



# Charting the LifeCourse and Person Centered Thinking

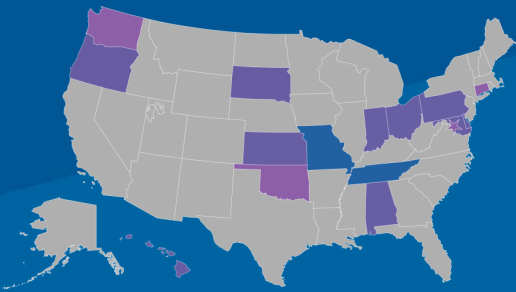
SIBLING   
LEADERSHIP  
NETWORK

Emma Shouse Garton, Tennessee

Barb Sapharas, Ohio

Alison Whyte, D.C.





## National Community of Practice for Supporting Families

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.

## National Partners



# Barb's Story

- sister of Nick and Jim
- Worked in IDD field for over 40 years
- Cleveland, Ohio area
- Member of National Charting the LifeCourse Nexus Team
- Mentor Trainer in The Learning Community for Person Centered Practices (TLC-PCP)



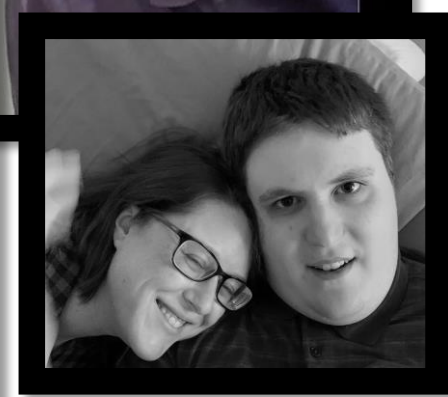
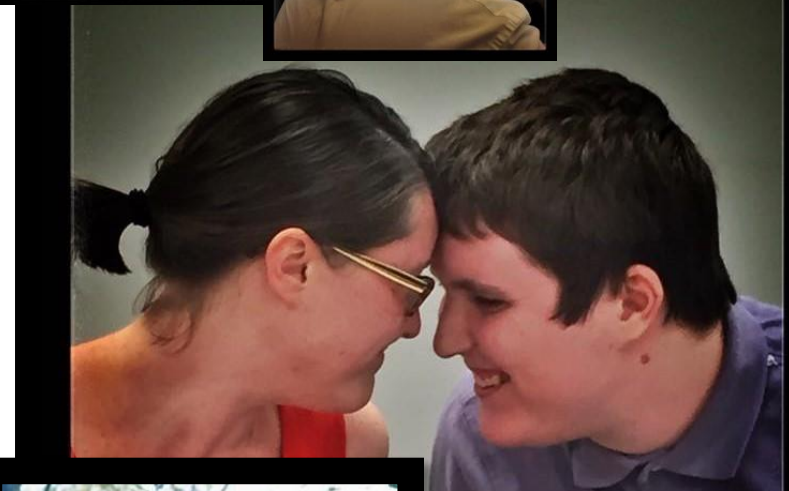
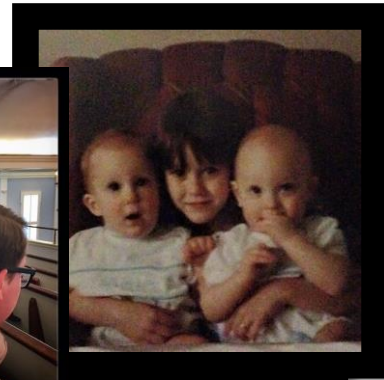
# Alison's story

- Grew up in Michigan with an older sibling with a disability
- I live in Washington, DC with my spouse and cats. My sibling lives in Wisconsin. My parents still live in Michigan.
- My sister visits me in DC once a year and we usually see each other in the Midwest a few times too.
- One lesson learned from this work: Families are complicated! While we may share similar experiences, we are all also on unique journeys. PCT and CtLC are also about having compassion for each other as we navigate our worlds.



# Emma's story

- Grew up near and still live in Nashville, TN
- Public Information Specialist at the TN Council on Developmental Disabilities since 2011
- Coordinate the state sibling support chapter of the national Sibling Leadership Network for TN – “TABS”, TN Adult Brothers and Sisters
- Have 2 younger brothers, Evan and Brendan; Evan has autism and other disabilities.
- One lesson learned from this work – all members of families need support, and that support will look different over time and life stage of all members.





# Reframing Support Systems

Person-Centered Supports within Context of the  
Family and Community

# Charting the LifeCourse Framework



*Developed by and for people with disabilities  
and their families*





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



9



The focus is on the “person with a disability”  
but this does NOT mean that  
“Family Engagement” supersedes the  
INDIVIDUAL

It is not.....

family involvement VS person-centered

It is....

Person and Family Centered Supports

## Family Engagement

*Family Engagement* is a component of a holistic approach to person centered supports that recognizes the context and impact of the family in practice and policy implementation.



# Individuals live within the context of their Families and Community

Families.....

- Are defined by the individual
- Need supports that adjust as roles and needs of all members change
- Aren't only defined by where the person lives





# Reciprocal Roles of ALL Members



Caring About

**Affection & Self-Esteem**

**Repository of knowledge**

**Lifetime commitment**



Caring For

**Provider of day-to-day care**

**Material/Financial**

**Facilitator of inclusion & membership**

**Advocate for support**



# Achieve “Good Life for All”

## 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

**DISCOVERY  
AND NAVIGATION**  
Knowledge & Skills

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

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



\* Hecht, E., Reynolds, M., Agosta, J., & McGinley, K. (2011). *Building an agenda for supporting families with a member with intellectual and developmental disabilities. Report of the Wingspread Conference on building a family support agenda, March 6-8, 2011. Racine, Wisconsin: Johnson Foundation.*



# Person Centered Thinking

***Person Centered thinking underlies and guides respectful listening which leads to actions, resulting in people who:***

- Have positive control over the life they desire and find satisfying;
- Are recognized and valued for their contributions (current and potential) to their communities; and
- Are supported in a web of relationships, both natural and paid, within their communities




# Person Centered Thinking

Helps people  
get better lives

***Not just better  
paper***

# Supported Decision Making & Positive Control

**CHARTING the LifeCourse** 

**Tool for Exploring Decision Making Supports**

This tool was designed to assist individuals and supporters with exploring decision making support needs for each life domain.




