Person Centered Care for Aging Individuals with Intellectual/Developmental Disabilities

Debbie Pfeifer, Aetna

Jenny Turner, University Of Missouri-Kansas City

Jon and Brenda Jackson, student and parent

December 2020
Affiliates are committed to enhancing outcomes for:

- People and their families to reframe their understanding and expectations in order to plan, problem-solve, navigate, and advocate for integrated supports that lead to quality of life.

- Staff and professionals to use person and family centered practices for reframing conversations, problem-solving and planning to support individuals and their families to have a “good life.”

- Organizational cultural change at every level by using the Charting the LifeCourse framework for strategic thinking and planning, training and coaching staff, driving policy change, and engaging with stakeholders
Why Charting the LifeCourse

Member Focus
We organize our response to the life the member wants to lead, recognizing people are more than a set of health needs.
Complimentary to Aetna’s care planning model

Whole Person Approach

Bio, Psycho, Social Model

The right supports at the right time

Incorporates Social Determinants of Health

Person centered planning approach
Comments from Care Managers about CTLC:

1) Helpful in initiating difficult conversations with members.

2) Helpful in guiding conversations with members.

3) Has helped keep the member’s vision in the forefront of all we do.

4) Has helped us think differently about supports.
Nuts and Bolts of implementation

**Partnership with UMKC**
Curriculum and training development

**Training**
Aetna colleagues and community partners trained

**Community partners**
Kansas Council on Developmental Disabilities; local County Boards for Developmental Disabilities

**Internal Capacity building**
Community of Practice groups
Benefits from using CTLC

- Person centered focus
- Tools for members
- Universal Language
- Enhance communication
- Difference between services and vision of a good life
Future Plans

**Continue to Pave the way**
- 1st Managed Care Organization to have graduating Ambassador class

**Increase Stakeholder partnerships**
- Develop innovative partnerships around CTLC

**Increase member and family involvement**
- Increase community trainings on CTLC

**Research**
- Partnership with UMKC on SDoH, Charting the LifeCourse and health outcomes
Charting the LifeCourse

- Framework for Driving Transformational Change
- Icons and Language for Engaging Others
- Tools and Strategies for Implementing into Practice
- Network for On-going Learning and Sharing
Transformation at All Levels

Explore life possibilities
Share ideas, hopes, and fears
Set higher expectations
Navigate Future
Advocate for Vision
Problem-Solve and Plan

Individuals
Family Members
Professionals
Organizational Leadership
Systems Change Agents
Community Members
A central location for the intersection of ideas, collaboration, and transformation. The LifeCourse Nexus supports the growth, expansion, and spreading of the innovations.
Transforming Services and Supports

Everyone exists within the context of family and community

Person in relation to Traditional Disability Services

Integrated Services and Supports within context of person, family and community
What is Charting the LifeCourse

Created 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
• discover what it takes to live the lives they want to live.
What is Charting the LifeCourse??

Guiding Framework

Guides thinking and problem-solve

Practices

Specific Area (action, policy, procedure) to enhance or change

Tools

Educational Resources Planning & Problem-solving Worksheets

Proprietary
Core Belief

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

All people, regardless of age, ability or family role, are considered in our vision, values, policies and practices for supporting individuals and families. All families have choices and should have access to the supports they need.
Enhancing Practices: Support Coordination

Not Receiving Services

Receiving Services

Intake

TCM Only

Less Than 24 hrs

24-7 Level of Supports

Not Receiving Services
Person in the Context of Family

People exist and have reciprocal roles within a family system, defined by that individual. Roles adjust as the individual members of the family system change and age. The entire family, individually and as a whole, needs support to ensure they all are able to successfully live their good life.
## Family Functions and Roles

<table>
<thead>
<tr>
<th>Caring About</th>
<th>Caring For</th>
</tr>
</thead>
<tbody>
<tr>
<td>Share Love, Affection and Trust</td>
<td>Supports Day-to-Day Needs</td>
</tr>
<tr>
<td>Spend Time and Create Memories Together</td>
<td>Ensures Material and Financial Needs are Met</td>
</tr>
<tr>
<td>Know About Personal Interests, Traditions, and Cultures</td>
<td>Connects to Meaningful Relationships and Roles</td>
</tr>
<tr>
<td></td>
<td>Advocates and Supports Life Decisions</td>
</tr>
</tbody>
</table>
Trajectory and Life Experiences

All people, regardless of age, ability or family role, are considered in our vision, values, policies and practices for supporting individuals and families. All families have choices and should have access to the supports they need.
Trajectory Towards a Good Life

