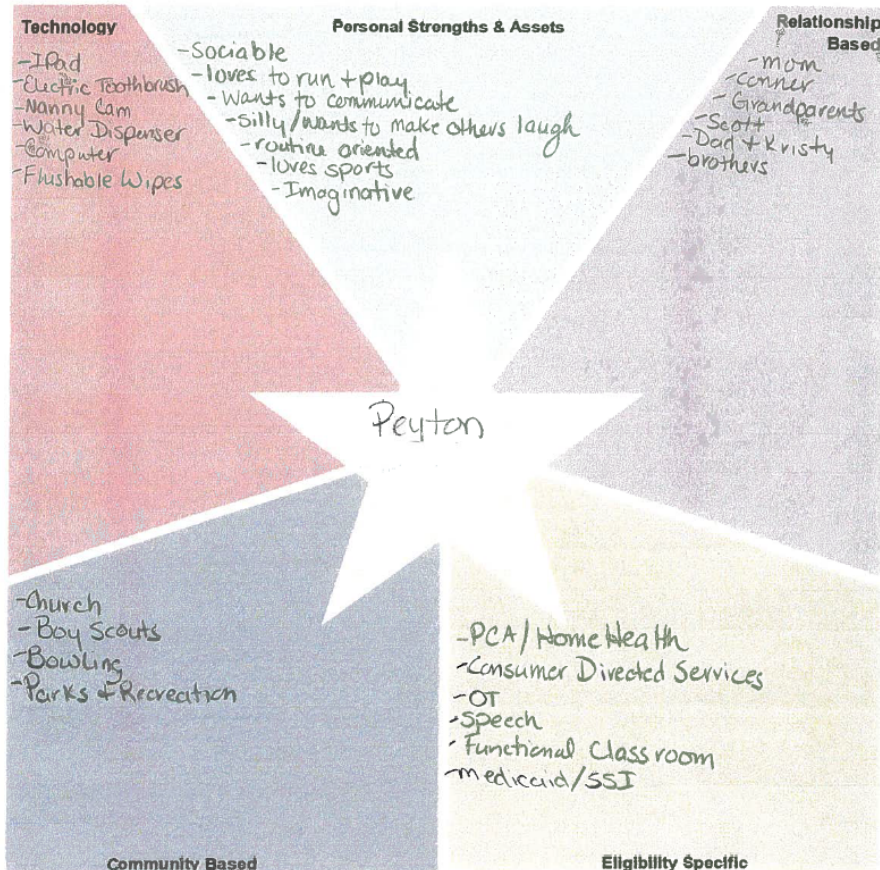
CHARTING the life course



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.