Name of Individual: \_\_\_\_\_

Name of person completing this form: \_\_\_\_\_

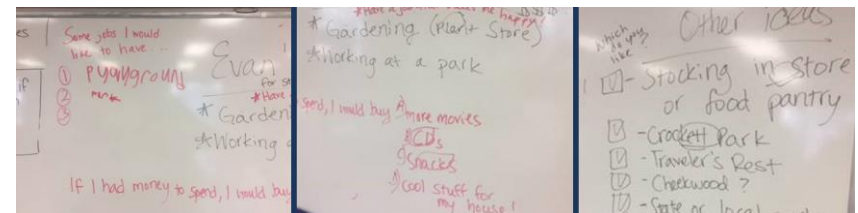
Relationship to individual (circle one): Self Family Friend Guardian Other: \_\_\_\_\_

How long have you known the individual? \_\_\_\_\_

For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.

	 I can decide with no extra support	 I need support with my decision	 I need someone to decide for me
<b>DAILY LIFE &amp; EMPLOYMENT</b>			
Can I decide if or where I want to work?			
Can I look for and find a job (read ads, apply, use personal contacts)?			
Do I plan what my day will look like?			
Do I decide if I want to learn something new and how to best go			

- How can we support someone to make as many of their own choices as possible?
- What does that support look like for your sibling?







# Core Concepts of Person Centered Thinking

- Identify:
  - What is important TO the person
    - People to be with/relationships, status and control, things to do and places to go, rituals and routines, rhythm or pace of life, things to have
  - What is important FOR the person
    - Health, safety, and valued as contributing member of community
- And find the balance

What is *important to a person* includes those things in life which help us to be satisfied, content, comforted, fulfilled, and happy. It includes:

- People to be with/relationships
- Status and control
- Things to do and places to go
- Rituals or routines
- Rhythm or pace of life
- Things to have



What is  
important  
TO A PERSON

## Important FOR a person

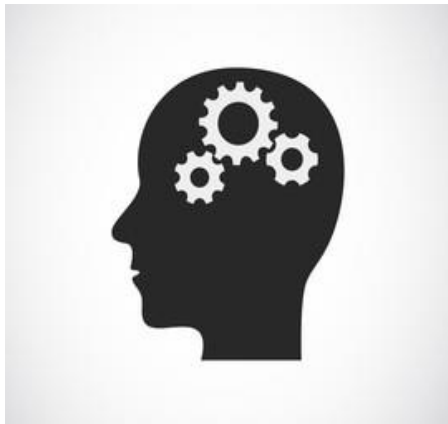
- Issues of *health*:
  - Prevention of illness
  - Treatment of illness / medical conditions
  - Promotion of wellness (e.g.: diet, exercise)
- Issues of *safety*:
  - Environment
  - Well being ---- physical and emotional
  - Free from fear
- What others see as necessary to help the person:
  - Be valued
  - Be a contributing member of their community



What is  
important  
FOR A PERSON

# Valued, Contributing Member of Community

## -Share our Gifts



**Head**



**Heart**



**Hands**

# What is a GOOD LIFE?

- Have dreams
  - Without dreams, we don't have a life and all we get is what we are given
- Have people who believe in us
- Have what is important TO us
- Respected and valued as a contributing member of our community
- Have more good days than bad
- Feel healthy and safe
- Have control

