An Overview of Charting the LifeCourse for Children, Youth and Adults
Funded in 2012 by

National Partners

[Logos of various organizations]
Charting the LifeCourse Trainings are provided by

The Ohio State University
Nisonger Center

and

UCEDD
University Center for Excellence in Developmental Disabilities

Funding for this statewide effort is provided by

Ohio Department of Developmental Disabilities
National Communities of Practice for Supporting Families

Project Outcomes:
- Consensus
- Enhanced Systems
- Enhanced Practices
- All to better and more efficiently support families
Ohio LifeCourse Ambassadors

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We are all on life’s course, following different paths, creating different stories. . . Sometimes our story changes, and as our story changes, so does the course of our life...

“Be grateful for the obstacles in your life. They have strengthened you as you continue with your journey…”

author unknown
This is the story... 
That changed the course of my life.
What is the LifeCourse Framework

The LifeCourse Framework was created by families to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live.
What is the LifeCourse Framework

* Created by families for families
* To help individuals and families
* Develop a vision for a good life
* What they need to know and do,
* How to find or develop supports
* What it takes to live the good life
All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.
Services and Supports have changed across time
Services and Supports Evolve

Everyone exists within the context of family and community

Traditional Disability Services

Integrated Services and Supports within context of person, family and community
Nationwide, 1 in 4 persons with Intellectual or Developmental Disabilities (I/DD) receive formal State DD services.

100%
4.7 Million people with developmental disabilities

75%
National % Receiving State DD Services

25%
** Based on national definition of developmental disability with a prevalence rate of 1.49%
Consider the impact…

- On the person, the family, community, and
- The delivery of services
Why focus on supporting families?

“Family members play key roles in identifying and securing opportunities for their family members to participate in meaningful ways within their community and ensuring access to self-determined lives.”

Wingspread Report 2012
All people exist within the context of family

- Family is defined by the individual
- Individuals and their family may need supports that adjust as roles and needs of all members change
- Not dependent upon where the person lives
# Reciprocal Roles of ALL Family Members

<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 and membership</td>
</tr>
<tr>
<td><em>Adapted from Bigby &amp; Fyffe (2012), Dally (1988), Turnbull et all (2011)</em></td>
<td>Advocate for support</td>
</tr>
</tbody>
</table>
“Good Life Outcomes for ALL”

The Individual
- self-determination,
- interdependence,
- productivity,
- Integration/inclusion in all facets of community life at a level that they desire

Families
- maximize their capacity
- strengths, and unique abilities
- to best nurture, love, and support all individual members in achieving their goals
Defining Supports to Families

Discovery & Navigation (Info and Training)
Connecting & Networking (Talking to Someone that has been there)
Goods & Services (Day to Day, Medical, Financial Supports)

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
# Three Strategies for Supporting Families

<table>
<thead>
<tr>
<th>Discovery &amp; Navigation</th>
<th>Connecting &amp; Networking</th>
<th>Day-to-Day Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge and Skills</td>
<td>Mental Health and Self-efficacy</td>
<td>Instrumental Supports</td>
</tr>
<tr>
<td><strong>•</strong> Information on disability</td>
<td><strong>•</strong> Parent-to-Parent Support</td>
<td><strong>•</strong> Self/Family-Directed services</td>
</tr>
<tr>
<td><strong>•</strong> Knowledge about best practices and values</td>
<td><strong>•</strong> Self-Advocacy Organizations</td>
<td><strong>•</strong> Transportation</td>
</tr>
<tr>
<td><strong>•</strong> Skills to navigate and access services</td>
<td><strong>•</strong> Family Organizations</td>
<td><strong>•</strong> Respite/Childcare</td>
</tr>
<tr>
<td><strong>•</strong> Ability to advocate for services and policy change</td>
<td><strong>•</strong> Sib-shops</td>
<td><strong>•</strong> Adaptive equipment</td>
</tr>
</tbody>
</table>

**•** 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 and training
What is your vision of a Good Life
Trajectory towards Good Life

Trajectory towards Life Outcomes

Trajectory towards things unwanted
Trajectory towards Good Life

Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

Vision of What I Don't Want
Trajectory towards Good Life

- Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

Trajectory towards Life Outcomes

- Poverty, loneliness, segregation, restrictions, lack of choice, boredom, institutions
Life Experiences = Life Outcomes

