Charting the LifeCourse and Person Centered Thinking

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National Community of Practice for Supporting Families

Project Goal

To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families that include a member with I/DD across the lifespan.

Hosted by:

National Association of State Directors of Developmental Disability Services

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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.
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
• 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.
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

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<table>
<thead>
<tr>
<th>Caring About</th>
<th>Caring For</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affection &amp; Self-Esteem</td>
<td>Provider of day-to-day care</td>
</tr>
<tr>
<td>Repository of knowledge</td>
<td>Material/Financial</td>
</tr>
<tr>
<td>Lifetime commitment</td>
<td>Facilitator of inclusion &amp; membership</td>
</tr>
<tr>
<td></td>
<td>Advocate for support</td>
</tr>
</tbody>
</table>

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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

**DISCOVERY AND NAVIGATION**
Knowledge & Skills

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

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


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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

- 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
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)

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

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

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

Safety and Security
(emergencies, well-being, legal rights and issues, guardianship options and alternatives)

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

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Vision for Good Life

Dreams
Have what is important TO us
Have people who believe in us
Respected and valued as a contributing community member
Feel safe and healthy
more good days than bad

Control and Choice

Vision of What I Don’t Want

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Life Experiences = Life Outcomes

- Experiences
- Expectations
- Opportunities
- Vision
- More Possibilities

Experiences → Expectations → Opportunities → Vision → More Possibilities → Experiences
Charting the LifeCourse PORTFOLIOS

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

**Employment Trajectory Worksheet**

**Past Life Experiences**
- Supportive teachers/advisors, IEP team
- Making choices about activities
- Trying job tasks like sorting, shredding
- Computer/typing skills

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

**Write current age here**

**List life experiences to avoid because they push you 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

**VISION for a GOOD LIFE**
- A job he looks forward to going to
- Appreciated and valued by coworkers, supervisors
- Gifts/Strengths recognized
- Makes choices about how he spends his day
- Stays healthy, active
- Valued at church, in social groups
- A good place to live that feels like home
- A job he enjoys

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

**Preferences**
- Variety of tasks
- Indoor and outdoor
- Physical activity/movement

**Support Needs**
- Sensory breaks
- Help learning routine in new tasks
- Motivated by affirmation

**What I DON’T Want**
- 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

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My LifeCourse Portfolio is a template of the UMKC IHD, UCEDD. More materials at lifecoursetools.com

OCTOBER 2016
Integrated Star for Supporting Good Lives
Integrated Supports STAR

**Personal Strengths & Assets**
resources, skills, abilities, characteristics

**Technology**
i-pad/smart phone apps, remote monitoring, cognitive accessibility, Adaptive equipment

**Relationships**
family, friends, neighbors, co-workers, church members, community members

**Community Based**
school, businesses, church faith based, parks & rec, public transportation

**Eligibility Specific**
SHS services, Special Ed, Medicaid, Voc Rehab, Food Stamps, Section 8
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

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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

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Integrated Supports STAR for Problem Solving and Exploring Options

**ELIGIBILITY SPECIFIC SUPPORTS**

*Disability Specific:*
Supports received based on a diagnosis, i.e.: Special Education, Government Funded Disability Supports

*Needs-based:*
Supports based on age, gender, geographics, income level or employment status

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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?

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# 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.