CHARTING the life course



Long Term Support Needs

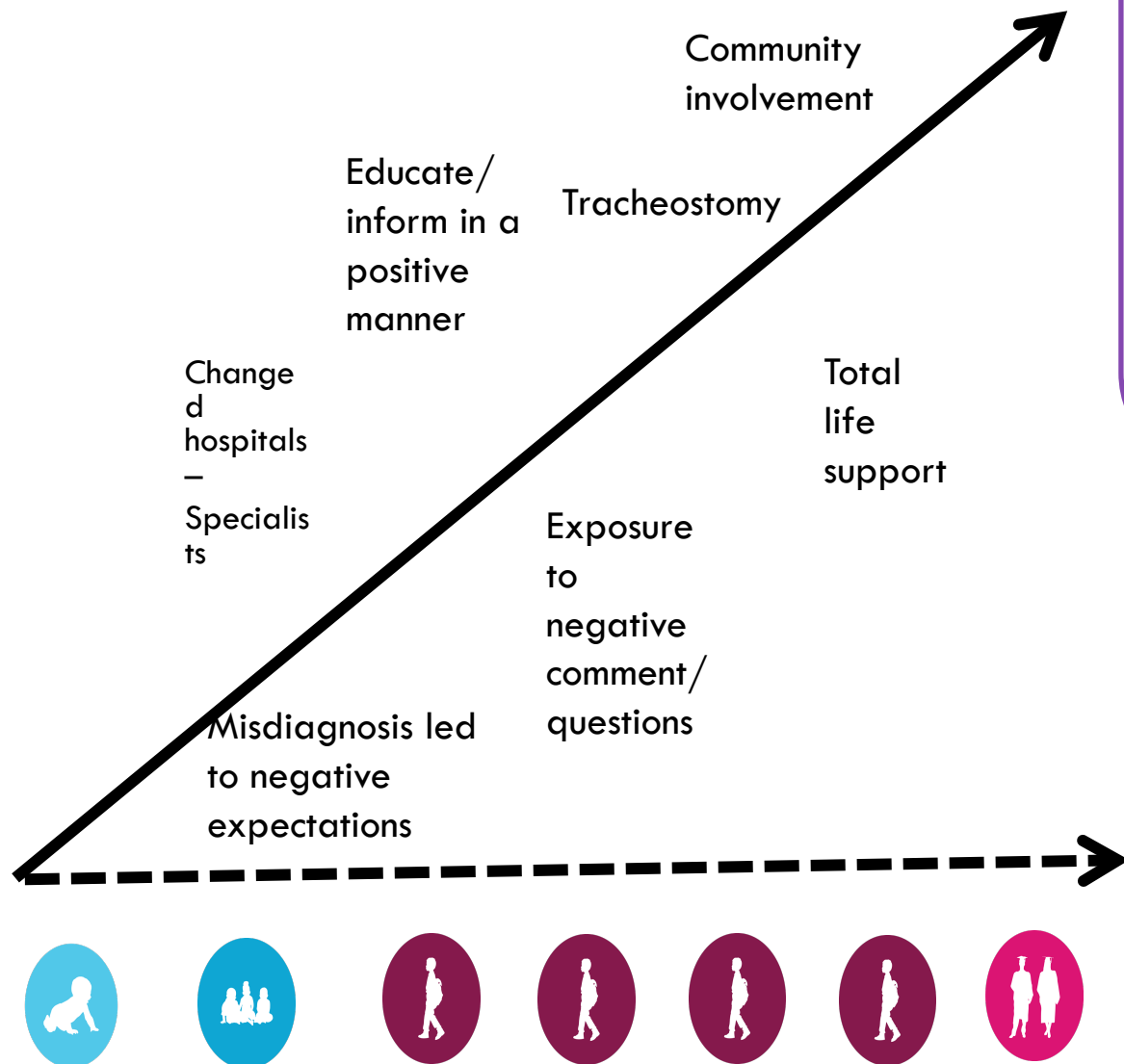
TIME	MON	TUES	WED	THURS	FRI	SAT	SUN
6-6:30 AM							
6:30-7 AM							
7-7:30 AM							
7:30-8 AM							
8-8:30 AM							
8:30-9 AM							
9-9:30 AM							
9:30-10 AM							Church
10-10:30 AM							
10:30-11 AM							
11-11:30 AM							
11:30-12 PM							
12-12:30 PM							
12:30-1 PM						PCA/	Time with family
1-1:30 PM							
1:30-2 PM						Home Health	
2-2:30 PM							
2:30-3 PM							
3-3:30 PM							
3:30-4 PM							
4-4:30 PM	PCA/	PCA/	PCA/	PCA/	PCA/		
4:30-5 PM	Home Health	Home Health	Home Health	Home Health	Home Health		
5-5:30 PM							
5:30-6 PM							
6-6:30 PM							
6:30-7 PM							
7-7:30 PM	Boy Scouts						
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM							

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

- Self-determination
- Participation in activities he likes
- Learn medical self-care