# Life Domains = Outcomes



**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 and issues, guardianship options and alternatives )

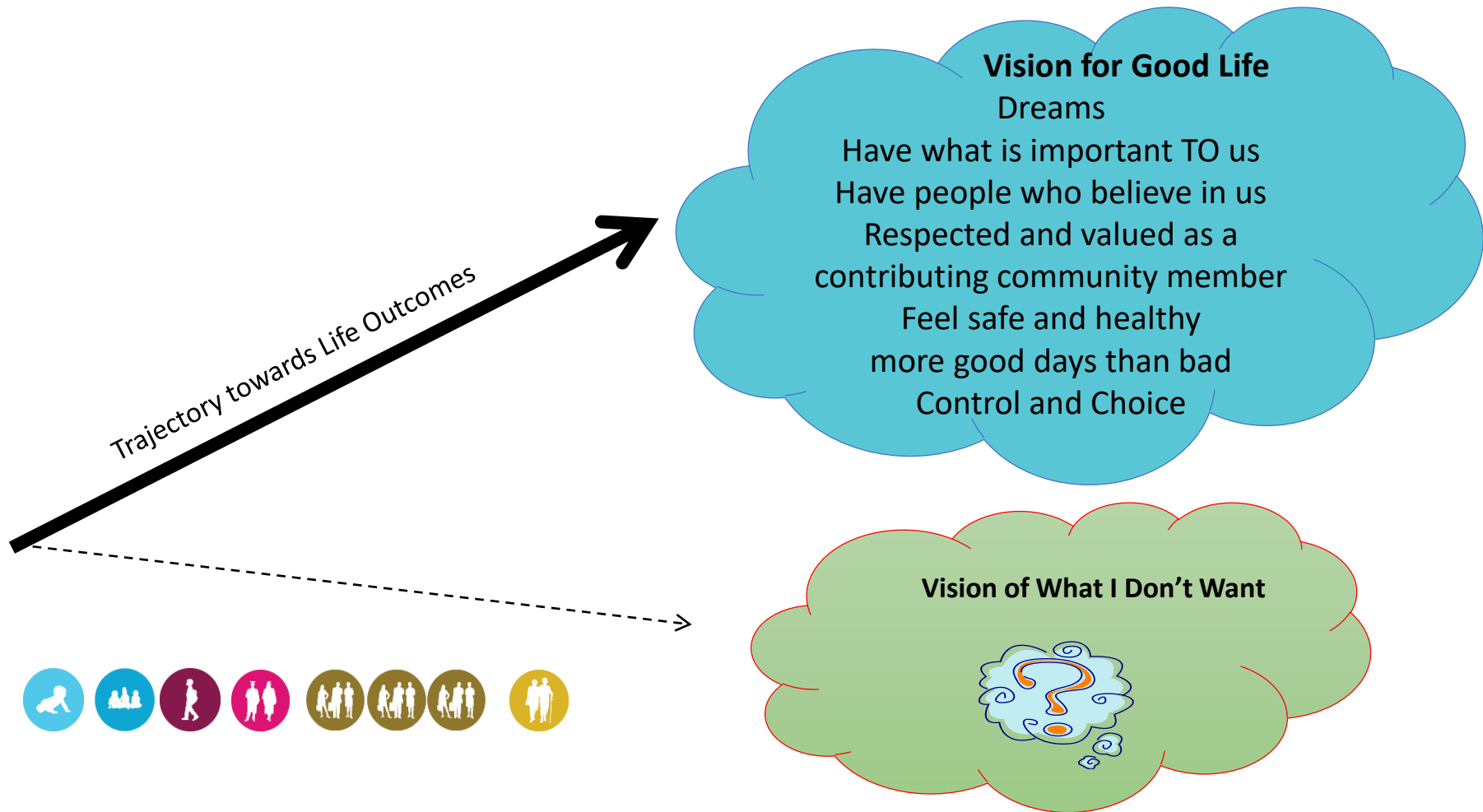


**Social and Spirituality**  
(friends, relationships, leisure activities, personal networks, faith community)



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

# Trajectory towards Good Life



# Life Experiences = Life Outcomes





# Charting the LifeCourse PORTFOLIOS

**Life Trajectory Worksheet**

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

**Write current state here**

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

**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...

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

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

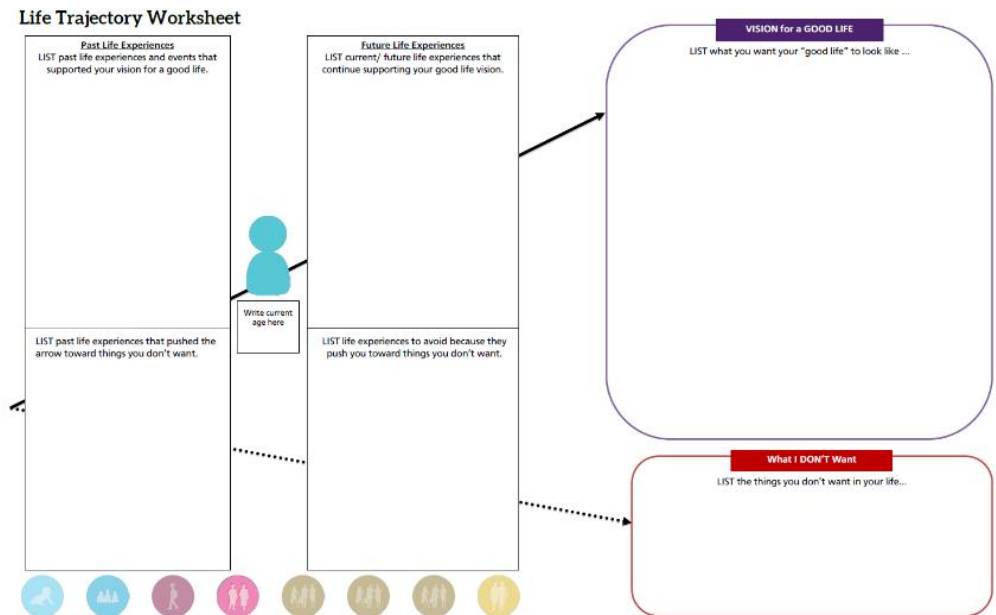
The diagram shows a central figure with an arrow pointing right. To the left, a box for 'Past Life Experiences' has an arrow pointing to the figure. Below it, a box for 'Write current state here' has a dotted arrow pointing to the figure. To the right, a box for 'Future Life Experiences' has an arrow pointing to the figure. Further right, a large box for 'VISION for a GOOD LIFE' has an arrow pointing from the 'Future Life Experiences' box. Below the vision box, a box for 'What I DON'T Want' has a dotted arrow pointing from the 'Future Life Experiences' box. At the bottom left, there are icons for a person, a group of people, a person with a star, a person with a heart, a person with a gear, a person with a lightbulb, and a person with a star. At the bottom right, it says 'OCTOBER 2016'.

## 3 TOOLS

- One Page Description
- Expanded Trajectory
- Integrated Star

# LifeCourse Trajectory (Expanded Version)

- Things to consider:
  - What is your vision of a good life for yourself/your family member ?
  - What do you want to avoid?
  - Consider: all the life domains, what is important to you, your dreams, being valued
  - Be specific! (Don't just write categories - family, home, health, finance)
  - Without the details, the info is not clear and does not provide guidance
  - Info should be from person (if from other's perspective- identify)



# Charting the LifeCourse Trajectory

EVAN SHOUSE

## Employment Trajectory Worksheet

**Past Life Experiences**  
LIST past life experiences and events that support your employment vision.

- Supportive teachers/aides, IEP team
- Making choices about activities
- Trying job tasks like sorting, shredding
- Computer/typing skills

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

- Not always being challenged
- Few social outlets or activities
- Not yet found effective communication system
- Others talking for Evan, not allowing him to make choices

Write current age here  
21

**Future Life Experiences**  
LIST current/ future life experiences that continue supporting your employment 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 OVERALL "good life" to look like ...

- A good place to live that feels like home
- A job he enjoys
- Valued at church, in social groups
- Stays healthy, active
- Makes choices about how he spends day

LIST what you want for your "good life" EMPLOYMENT vision...

- A job he looks forward to going to
- Appreciated + valued by coworkers, Supervisors
- Gifts/strengths recognized

Conditions:

- Quiet + calm environment
- Uniform pace, predictable routine
- Can interact some w/ peers (adults, not kids)

Preferences:

- Variety of tasks
- Physical activity/movement
- Indoor + outdoor work

Support Needs:

- Sensory breaks
- Motivated by affirmation
- Visual schedule
- Help learning routine + new tasks

**What I DON'T Want**

LIST what you DON'T want in your OVERALL life...

- Feeling lonely
- Feeling bored
- Lack of choices
- Feeling powerless
- Disrespected, ignored
- Poverty

LIST the things you don't want in EMPLOYMENT...