<table>
<thead>
<tr>
<th>LIFE DOMAIN</th>
<th>Personal Strengths &amp; Assets</th>
<th>Relationship Based Supports</th>
<th>Technology</th>
<th>Community Resources</th>
<th>Eligibility Based Supports</th>
</tr>
</thead>
</table>
| **Daily Life Employment** | Work/volunteer experience  
   • Summer jobs  
   • Vision or dream for job or career  
   • Responsibitys at home or school  
   • Makes choices and decisions  
   • Communicates ideas, needs, thoughts to others  
   • Knowledge of a variety of different jobs/careers  
   • Good social skills  
   • Practices everyday Living skills | Coworkers  
   • Parents, siblings, spouse, children, grandparents, other family  
   • Friends  
   • Teacher  
   • Mentors  
   • Parents/family of friends  
   • Business partner | Electronic reminders  
   • Alarm clock  
   • Cell phone  
   • Ipad educational/life skills apps  
   • Online resume builders  
   • Online class or training  
   • Internet job search  
   • Calculator  
   • Computer  
   • Iphone/smart phone  
   • Ipad apps | Volunteering  
   • Competitive employment/careers  
   • Colleges, universities, tech school  
   • Micro-enterprises  
   • Self employment  
   • Tutors  
   • Parent/Teacher Association (PTA)  
   • Summer Reading Program (Library)  
   | Work areas/venues  
   • Job coaches  
   • Supported employment  
   • Special college programs  
   • Special Education/IEP's  
   • HeadStart  
   • Vocational Rehabilitation  
   • Case managers/support coordinators  
   • Sheltered workshops  
   • Day habilitation |
| **Community Living** | Knowledge of how to navigate community  
   • Driver, rides bus, car, or other public transportation  
   • Housekeeping skills  
   • Can prepare simple meals/meals  
   • Can spend time alone or away from family  
   • Knowledge of different types of living options  
   • Has hobbies and interests and needed supplies  
   • Knowledge/experience playing games or other social activities  
   • Outgoing, friendly personality  
   • Understands social cues and norms  
   • Has money/budget for social activities  
   • Interest in/held in faith/higher power  
   • Belongs to/has roles in a faith community  
   • Exposure/experience going to weddings/funerals  
   • Good conversation skills | Parents, siblings, spouse, children, grandparents, extended family  
   • Friends  
   • Roommates  
   • Neighbors  
   • Same age peers (college age, aging) | Adopted living space  
   • Environmental technology  
   • Remote monitoring  
   • Ipad apps  
   • Facetime/skype  
   • Electronic reminders | Home Ownership  
   • Rental house/apartment  
   • Co-op for housing or transportation  
   • Public transportation (bus, train, taxi)  
   • Universal design  
   • Neighborhood Watch  
   • Home Owner’s Association  
   • Food Pantries  
   • Parks and Recreation  
   • Service/social club/groups  
   • Inclusive faith community  
   • Sports teams and clubs  
   • Preschool  
   • Playgrounds  
   • Community Centers  
   • Churches/Moms of Worship | Independent Supported Living (ISL)  
   • Independent Living Center  
   • Shared Living/house family  
   • Institutions  
   • Intermiate Care Facility (ICF)  
   • Group Homes  
   • Meals on Wheels  
   • Section 8 Housing Vouchers  
   • Separate or special church service  
   • Special group outings & activities  
   • Special Olympics  
   • Special passes  
   • Social skills classes |
| **Social & Spirituality** | Communications with doctors and other medical professionals  
   • Knowledgeable about own disability or special healthcare needs  
   • Knows how/when to seek help for health issues  
   • Understands changes as body becomes adult,  
   and has well woman/man checkups  
   • Manages (or helps manage) own medication and other healthcare needs  
   • Understands health risks associated with smoking, drinking, drug use, unprotected sex  
   • Knowledge and/or ability to plan/consume healthy meals; eat a healthy diet  
   • Has health insurance  
   • Gym membership/exercises regularly/rides bike  
   • Medical home | Family member or school staff implement therapy  
   • Parents, siblings, grandparents, other family members (help with meals, healthy eating, etc.)  
   • PW-conditions  
   • Chat with a nurse/nurse line  
   • Take-a-line  
   • Web-MD  
   • Fit-Bit/Hike Fund Band  
   • Exercise equipment (be treadmill)  
   • Health/fitness apps for ipad  
   | Gym membership  
   • Community Centers  
   • Neighborhood/City Pool  
   • Community Health Centers  
   • Health Fairs  
   • Family/General practice providers  
   • YMCA  
   | Center-based therapies (PT, OT, Speech, etc)  
   • Speech/Institutional medical care  
   • Home/community-based therapies  
   • Special Olympics Healthy Communities Initiative  
   • Medical home  
   | IHP |

Developed by the UMKC Institute for Human Development, UCEED. More tools and materials at lifecoursetools.com

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Yarmi’s Star
Looking for a Job!

CHARTING the LifeCourse

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.

- Technology
  - Current
    - IPAD
    - Wheelchair
  - Future
    - Get a button at home to make getting in and out of the doors at home easier.
    - Find apps for cooking that are accessible for screen readers and speech to text.
    - Location and mapping apps and a cell phone to help parents feel comfortable.
- Personal Strengths & Assets
  - Current
    - Willing to try new things
    - Great sense of humor – people person
    - Independent person and good at traveling around town on her own
    - Good with kids
    - Good cook and baker
  - Future
    - Not afraid of asking for what she wants!
- Relations
  - Current
    - Strong family support, including parents and siblings
  - Future
    - Relationships with new friends
    - Friends at church

Yarmi
Looking for a job!

- Explore route to bakery for more local places to connect with
- Explore life coaching
- Eligibility Status
  - Personal Care Attendant (PCA)
  - MetroAccess
  - Active in church
  - Goes to local bakery often
Shift the narrative, the way people with disabilities are talked about, from:

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

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

Important TO:
- Chatting with sis, Barb, every night
- Going to family events
- Privacy
- Time alone at home and about
- Greek culture, traditions and religion
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
• 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
Self-Advocate Tools & Resources

Family Perspective Tools

Planning for Life Outcomes and/or Service Planning

Formal Planning Tools and Forms
Where to get more information:

www.supportstofamilies.org
www.ucucedd.com
www.frnohio.org
www.tlcpcp.com

Facebook
Lifecoursetools.com

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