More Possibilities

Vision

Opportunities

Expectations

Experiences & Transitions
Experiences and Transitions become points on the Trajectory

- **Getting New Diagnosis**
- **Parents Turn 65 Medicare & SSDI**
- **Leaving Early Childhood/enter school**
- **Transition planning**
- **Turning 18. Leaving school at 18 or 21**
- **Living Adult Life**
- **Loosing the support of your parents**

**Making Choices**
- Learning to be a “member” of the family and of the community

**Understanding and Owning Expectations**
- Parties with friends

**Making Mistakes**
- Summer jobs, babysitting
- Playing sports or an instrument

**Chores and Allowance**
- Scouts, 4H, faith groups
- Learning to say “no”

**Meeting Milestones**
- My parents have passed away, what do I do?
- Parents Turn 65 Medicare & SSDI
Trajectory towards Life Outcomes

**Focus on Past, Present and Future Life Experiences at any Life Stage**

- Adapted from “Life Course Theory” and Rethinking MCH: The Life Course Model as an Organizing Framework, HRSA, Maternal and Child Health Bureau

**Vision of What I Don’t Want**

- Friends, family, self-determination, community living, social capital and economic sufficiency
Charting the LifeCourse Trajectory

**Life Trajectory Worksheet**

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

*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...

*Write current age here*
<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Life and Employment</td>
<td>School/education, employment, volunteering, routines, life skills</td>
</tr>
<tr>
<td>Community Living</td>
<td>Housing, living options, home adaptations and modifications, community access, transportation</td>
</tr>
<tr>
<td>Social and Spirituality</td>
<td>Friends, relationships, leisure activities, personal networks, faith community</td>
</tr>
<tr>
<td>Healthy Living</td>
<td>Medical, behavioral, nutrition, wellness, affordable care</td>
</tr>
<tr>
<td>Safety and Security</td>
<td>Emergencies, well-being, legal rights &amp; issues, guardianship options &amp; alternatives</td>
</tr>
<tr>
<td>Citizenship and Advocacy</td>
<td>Valued roles, making choices, setting goals, responsibility, leadership, peer support</td>
</tr>
</tbody>
</table>
Tool for Developing a Vision – Individual
Forming a vision and beginning to plan for the future in each of the life domains helps plot a trajectory for a full, inclusive, quality life in the community. This tool is to help individuals with disabilities of all ages think about a specific vision in each life domain for how they want to live their adult life, and prioritize what they want to work on right now that will help move toward the life vision.

<table>
<thead>
<tr>
<th>LIFE DOMAIN</th>
<th>My Vision for My Future</th>
<th>priority</th>
<th>Current Situation/Things to Work On</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Life Employment</td>
<td>What do I think I will do/want to do during the day in my adult life? What kind of job/career might I like?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Living</td>
<td>Where would I like to live in my adult life? Will I live alone or with someone else?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social &amp; Spirituality</td>
<td>How will I connect with spiritual and leisure activities, and have friendships and relationships in my adult life?</td>
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<td></td>
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<tr>
<td>Healthy Living</td>
<td>How will I live a healthy lifestyle and manage health care supports in my adult life?</td>
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<td></td>
</tr>
<tr>
<td>Safety &amp; Security</td>
<td>How will I stay safe from financial, emotional, physical or sexual harm in my adult life?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Citizenship &amp; Advocacy</td>
<td>What kind of valued roles and responsibilities do/will I have, and how do/will I have control of how my own life is lived?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supports for Family</td>
<td>How do I want my family to still be involved and engaged in my adult life?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supports &amp; Services</td>
<td>What support will I need to live as independently as possible in my adult life, and where will my supports come from?</td>
<td></td>
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</tr>
</tbody>
</table>

This tool helps you set priorities for the vision you want to have for your life.
**CHARTING the LifeCourse**

**Exploring Life Possibilities**

There are many options for living, working, and playing in the community. What might have been great 30 years ago, may not work for today’s vision of a quality life in the community. This tool is to help individuals and families look at a variety of life options in each of the life domains, some of which are traditional or historic and no longer preferred by many, some that are known and tried, but not necessarily the norm, and others that are new or unfamiliar to individuals, families and professionals.