- Chaotic, loud, busy workplace
- To be around kids

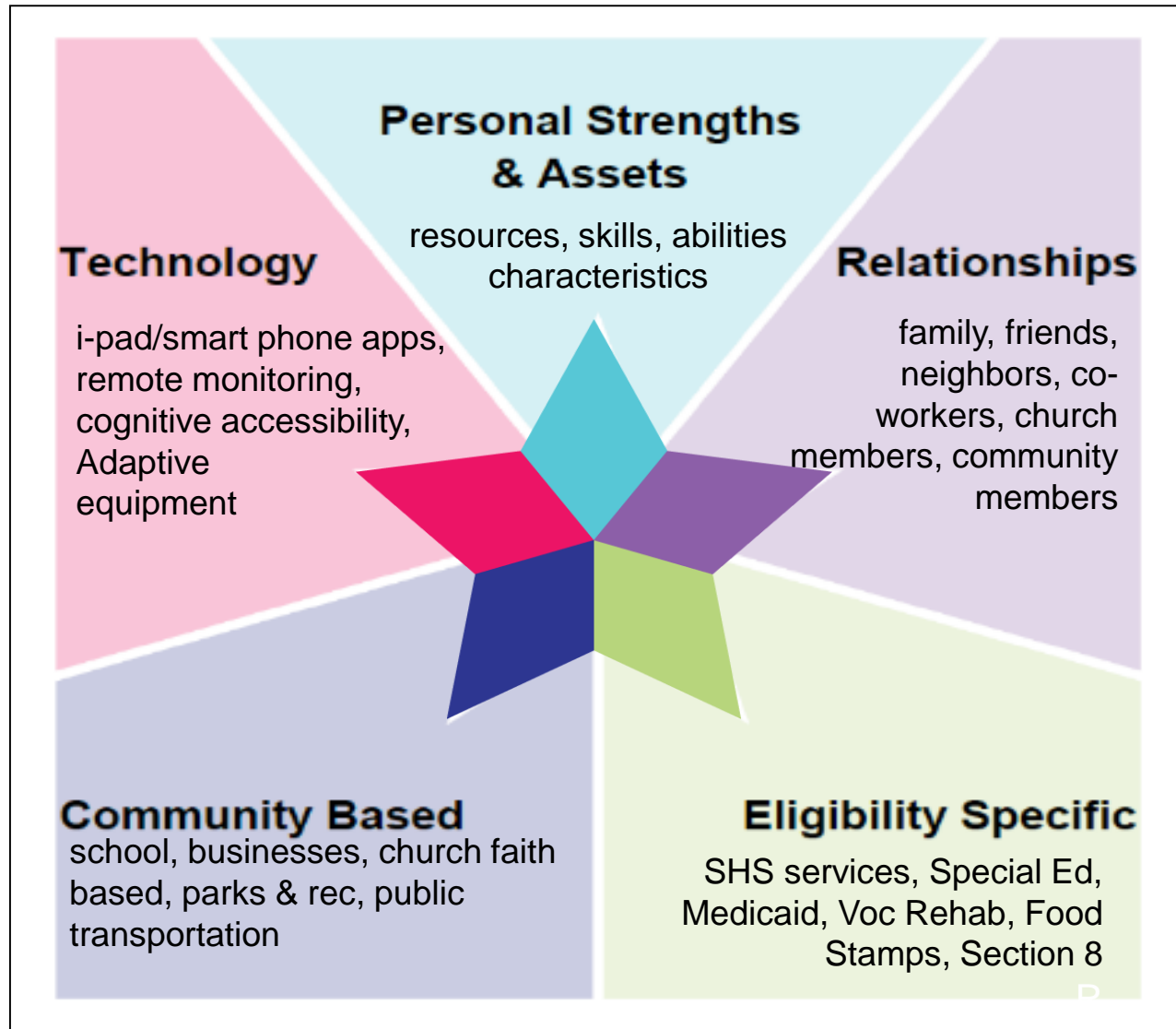




Integrated Star for Supporting Good Lives



# Integrated Supports STAR





# Integrated Supports STAR for Problem Solving and Exploring Options

## PERSONAL STRENGTHS & ASSETS

### **Strengths:**

Things a person is good at  
or others admire or like

### **Assets:**

Resources that are owned  
or can be accessed by the person

### **Skills:**

Personal abilities,  
knowledge or experience



# Integrated Supports STAR for Problem Solving and Exploring Options

## RELATIONSHIPS

### **Family:**

People that love, care about, and are committed to each other

### **Friends:**

People that enjoy spending time together, have things in common, and care about each other

### **Acquaintances:**

People that come into frequent contact with the person but don't know them well.





# Integrated Supports STAR for Problem Solving and Exploring Options

## TECHNOLOGY

**Personal Technology:**  
Common technologies  
used by anyone \*

**Environmental Technology:**  
Innovative technologies  
designed to help a person  
navigate or adapt their  
environment\*

**Assistive Technology:**  
Low-tech or specialized devices  
that assist a person with  
day-to-day tasks\*







# Integrated Supports STAR for Problem Solving and Exploring Options



## COMMUNITY RESOURCES

### **Places:**

Businesses, faith communities,  
parks and recreation, health care facilities

### **Groups:**

Civic and membership organizations

### **Government Resources:**

Local services, i.e.: public safety,  
legal, social programs



# Integrated Supports STAR for Problem Solving and Exploring Options



## **ELIGIBILITY-SPECIFIC SUPPORTS**

### **Disability Specific:**

Supports received based on a diagnosis,  
ie: Special Education, Government Funded Disability  
Supports

### **Needs-based:**

Supports based on age, gender, geographics,  
income level or employment status

# Integrated Supports Star



- Helps us problem solve and plan
- Put outcome or concern in middle in white star for yourself or your sibling
- Focuses on 5 possible areas of support, not just services
- Way to discover and document possibilities, integrated and community based
- Start with personal strengths and assets-want to start with strengths based assets, not deficit/disability
- End with eligibility-based supports
- Community resources-where do others get help/support?





# CHARTING the LifeCourse



## Integrated Support Options

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.