What We DON'T Want

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



Izaac's Integrated Services and Supports

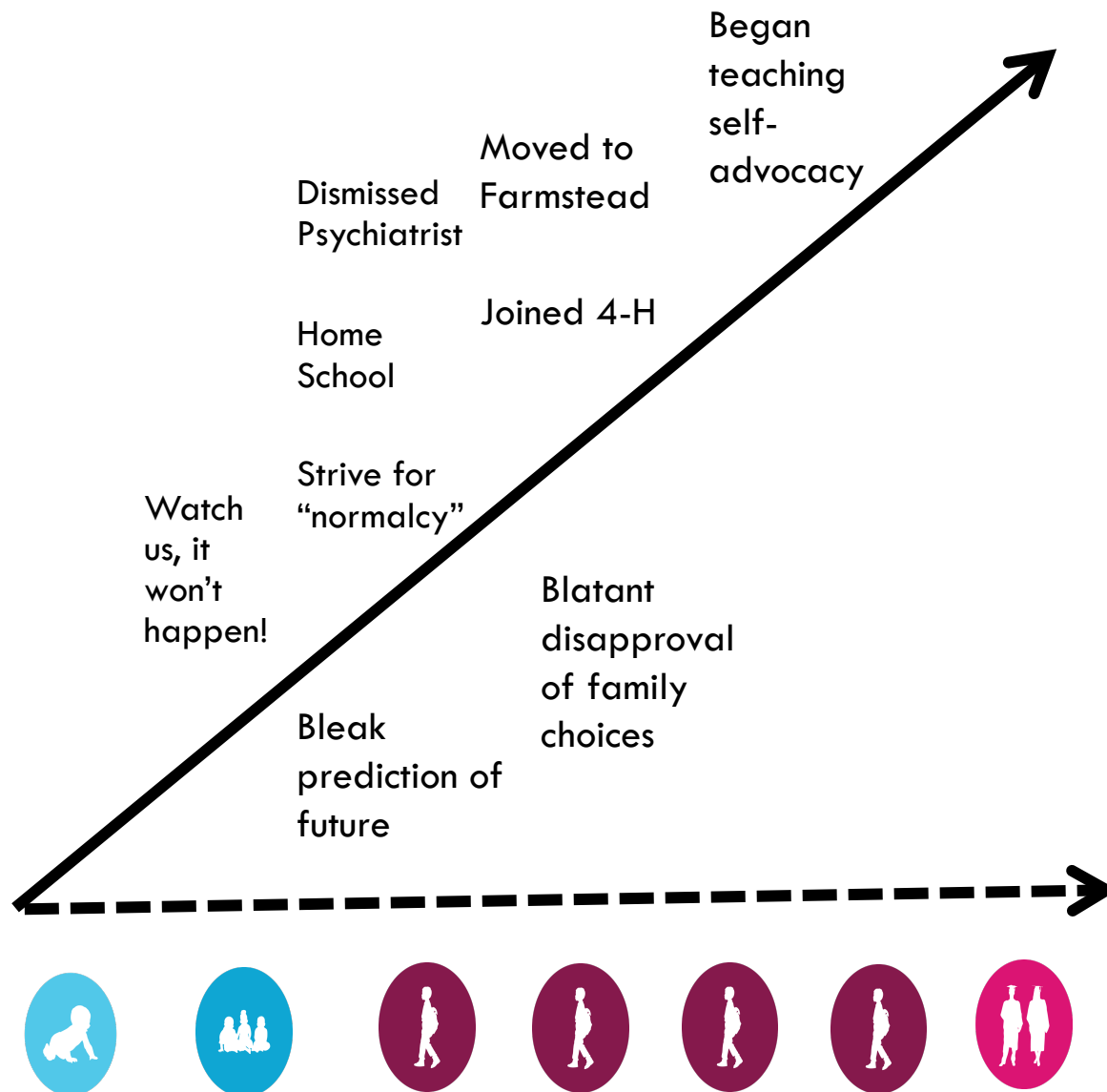


How the Story Began: Shaylee

- 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 I-pad daily
schedule

PERSONAL STRENGTHS & ASSETS

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

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.