<table>
<thead>
<tr>
<th>Daily Life &amp; Employment</th>
<th>Community Living</th>
<th>Social &amp; Spirituality</th>
<th>Healthy Living</th>
<th>Safety &amp; Security</th>
<th>Citizenship &amp; Advocacy</th>
<th>Supports for Family Unit</th>
<th>Supports &amp; Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Innovative Life Options</td>
<td>New ideas; things that someone has tried, and you replicate or adapt for your own needs; things that haven’t been thought of yet or tried.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Micropreneurs</td>
<td>Co-op</td>
<td>Gym membership</td>
<td>Limited / joint bank account, automatic bill pay, personal contract, agency agreement</td>
<td>Voting</td>
<td>Social Media</td>
<td>Exchange networks</td>
<td></td>
</tr>
<tr>
<td>Careers</td>
<td>Adapted living space</td>
<td>Community Health Centers</td>
<td>Personal safety devices</td>
<td>Neighborhood group or organization</td>
<td>Technology</td>
<td>Time banks</td>
<td></td>
</tr>
<tr>
<td>Competitive employment</td>
<td>Environmental technology</td>
<td>Health fairs</td>
<td>Limited guardianship</td>
<td>Self-Advocacy</td>
<td>Blogs</td>
<td>Human service co-ops</td>
<td></td>
</tr>
<tr>
<td>College or tech school</td>
<td>Shared living</td>
<td>Family practice providers</td>
<td>Remote monitoring</td>
<td>Visiting your legislator</td>
<td>Family &amp; friends</td>
<td>General education</td>
<td></td>
</tr>
<tr>
<td>Supported employment</td>
<td>Parks and Recreation</td>
<td>In-home or community based therapies</td>
<td>Special Needs Trust</td>
<td>People First/SABE</td>
<td>Peer Support/P2P</td>
<td>Self-Directed Supports</td>
<td></td>
</tr>
<tr>
<td>Work crews or enclaves</td>
<td>Inclusive faith community</td>
<td>Safety First Program</td>
<td>Disability Rights Day at the Capitol</td>
<td>Disability</td>
<td>Face-to-face local support groups</td>
<td>§§ follows the person</td>
<td></td>
</tr>
<tr>
<td>Job coaches</td>
<td>Service/social club/groups</td>
<td>Emergency Messaging System</td>
<td>Project STIR</td>
<td>Online Support Groups</td>
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<td></td>
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</tr>
<tr>
<td>Volunteering</td>
<td>Special Olympics</td>
<td>Special Needs</td>
<td>Ombudsman</td>
<td>SIB-shops</td>
<td></td>
<td></td>
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<tr>
<td>Special college programs</td>
<td>Social skills classes</td>
<td>Management</td>
<td></td>
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</tr>
</tbody>
</table>

**Traditional Life Options**

| Sheltered workshops | Institutions | Separate or special church service | Center-based therapies (PT, OT, Speech, etc) | Full guardianship | Paid advocate or having someone else advocate on your behalf | Institution or center based support group | |
|---------------------|-------------|-----------------------------------|---------------------------------------------|-----------------|-------------------------------------------------|---------------------------------------------| |
| Day habilitation    | Intermediate Care Facility (ICF) | Special group outings & activities | Special or institutional medical care | 24 hour supervision | Load advocate or having someone other advocate on your behalf | Intensive all-day parent training | |
|                     | Group Homes |                                   |                                             |                 |                                                 | Disability specific groups | |

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

May 2016
How to Identify, Develop and Integrate Supports & Services

PERSONAL STRENGTHS & ASSETS:
What skills or abilities do I have or do I need to learn and practice to have an integrated, active, inclusive life?

TECHNOLOGY:
How can I use my smartphone, i-pad or other technology to access and be active in my community and stay connected to family and friends?

RELATIONSHIPS:
Am I finding ways to spend time doing things with family, friends, and other people I care about?

COMMUNITY BASED:
What places do I go in the community and who do I spend time with? What activities do I like to do that are accessible to anyone in the community?

ELIGIBILITY SPECIFIC:
How can I use supports from the other parts of the STAR to maximize the services I am eligible to receive to lead an active and inclusive life?
Families need Support when Identifying and Integrating Supports
Tools to create a trajectory towards our good life outcomes

www.lifecoursetools.org
Where to get more information:

www.supportstofamilies.org

www.lifecoursetools.org

www.frnnohio.org