LIFE DOMAIN	Personal Strengths & Assets	Relationship Based Supports	Technology	Community Resources	Eligibility Based Supports
 Daily Life Employment	<ul style="list-style-type: none"> <li>• Work/volunteer experience</li> <li>• Summer jobs</li> <li>• Vision or dream for job or career</li> <li>• Responsibilities at home or school</li> <li>• Makes choices and decisions</li> <li>• Communicates ideas, needs, thoughts to others</li> <li>• Knowledge of a variety of different jobs/careers</li> <li>• Good social skills</li> <li>• Practices everyday living skills</li> </ul>	<ul style="list-style-type: none"> <li>• Coworkers</li> <li>• Parents, siblings, spouse, children, grandparents, other family</li> <li>• Friends</li> <li>• Teacher</li> <li>• Mentors</li> <li>• Parents/family of friends</li> <li>• Business partner</li> </ul>	<ul style="list-style-type: none"> <li>• Electronic reminders</li> <li>• Alarm clock</li> <li>• Cell phone</li> <li>• Ipad educational/life skills apps</li> <li>• Online resume builders</li> <li>• Online classes or training</li> <li>• Parents/family of friends</li> <li>• Internet job search</li> <li>• Calculator</li> <li>• Computer</li> <li>• Iphone/smart phone</li> <li>• Ipad apps</li> </ul>	<ul style="list-style-type: none"> <li>• Volunteering</li> <li>• Competitive employment/careers</li> <li>• Colleges, universities, tech school</li> <li>• Micro-enterprises</li> <li>• Self employment</li> <li>• Tutors</li> <li>• Parent/Teacher Association (PTA)</li> <li>• Summer Reading Program (library)</li> </ul>	<ul style="list-style-type: none"> <li>• Work crews/endaves</li> <li>• Job coaches</li> <li>• Supported employment</li> <li>• Special college programs</li> <li>• Special Education/IEP's</li> <li>• HeadStart</li> <li>• Vocational Rehabilitation</li> <li>• Case manager/support coordinator</li> <li>• Sheltered workshops</li> <li>• Day habilitation</li> </ul>
 Community Living	<ul style="list-style-type: none"> <li>• Knowledge of how to navigate community</li> <li>• Drives, rides bus, cab, or other public transportation</li> <li>• Housekeeping skills</li> <li>• Can prepare simple meals/snacks</li> <li>• Can spend time alone or away from family</li> <li>• Knowledge of different types of living options</li> </ul>	<ul style="list-style-type: none"> <li>• Parents, siblings, spouse, children, grandparents, extended family</li> <li>• Friends</li> <li>• Roommates</li> <li>• Neighbors</li> <li>• Same age peers (college age, aging)</li> </ul>	<ul style="list-style-type: none"> <li>• Adapted living space</li> <li>• Environmental technology</li> <li>• Remote monitoring</li> <li>• Ipad apps</li> <li>• Facetime/Skype</li> <li>• Electronic reminders</li> </ul>	<ul style="list-style-type: none"> <li>• Home Ownership</li> <li>• Rental home/apartment</li> <li>• Co-op for housing or transportation</li> <li>• Public transportation (bus, train, taxi)</li> <li>• Universal design</li> <li>• Neighborhood Watch</li> <li>• Home Owner's Association</li> <li>• Food Pantries</li> <li>• Parks and Recreation</li> <li>• Service/social club/groups</li> <li>• Inclusive faith community</li> <li>• Sports teams and clubs</li> <li>• Preschool</li> <li>• Playground</li> <li>• Community Centers</li> <li>• Churches/Places of Worship</li> </ul>	<ul style="list-style-type: none"> <li>• Independent Supported Living (ISL)</li> <li>• Independent Living Center</li> <li>• Shared Living/host family</li> <li>• Institutions</li> <li>• Intermediate Care Facility (ICF)</li> <li>• Group Homes</li> <li>• Meals on Wheels</li> <li>• Section 8 Housing Vouchers</li> <li>• Separate or special church service</li> <li>• Special group outings &amp; activities</li> <li>• Special Olympics</li> <li>• Special passes</li> <li>• Social skills classes</li> </ul>
 Social & Spirituality	<ul style="list-style-type: none"> <li>• Has hobbies and interests and needed supplies</li> <li>• Knowledge/experience playing games or other social activities</li> <li>• Outgoing, friendly personality</li> <li>• Understands social cues and norms</li> <li>• Has money/budget for social activities</li> <li>• Interest in/belief in faith/higher power</li> <li>• Belongs to/has roles in a faith community</li> <li>• Exposure/experience going to weddings/funerals</li> <li>• Good conversation skills</li> </ul>	<ul style="list-style-type: none"> <li>• Friendships</li> <li>• Dating/relationships</li> <li>• Members of your faith community</li> <li>• Friends of parents/siblings and other family members</li> <li>• People with a shared interest or hobby</li> </ul>	<ul style="list-style-type: none"> <li>• Online social clubs</li> <li>• Social media (Facebook, Twitter, Instagram, Pinterest, etc)</li> <li>• Online games</li> <li>• Email</li> <li>• Texting</li> </ul>	<ul style="list-style-type: none"> <li>• Online social clubs</li> <li>• Social media (Facebook, Twitter, Instagram, Pinterest, etc)</li> <li>• Online games</li> <li>• Email</li> <li>• Texting</li> </ul>	<ul style="list-style-type: none"> <li>• Online social clubs</li> <li>• Social media (Facebook, Twitter, Instagram, Pinterest, etc)</li> <li>• Online games</li> <li>• Email</li> <li>• Texting</li> </ul>
 Healthy Living	<ul style="list-style-type: none"> <li>• Communicates with doctors and other medical professionals</li> <li>• Knowledgeable about own disability or special healthcare needs</li> <li>• Knows how/when to seek help for health issues</li> <li>• Understands changes as body becomes adult, and has well woman/man checkups</li> <li>• Manages (or helps manage) own medication and other healthcare needs</li> <li>• Understands health risks associated with smoking, drinking, drug use, unprotected sex)</li> <li>• Knowledge and/or ability to plan/execute healthy meals; eats a healthy diet</li> <li>• Has health insurance</li> <li>• Gym membership/exercises regularly/rides bike</li> <li>• Medical home</li> </ul>	<ul style="list-style-type: none"> <li>• Family member or school staff implement therapy</li> <li>• Parents, siblings, grandparents, other family members (help with meds, healthy eating, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>• Pill-minders</li> <li>• Chat with a nurse/nurseline</li> <li>• Tele-medicine</li> <li>• Web-MD</li> <li>• Fit-Bit/Nike Fuel Band</li> <li>• Exercise equipment (ie treadmill)</li> <li>• Health/fitness apps for ipad</li> <li>• Smart Toothbrush</li> </ul>	<ul style="list-style-type: none"> <li>• Gym membership</li> <li>• Community Centers</li> <li>• Neighborhood/City Pool</li> <li>• Community Health Centers</li> <li>• Health fairs</li> <li>• Family/General practice providers</li> <li>• YMCA</li> <li>• Neighborhood pharmacy</li> </ul>	<ul style="list-style-type: none"> <li>• Center-based therapies (PT, OT, Speech, etc)</li> <li>• Special/institutional medical care</li> <li>• Home/community based therapies</li> <li>• Special Olympics Healthy Communities Initiative</li> <li>• Medical home</li> <li>• IHP</li> </ul>

