Charting the LifeCourse for Children, Youth and Adults
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.
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 are Evolving

Everyone exists within the context of family and community

Traditional Disability Services

Integrated Services and Supports within context of person, family and community
Current Reality of Service and Supports

- Expectations, Values, Culture
- Federal Policy
- Federal Budget
- Capacity of Work Force
- Demand for Services

- Community
- Family
- Services
- Person
Type of Change that is Needed

TRANSITIONAL CHANGE

“Retooling” the system and its practices to fit the new model

Mergers, consolidations, reorganizations, revising systematic payment structures,

creating new services, processes, systems and products to replace the traditional one

TRANSFORMATION CHANGE

Fundamental reordering of thinking, beliefs, culture, relationships, and behavior

Turns assumptions inside out and disrupts familiar rituals and structures

Rejects command and control relationships in favor of co-creative partnerships
Reframing leads to Transformational Change

‘Reframing’ means thinking and talking about things in a new way.
Reframing leads to Transformational Change

In order to reframe beliefs it is necessary to change our conversations.
Reframing leads to Transformational Change

Across the country, our culture is embracing the belief that ALL individuals have the right to live, love, work, play and pursue their aspirations in their communities.
Where is our conversation now?

- Services must be Person Centered
- allow the individual to direct the process and make choices,
- reflect their preferences and goals
- be written in a way that they understand
Where is our conversation now?

**HCBS Final Rule:**
Individuals have a right to receive their services in the community to the same extent as those not receiving services from the DD System.
Develop a Statewide Community of Practice
Develop State consensus based on the national framework and agenda for improving support for families with members with I/DD.
Supporting All Families where they are

Support 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.

All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.
All People
Nationally 1 in 4 Persons with I/DD Receive Formal State DD Services

100%
4.7 Million people with developmental disabilities

75%
25%
National % Receiving State DD Services

** Based on national definition of developmental disability with a prevalence rate of 1.49%
Ohioans with Disabilities

49% (89,737)

29%

20%

2%

Is Active, Not on a Waiver

Enrolled Waiver Services

ICF/DD
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
Family’s lifelong impact on it’s members

Family Life Experience Impacts Trajectory

Biology: Likes, dislikes, skills, abilities

Policy: Dreams, aspirations, house rules, cultural rules, expectations

Environment: Neighborhood, socio-economic, education

Social: Family and friend network, connection with community members

Family Unit Impacts Individual Level Characteristics

Family Cycle Impacts Member Life Cycle

Family Life Experience Impacts Trajectory
Defining Supports to Families

**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 & Navigation**
*Info and Training*

**Connecting & Networking**
*Talking to Someone that has been there*

**Goods & Services**
*Day to Day, Medical, Financial Supports*
So where do we begin?

The best way to predict the future is to create it.

Abraham Lincoln
What is your vision of a Good Life
Trajectory towards Good Life

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

Vision of What I Don’t Want
Life Experiences = Life Outcomes

- Vision
- Expectations
- Opportunities
- More Possibilities

Life Experiences lead to life outcomes through the cycle of vision, expectations, opportunities, and more possibilities.
Ben’s Life Trajectory

**Past Life Experiences**
- Chores; boy scouts;
- School inclusion/circle of friends;
- Birthday parties;
- Riding bike;
- Family vacations;
- Church youth group;
- Debit card;
- Football manager;
- Homecoming king;
- Volunteering;
- High School diploma

**Future Life Experiences**
- Volunteer at fire station;
- Find more volunteer ops;
- Workout regularly;
- Keep in touch w/ friends;
- Increase alone time;
- Go out with friends;
- Spend daytime hours out of the house;
- Explore micro enterprise;

**Life Trajectory Worksheet**

**What I DON'T Want**
- Poor health, heart disease, diabetes;
- Poverty/no money;
- Guardianship; institution/group home;
- Segregation/isolation; being lonely;
- Being treated differently;

**VISION for a GOOD LIFE**
- LIST what you want your "good life" to look like ...
Achieving Outcomes for Connected 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)
Trajectory towards Life Outcomes

Focusing on Past, Present and Future Life Experiences

Friends, family, self-determination, community living, social capital and economic sufficiency

Vision of What I Don’t Want

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

75%
People with I/DD not receiving formal DD services

25%
People with I/DD receiving formal DD services

100%
People with I/DD receiving integrated services and supports
Focusing ONLY on Eligibility Supports

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

Poverty, loneliness, segregation, restrictions, lack of choice, boredom, institutions
Integrating Supports for Preferred Life Outcomes

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

Poverty, loneliness, segregation, restrictions, lack of choice, boredom, institutions