SHAYLEE'S INTEGRATED SUPPORTS

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

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

COMMUNITY-BASED

ELIGIBILITY-SPECIFIC

Shaylee's Integrated Services and Supports

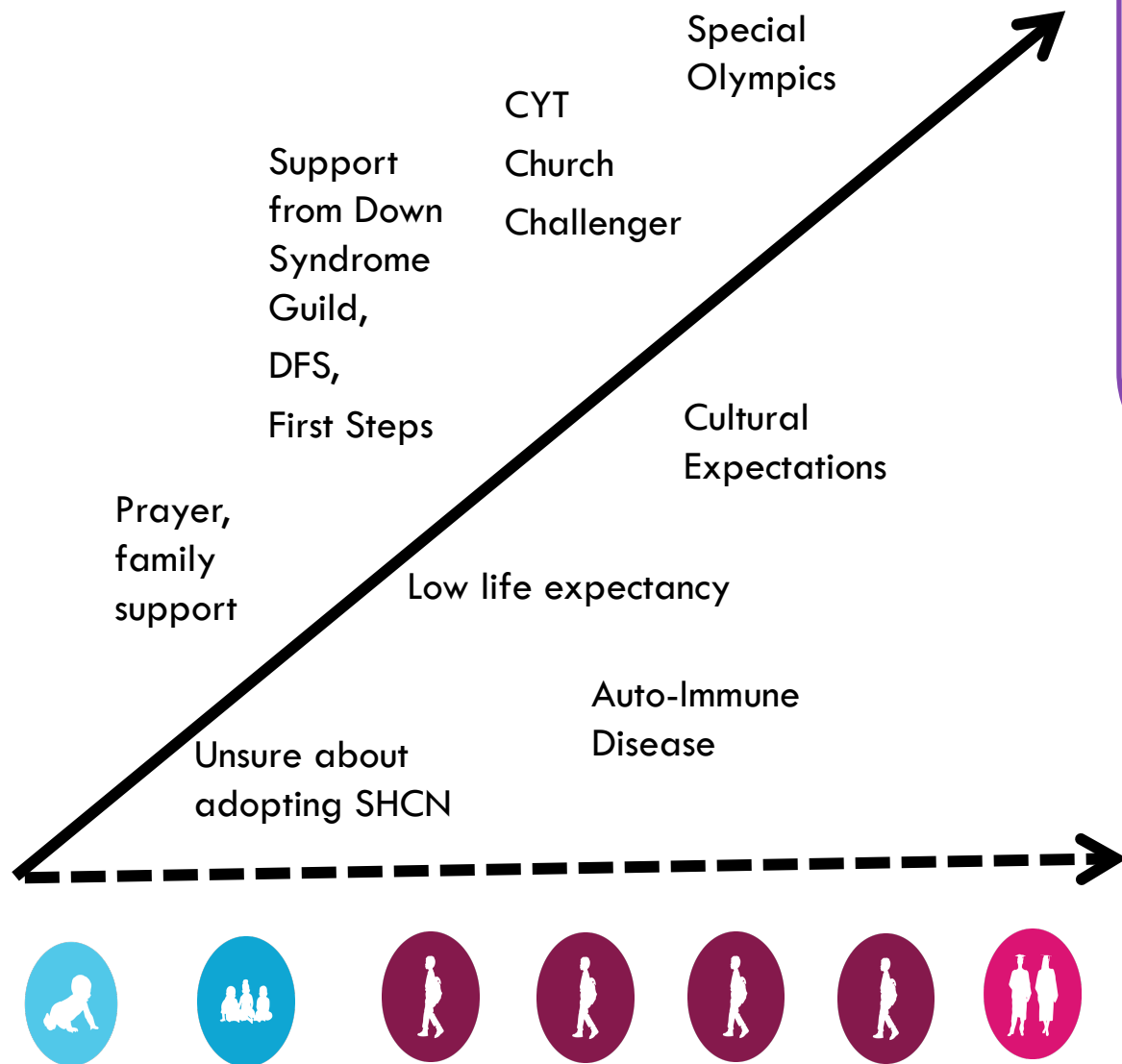


How the Story Began: Darcie

- Premature birth to incarcerated mother
- Drug/alcohol exposed
- Down syndrome
- Division of Family Services
- Foster/adoptive care



Shaping the Rest of the Story: Darcie



What We Want

- Increase independence skills
- Increase appropriate social interactions
- Make a good transition to high school

What We DON'T Want

- Others to make decisions for our family
- Don't want her disability to impact how she's treated by others
- Unnecessary testing

TECHNOLOGY BASED

Tablet
Laptop
Smart phone apps
Chrome Book –
school
Microwave Popcorn
TV/DVD

PERSONAL STRENGTHS & ASSETS

Friendly
Outgoing
Compassionate
Loving
Sassy

RELATIONSHIP BASED

Family
CYT Friends, church
friends, school
friends, Teachers at
school and church
Family friends
Helping Friend
STARS Friends

DARCIE'S INTEGRATED SUPPORTS

Grocery stores, clothing stores,
thrift stores, etc
Christian Youth Theater
Church
Down Syndrome Guild of
Greater KC

Down Syndrome Clinic
Special Olympics
Insurance

COMMUNITY-BASED

ELIGIBILITY-SPECIFIC

Darcie's Integrated Services and Supports



For more information:

Contact Sheli Reynolds

reynoldsmc@umkc.edu

Check out the resources on:

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

[Supportstofamilies.org](http://supportstofamilies.org)

Mofamilytofamily.org