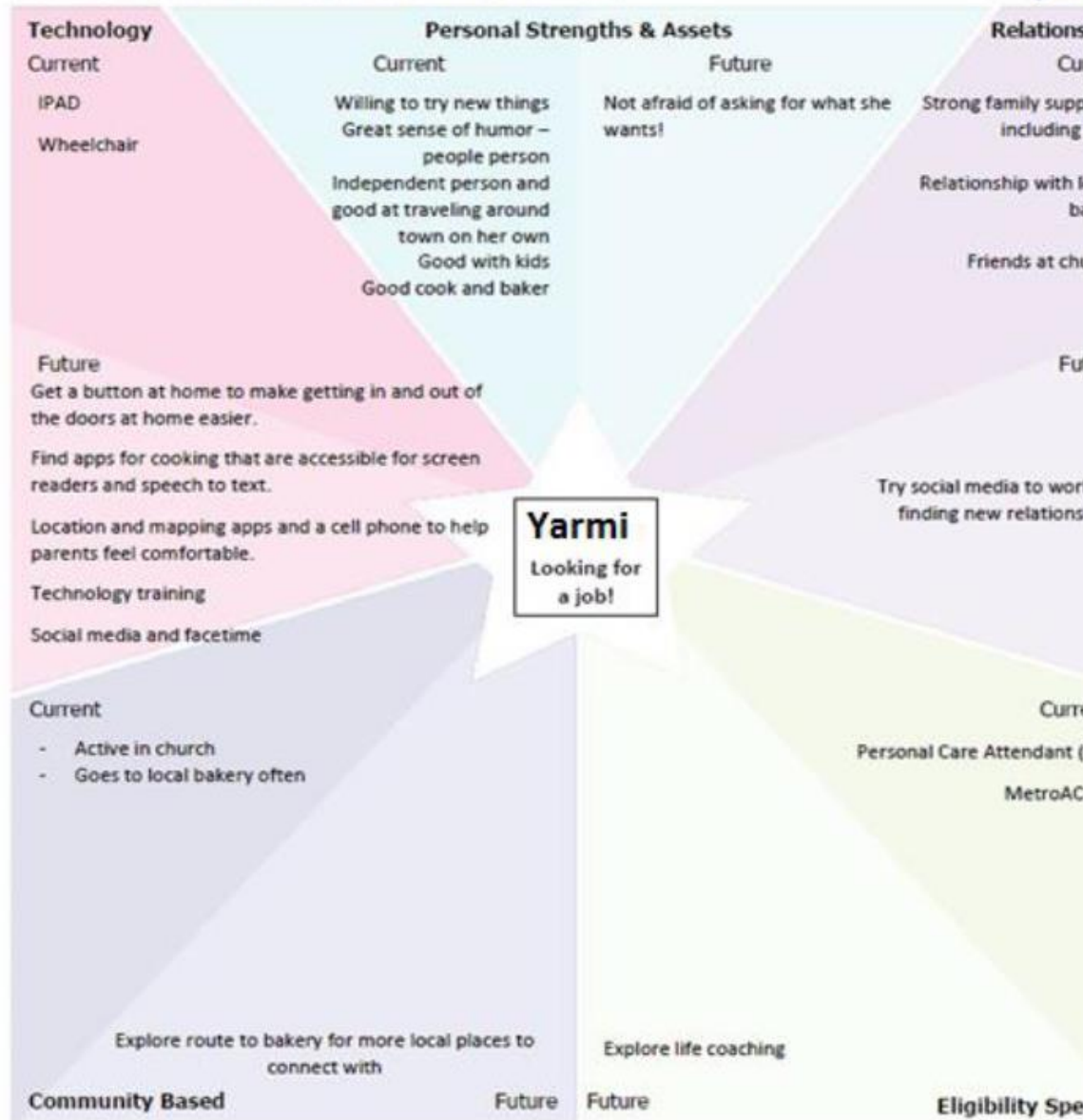


## Integrated Supports

This integrated supports star was created by the DC Supporting Families Community of Practice based on a hypothetical case study. The story was used in order to practice sorting supports into different categories, in order to think of ideas and goals for job searching.

# Yarmi's Star

## Looking for a Job!





# One Page Profile

Shift the narrative, the way people with disabilities are talked about, from:

- Disability-based to person-centered
- Needs to support-based

\_\_\_\_\_ 's ONE-PAGE PROFILE

What people like & admire about me

What's Important to ME

How to Best Support ME



# One Page Profile

A template for a 'One Page Profile' form. It consists of three rounded rectangular sections. The top section is light blue and contains the text: '\_\_\_\_\_'s ONE-PAGE PROFILE' and 'What people like & admire about me'. The bottom left section is orange and contains the text 'What's Important to ME'. The bottom right section is white and contains the text 'How to Best Support ME'.