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

Vision of What I Don’t Want

Trajectory towards Life Outcomes

Trajectory towards things unwanted
People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life. Life domains are the different aspects and experiences of life that we all consider as we age and grow.
Focusing on Life Domains

- **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 & issues, guardianship options & alternatives)
- **Citizenship and Advocacy** (valued roles, making choices, setting goals, responsibility, leadership, peer support)
<table>
<thead>
<tr>
<th>LifeCourse Domains</th>
<th>Social Determinants of Health Domains (Healthy People 2020)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Education:</strong></td>
</tr>
<tr>
<td></td>
<td>• High School Graduation</td>
</tr>
<tr>
<td></td>
<td>• Enrollment in Higher Education</td>
</tr>
<tr>
<td></td>
<td>• Language &amp; Literacy</td>
</tr>
<tr>
<td></td>
<td>• Early Childhood Education &amp; Development</td>
</tr>
<tr>
<td></td>
<td><strong>Economic Stability:</strong></td>
</tr>
<tr>
<td></td>
<td>• Poverty</td>
</tr>
<tr>
<td></td>
<td>• Employment</td>
</tr>
<tr>
<td></td>
<td>• Food Security</td>
</tr>
<tr>
<td></td>
<td>• Housing Stability</td>
</tr>
<tr>
<td></td>
<td><strong>Neighborhood &amp; Built Environment:</strong></td>
</tr>
<tr>
<td></td>
<td>• Quality of Housing</td>
</tr>
<tr>
<td></td>
<td>• Environmental Conditions</td>
</tr>
<tr>
<td></td>
<td>• Access to Healthy Foods</td>
</tr>
<tr>
<td></td>
<td><strong>Health &amp; Health Care</strong></td>
</tr>
<tr>
<td></td>
<td>• Access to Health Care</td>
</tr>
<tr>
<td></td>
<td>• Access to Primary Care</td>
</tr>
<tr>
<td></td>
<td>• Health Literacy</td>
</tr>
<tr>
<td></td>
<td><strong>Economic Stability:</strong></td>
</tr>
<tr>
<td></td>
<td>• Food Security</td>
</tr>
<tr>
<td></td>
<td>• Neighborhood &amp; Built Environment:</td>
</tr>
<tr>
<td></td>
<td>• Access to Healthy Foods</td>
</tr>
<tr>
<td></td>
<td><strong>Social &amp; Community Context:</strong></td>
</tr>
<tr>
<td></td>
<td>• Social Cohesion</td>
</tr>
<tr>
<td></td>
<td>• Incarceration</td>
</tr>
<tr>
<td></td>
<td><strong>Social &amp; Community Context:</strong></td>
</tr>
<tr>
<td></td>
<td>• Civic Participation</td>
</tr>
</tbody>
</table>
Individualized Supports and Services

_Individual and family supports address all facets of life and adjust as roles and needs of all family members change._
Supporting **Persons** Three Buckets of Needs

**Discovery & Navigation**
Skills, Information and tools to navigate life

**Connecting & Networking**
Self-confidence, strong mental health and connections to family, friends, peers and others.

**Goods & Services**
Things you buy, use or access in your day-to-day life
Integrated Supports and Services

*Individuals and families access an array of integrated supports to achieve their envisioned good life.*
LifeCourse
Integrated
Supports
STAR

PERSONAL STRENGTHS & ASSETS
Skills, personal abilities, knowledge or life experiences;
Strengths, things a person is good at or others like and admire;
Assets, personal belongings and resources

TECHNOLOGY
Personal technology anyone uses;
Assistive or adaptive technology with day to day tasks;
Environmental technology designed to help with or adapt surroundings

RELATIONSHIPS
Family and others that love and care about each other;
Friends that spend time together or have things in common;
Acquaintances that come into frequent contact but don’t know well

COMMUNITY BASED
Places such as businesses, parks, schools, faith-based communities, health care facilities;
Groups or membership organizations;
Local services or public resources everyone uses

ELIGIBILITY SPECIFIC
Needs based services based on age, geography, income level, or employment status;
Government paid services based on disability or diagnosis, such as special education or Medicaid
# Returning Home from the Hospital

**Integrated Services and Supports:**

People need support 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.

