Supporting Families; Charting the LifeCourse
Pennsylvania Family Support and Home Visiting Conference
March 23, 2020

Setting the Stage
What is the LifeCourse Framework?

- A Framework developed to help people, children and families of all abilities
- Any age or stage of life develop a vision for a good life
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

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.

Project Outcome
- State and national consensus on a national framework and agenda for improving support for families with members with I/DD.
- Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families.
- Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems.
GUIDING PRINCIPLES FOR THE SUPPORTING FAMILIES LIFECOURSE FRAMEWORK

Core Belief:
All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.
Expectations (Erik Carter)

- Expectations of professionals and parents are the strongest predictor of post-school outcomes
- Kids exposed to high expectations
  - 5x more likely to have paid community job in adulthood
  - 15x more likely to have a paid job
- Expectations shape experiences
- Experiences shape the future
Life Stages and Individual and Family Cycles

Individual Life Stages:
- Birth
- Early child
- School
- Transition
- Adulthood
- Aging

Family Life Cycle:
- Single Adult
- New Couple
- Couple with Children
- Launching Children
- Family Later in Life

Impact on All Family Members

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The future is not something we enter. The future is something that we create. And creating that future requires us to make choices and decisions that begin with a dream.

- Leonard L. Sweet
“Good Life for All”

The 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 all individual members to achieve their goals.

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 Life Outcomes

Trajectory towards things unwanted
Joshua
3 years old

What I Want

Trajectory towards Good Life

Vision of What I Don't Want

Trajectory towards Life Outcomes

Trajectory towards things unwanted

Vision of What I Don't Want
Life Experiences and Life Transitions

“Anticipatory Guidance for Life Experiences”

Chores and allowance
Learning to say “no”
Playing sports or an instrument
Birthday parties with friends
Scouts, 4H, faith groups
Summer jobs, babysitting
Making Mistakes
Turning 18. Leaving school at 18 or 21
Transition planning
Leaving Early Childhood, enter school
Getting New Diagnosis

Individualized Supports to Achieve a Good Life
Three Types of Supports

- **Discovery & Navigation (Info and Training)**
  - Information on disability
  - Knowledge about best practices and values
  - Skills to navigate and access services
  - Ability to advocate for services and policy change

- **Connecting & Networking (Talking to Someone that has been there)**
  - Parent-to-Parent Support
  - Self-Advocacy Organizations
  - Family Organizations
  - Sib-shops
  - Support Groups
  - Professional Counseling
  - Non-disability community support

- **Goods & Services (Day to Day, Medical, Financial Supports)**
  - Self/Family-Directed services
  - Transportation
  - Respite/Childcare
  - Adaptive equipment
  - Home modifications
  - Financial assistance
  - Cash Subsidies
  - Short/Long term planning
  - Caregiver supports & training

Types of Supports

<table>
<thead>
<tr>
<th>Discovery &amp; Navigation: Knowledge &amp; Skills</th>
<th>Connecting &amp; Networking: Mental Health &amp; Self-efficacy</th>
<th>Day-to-Day Services: Instrumental Supports</th>
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Integrated Star for Problem Solving & Exploring Options

We all use a variety of supports in our daily lives!

- Relationships
- Technology
- Community
- Personal assets and strengths
- Eligibility based supports and services
Integrated Supports Star

**TECHNOLOGY BASED**
- i-pad/smart phone
- apps, remote monitoring
- adaptive equipment, appliances, etc.

**PERSONAL STRENGTHS & ASSETS**
- Skills, talents, likes, interests, abilities, strengths, characteristics

**RELATIONSHIP BASED**
- family, friends, neighbors, co-workers, community members, church members

**INTEGRATED SUPPORTS**
- Public safety, municipal services, school, businesses, faith-based organizations, public transportation, parks and recreation,

**COMMUNITY BASED**
- healthcare benefits, Social Security, drivers license, pension/retirement program, Medicaid/Medicare benefits, other government programs

**ELIGIBILITY-SPECIFIC**

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Johnny

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[Image of Johnny]
LifeCourse in Action

- Prepare for IFSP/IEP meetings
- Problem Solving
- Working on self-directing or self-determination skills
- Exploration & Planning

Elizabeth’s Health Trajectory
As Told by Her Mother

VISION for a GOOD LIFE
Self determination
Choice
Privacy

What I DON’T Want
Unnecessary medications
Unnecessary procedures
Limiting choices
Limiting self-determination
Elizabeth’s Life Trajectory

Life Trajectory Worksheet

**Past Life Experiences**
- Community involvement
- Volunteer work
- School activities
- Church involvement
- Sports participation
- Community service
- Artistic endeavors
- Music training
- Academic achievements

**Future Life Experiences**
- College attendance
- Entrepreneurial ventures
- Professional development
- International travel
- Social advocacy
- Leadership roles

**Things I Want to Avoid**
- Falling behind
- Feeling overwhelmed
- Feeling left out

**Things I Don’t Want**
- Change
- Failure
- Struggle

**Past Mistakes**
- Missed opportunities
- Self-doubt
- Overcoming challenges

**Future Goals**
- Building confidence
- Pursuing passions
- Setting realistic expectations

**Elizabeth, age 6**
Kylie
4 yrs old:
Support Planning

How the Story Began: Izaac

- Achondroplasia
- Severe Sleep Apnea/O2/Monitors
- Severe pneumonia/coded
- Multiple hospitalizations
- Trach/ventilator
- Delayed walking/talking
Izaac’s Trajectory

What We WANT

- Self-determination
- Participation in activities he likes
- Learn medical self-care

What We DON’T WANT

- People always doing things for him
- Unnecessary medications
- Unnecessary procedures

Izaac’s Integrated Supports

- Kindle
- Wii
- X-box
- YouTube
- Scooter
- Vent/trach Life Support Equipment
- Extremely outgoing, funny, natural leader, cute, thick-skinned, nonchalant
- Family, neighbors, school friends, nurses, church, cheer, tae kwon do, dog
- Service Coordination
- Nursing
- Adaptive Equipment
- Medical Supplies
- Insurance
- Athlete’s Plus Cheer
- Tai Kwon Do
- McAllister’s family night
- Church
- School

Izaac’s Integrated Supports
Ways to Learn More:
- Webinars
- CoP Listserv
- Website Links

supportstofamilies.org
lifecoursetools.com
mofamilytofamily.org
THANK YOU!

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