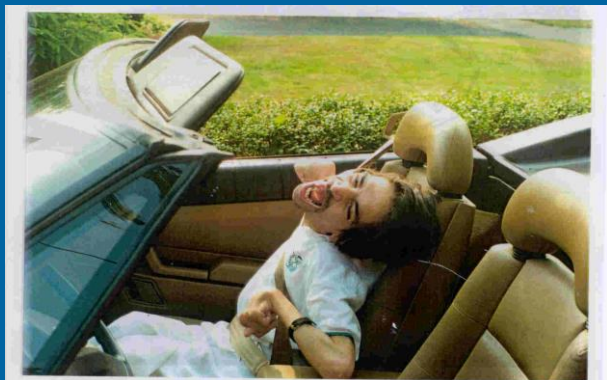
- For a specific purpose:
  - new situations like a new job;
  - meeting new people;
  - at the front of the persons records.
- An at-a-glance positive way to share key information about:
  - *What people like and admire*
  - *What is most important to*
  - *How to best support*

**All one page descriptions have these three sections at minimum**

For more information

<http://learningcommunity.us/onepageprofiles.htm>

# Nick the Greek



## Important TO:

- Chatting with sis, Barb, every night
- Going to family events
- Privacy
- Time alone at home and about
- Greek culture, traditions and religion

## Great things about Nick:

- Intuitive
- Sense of humor
- Trustworthy
- Loving
- Caring
- Devoted
- Honest

## How best to support:

- use spoon to feed me, left side, between teeth
- do not read over my shoulder or listen to my conversations
- I can hear and understand you, do not yell, use a 'parent' voice; I could be old enough to be your father
- put me on my stomach in bed with a pillow between my knees



# LIKE AND ADMIRE-qualities (not what you do)

- Artistic
- Musical
- Thoughtful
- Creative
- Helpful
- Organized
- Good listener
- Loyal
- Truthful
- Dependable
- Courteous
- Courageous
- Nice
- Friendly
- Honest
- Reliable
- Polite
- Generous
- Funny
- Hard-working
- Cheerful
- Trusting
- Clever
- Pleasant
- Warm
- Responsible
- Warm-hearted
- Reasonable
- Pleasant
- Kind
- Interesting
- Enthusiastic
- Resourceful
- Efficient
- Ambitious
- Polite
- Respectful

# One Page Description-Like and Admire

- What would the following say?
  - Family
  - Friend
  - Co-worker
- \* What is the best compliment you have ever received?

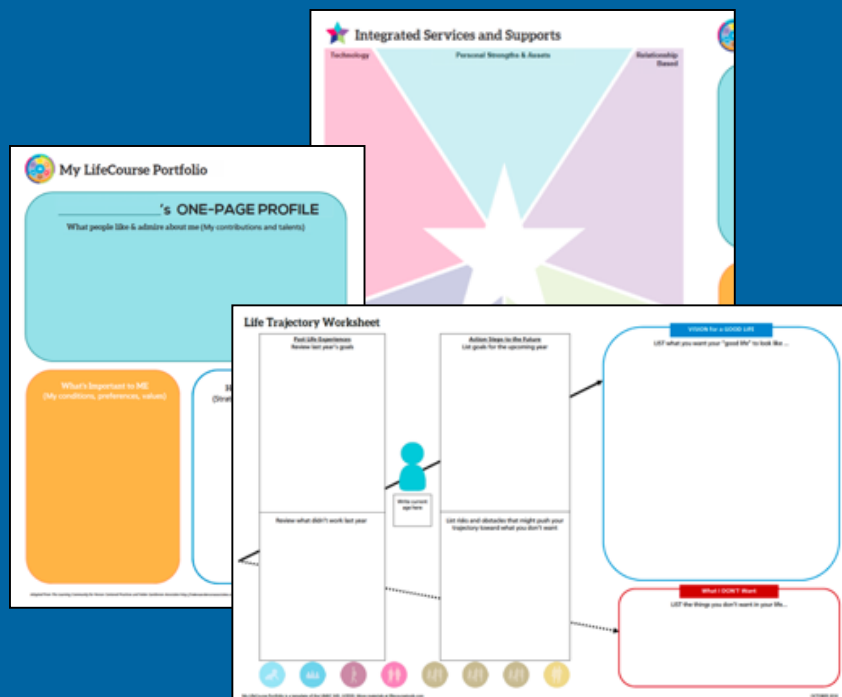
# How to best support me

- Describe what others need to do, not a diagnosis, for example:
  - Give me directions in writing, using pictures, video, etc.
  - Don't talk to me like I am a child
  - Remind me to wear my headphones if I am in a noisy place
  - Help me learn to cook the food that I like
  - When teaching me something new, show me, tell me, make a video, and then tell me how I am doing
  - help me to take my medications (per my Self-Administration Medication assessment)