### Technology
- Alarm clock
- Cell phone
- Computer
- TV
- Comcast internet
- A11 security
- Walker
- Cane
- Raised toilet seat/rollers
- Home loan
- LIFE ALERT

### Personal Strengths & Assets
- Owns home
- Owns car
- S33993
- Robert
- Intellige
- Social
- Thoughtful
- Caring

### Relationships
- Rachel
- Linda
- Lorie & Lisa
- Life group/ friends: Gery, Barbara, Margaret
- Inpatient friends: Kim, Diann, Margaret
- Social lady
- Yvelisa & Nick
- Jennings relation

## Barbara’s Long Term Support Schedule

<table>
<thead>
<tr>
<th>TIME</th>
<th>MON</th>
<th>TUES</th>
<th>WED</th>
<th>THURS</th>
<th>FRI</th>
<th>SAT</th>
<th>SUN</th>
</tr>
</thead>
<tbody>
<tr>
<td>6:00 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6:30 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7:00 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7:30 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8:00 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8:30 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9:00 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9:30 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10:00 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10:30 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11:00 AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12:00 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1:00 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2:00 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3:00 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4:00 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5:00 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6:00 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7:00 PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8:00 PM</td>
<td>Rachel</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9:00 PM</td>
<td>Rachel</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10:00 PM</td>
<td>Rachel</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11:00 PM</td>
<td>Rachel</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Notes
- Rachel takes grandma to church and attends
- Lifegroup with friends

---

**MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD**
Strategies and Tools for Implementing LifeCourse into Practice

Person Centered Tools

Family Perspective Tools

Planning Tools for Professionals

LifeCourse Foundational Tools
Member/Family Perspective

Jon and Brenda Jackson
brendajeffjackson@earthlink.net
Changing the conversation

- Jon's vision for his life
- Employment and education not enclave work
- Independence not residential supports
- Easy to understand and use
- Strengths not Deficits
- Planning for life transitions earlier
- Don't sign me up for stuff without asking.
Jon

What do People Like & Admire About Me?
• Unique Personality
• Play D&D
• Eagle Scout
• Good at science and Math
• Friends at Church
• Brother, cousins and family
• Good sense of humor
• Nice

What is Important to Me?
• Brother and family
• Going to college and getting a job
• Friends
• Going to church
• Living at home
• Being healthy (maybe)
• Scouts and D&D
• Video games

What Are the Best Strategies to Support Me?
• Dekeysha/Dillon, parents, church friends, and scout leaders
• Driving me around
• Brother – emotional support
• Food, medicine, house, clothes – Parents
• Exercise – Regina, Dillon
• Family Calendar
Jon’s Quality of Life Domains

Daily Life and Employment
- Summer Job at Juniper Farms
- Chores at Home
- Food Prep
- College

Community Living
- Practice riding the bus
- Go to the library and Game stop
- Practice driving and get license

Social and Spirituality
- Friends
- Read emails and surf the web
- Go to D&D, scouts, church

Healthy Living
- Make good decisions and follow diet
- Learn to manage medications
- Talk to doctors
- Exercise more (swim, run, bike)
- Go shopping with a list

Safety and Security
- Debit card

Citizenship and Advocacy
- Volunteer at Harvestors
- Scout leader
- Vote
- Get Driver’s license
# Jon’s Life Trajectory

## Vision for a GOOD LIFE

LIST what you want your “good life” to look like...

**Job**
- Live with family or on my own

**Friends**
- Go to church
- Go to Scouts and D&D

**Be more independent**
- Chores
- Lifeskills
- Driver’s
- Income/bills

## Past Life Experiences

LIST past life experiences and events that pushed you toward the things you want

- Chores;
- Boy scouts;
- School inclusion;
- Birthday parties;
- Family vacations;
- Church youth group;
- Debit card;
- Volunteering;
- High School diploma;
- Job experience:
  - Nature Center
  - Camp Counselor
  - Juniper Hills Farm
  - Two years of college

## Future Life Experiences

LIST current/future life experiences that continue supporting your good life vision.

- Find more volunteer ops;
- Workout regularly;
- Keep in touch w/ friends;
- Continue to do well in college;
- Job at Juniper Farms next summer

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

- Sitting at home watching TV all day;
- Rely on paid supports;
- Gain weight;
- Eat unhealthy foods or drink too much

## What I DON’T Want

- Death
- Diabetes
- Hospital
- Live in a group home
- Not have a job
Jon: Integrated Supports

**Personal Strengths & Assets**
- Intelligent, nice, wallet, registered to vote, Eagle Scout, can prepare simple food, has hobbies

**Technology**
- I-phone, calendar, pill minder, e-mail, exercise equipment, bank account/direct deposit, D2L

**Relationships**
- Brother, family, parents, scout friends, church friends, D&D friends, Washburn friends, extended family

**Community Based**
- Church, Scouts, Washburn, Country Club, Gym, Doctors, Bank, health insurance

**Eligibility Specific**
- Waiver coverage, Vocational Rehabilitation, Pre-ETS, Social Skills Class, SSI, Guardianship, Special Needs Trust

Jon’s Services & Supports