COMMUNITY
FAMILY
PERSON

integrated
Transformational Strategies of Support Across the LifeCourse

- Family and Self-Advocacy Networks
- Aging and Disability Resource Centers
- No Wrong Door Initiatives
- Area Agencies on Aging
- Parent Training Info Centers for Education
- United Way 211

Community Resources:
- Accessed by all citizens:
  - Faith based communities
  - Parks and Recreation
  - Businesses
  - Emergency Personnel

Public-Private Partnerships

Government

Long Term Services and Supports
ALL: Public Health Framework

- Hand Washing
- Anti-Bacterial Soap
- Flu Shot
- Medical System
Families Need Assistance in Identifying, Developing and Integrating Supports & Services

Technology Based
- i-pad/smartphone
- apps, remote monitoring, cognitive accessibility, adaptive equipment

Personal Strengths & Assets
- person or family resources, abilities, strengths, characteristics

Relationship Based
- family, friends, neighbors, co-workers, community members, church members

Community Based
- school, businesses, church/faith based, public transportation, parks and recreation

Eligibility-Specific
- SHS services, Special Ed, Medicaid, section 8, Food Stamps, Vocational Rehab (VR)
Izaac’s Integrated Services and Supports

**Technology Based**
- Kindle
- Wii
- X-box
- You tube
- Scooter
- Vent/trach
- Life Support Equipment

**Personal Strengths & Assets**
- Extremely outgoing
- Funny, natural leader
- Cute, thick-skinned, nonchalant

**Relationship Based**
- Family
- Neighbors, school friends
- Nurses, church, cheer
- Dog, Tai kwon do

**Community Based**
- Athlete’s Plus Cheer
- Tai Kwon Do
- McAllister’s family night
- Church
- School

**Service Coordination**
- Nursing
- Adaptive Equipment
- Medical Supplies
- Insurance
LifeCourse Integrated STAR: Problem Solving

**PERSONAL STRENGTHS & ASSETS:**
What skills or abilities do I have, can I learn or improve upon; what “things” do I have access to that might help the situation?

**TECHNOLOGY:**
Can I use a smartphone, computer, electronic device, remote monitoring, or other form of high or low tech to help solve the problem or make it better?

**RELATIONSHIPS:**
Do I have family, friends, co-workers, classmates or other people in my life that can do something to help me solve this problem or issue?

**COMMUNITY BASED:**
What are the resources, places, organizations, or people in the community, available to anyone, that could help me with problem solving this issue?

**ELIGIBILITY SPECIFIC:**
What services based on age, ability, socio-economic status, or other factors could I use along with supports from other parts of the STAR to solve this problem?
PROBLEM SOLVING FOR SPECIFIC ISSUE OR GOAL
PROBLEM SOLVING FOR SPECIFIC ISSUE OR GOAL
LifeCourse Integrated STAR: Exploration & Discovery (Mapping)

PERSONAL STRENGTHS AND ASSETS:
What skills or abilities do I have or could I work on to help me achieve my vision of a good life?

RELATIONSHIPS:
Are there people in my life – family, coworkers, friends, church members – who will be there for me when I need help with something?

TECHNOLOGY:
Do I have access to and know how to use technology such as a smart phone, I-pad, computer, or other kinds of devices to help support my needs?

COMMUNITY:
Am I well known in my community, and what are the places I go and who are the people I see who will be part of my good life?

ELIGIBILITY SPECIFIC:
What services am I eligible to receive based on age, disability, income, or other factors, that can be used in partnership with my other supports for my good life?
LifeCourse Integrated STAR:
Life Activities

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?
**LifeCourse Integrated STAR: Support & Service Planning**

**PERSONAL STRENGTHS & ASSETS:**
What skills or abilities do I have, can I learn or improve upon, so I am able to spend some time alone or with minimal supports?

**TECHNOLOGY:**
Can I use remote monitoring, smart phone apps, or other types of technology to help make sure I have supports I need around the clock?

**RELATIONSHIPS:**
Can family, friends, roommate, or co-workers provide some of the daily support I need, at home, at work, or in the community?

**COMMUNITY BASED:**
Do I spend time in the community in places where I can be supported by the people that are already there, and are there other resources that I could access for support?

**ELIGIBILITY SPECIFIC:**
What services based on age, ability, socio-economic status, or other factors, can I use in partnership with other parts of the STAR, to have enough around the clock support?
Ways to Get Involved:
- Webinars
- CoP Listserv
- Website Links

supportstofamilies.org
lifecoursetools.org
mofamilytofamily.org
Questions?