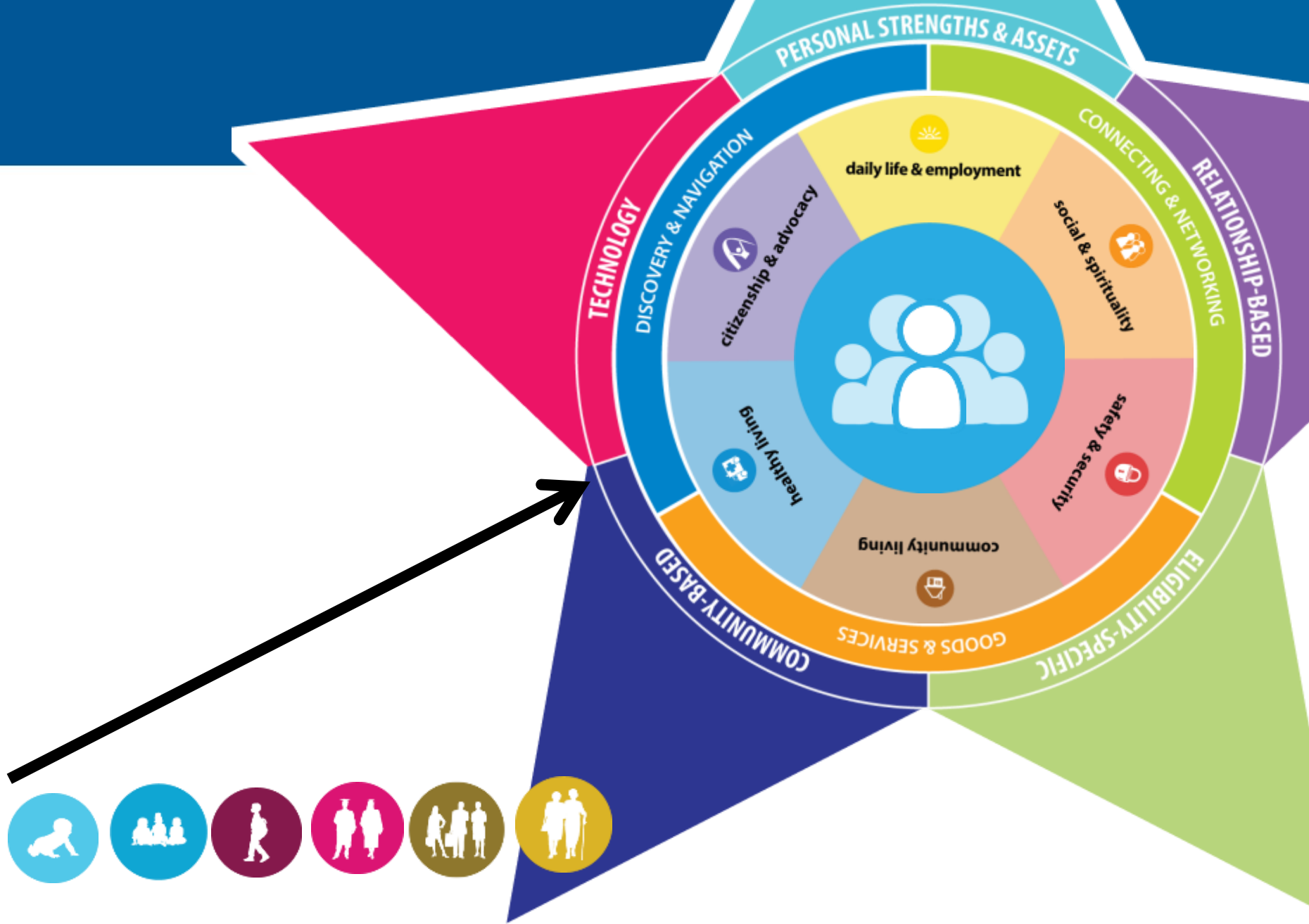
# Person Centered Description

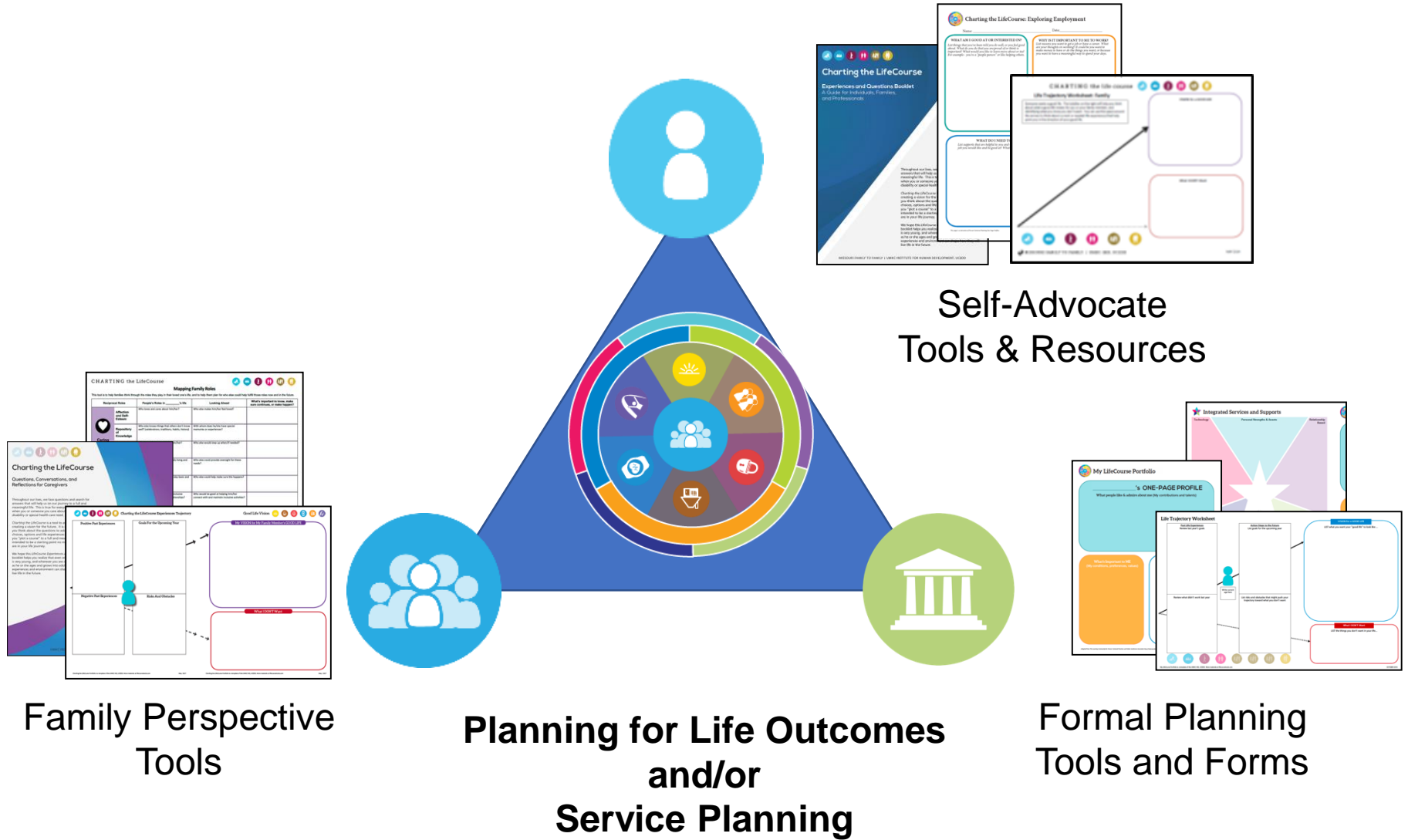
- Many uses: transitions (early intervention, school, job, respite, residential)
- Medical appointments
- Job Seekers
- Interview providers
- Orientation for staff (day and residential)
- Part of résumé

# Charting the LifeCourse PORTFOLIO



- A succinct way for people with disabilities and families to collect, document and organize their vision for the person they love, WHO the person is, and guide planning
- User friendly
- Can be shared with others to keep them focused on the person's outcomes
- “**How** can you help me have my good life?” not “**Can** you help me?”
- Easy quick resource
- Can change over time





Family Perspective Tools

Planning for Life Outcomes and/or Service Planning

Self-Advocate Tools & Resources

Formal Planning Tools and Forms

# Where to get more information:

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

[www.ucucedd.com](http://www.ucucedd.com)

[www.frnohio.org](http://www.frnohio.org)

[www.tlcpcp.com](http://www.tlcpcp.com)

Facebook

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

Group: Charting the LifeCourse in Action





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