

# ISAC Recommendation #4 – Support Families Throughout the LifeSpan

April 2025



4/14/2025



The <u>Charting the LifeCourse (CtLC)</u> framework is the foundation for intake so that individuals and families can start developing their vision and access integrated supports to respond to immediate needs. Families receive all information about possible/available services and supports, as well as where to go when they are ready for next steps.

## Strategy 1: New Activities to Help Reach This Vision





### LIFE TRAJECTORY | PLANNING

#### Past Life Experiences

List past life experiences and events that have supported your vision for a good life

- \* SNU #'s are helpful
- \* EPSDT
- \* Community nights with system presence as a
- \* attending the transition meetings
- \* Person centered and family centered planning (including the LifeCourse Framework)
- \* PA Navigate by findhelp Search and Connect to Social Care (pa-navigate.com)
- \* PA Link to Aging and Disability Resources | Department of Aging | Commonwealth of
- \* anticipatory guidance
- \* COMPASS as a "no wrong door" effort
- \* El Connect (has some hit or miss impact)

2-1-1

List past life experiences that pushed your trajectory toward things vou don't want

- \* Systems not communicating with one another
- \* The benefit of connecting early and planning early
- not being valued by all involved
- \* People not understanding the long term implications of not connecting them
- \* Families try to get connected to the wrong system at the wrong time.

#### **Moving Forward**

List current or future life experiences or goals that will continue to support your good life vision

- \* Cross walk/map of resources across life domains and life stages that can be added to at the local level
- \* Create a short video that counties can add to their pages about navigating the system
- \* Expand awareness and use of PA Navigate and PA Link - possibly a resource fair for SCs to explore different tools
- \* Family friendly formats that make the conversations less scary
- \* Could someone from the DHS SNU come and talk to
- \* Could we ask ODP regional quarterly leads to include some of this in meetings
- \* ECM Stay informed as it develops; keep an eye for how this will be presented to families/support them through the process; be knowledgable

Pre-front door '24

List things to avoid that could keep you from your good life vision or lead to what you don't want

\* System handoff not working

#### Vision for What I Want

List what you want your "GOOD LIFE" to look like

Create messaging and a resource (toolkit) for all who have a touchpoint with families with a loved one who has an intellectual, developmental disability or autism (IDD/A) so that:

- \* Families have improved access to needed information, supports, and services throughout their lifespan.
- \* Families have improved navigation across systems.

Birth through 18 to be connected with the DD system (recognize that not all young families need to be connected) Supporting their parents to have the resources and information that they need

For PA DD service system to have an open door to parent of younger children

AE's to have good messaging to give to younger families

For birth-3 providers to have the information to give in transition packets along with service coordinators

For teachers at all levels to have buy-in, information, and skills needed

Prevent the crisis by offering support ahead that is easily found using search engines

broad picture navigation map

- 1. Interactive, Videos that are posted?, QR codes, Something new or different?, Padlet?, Google searchable, Where to house it? DHS? Commonwealth of PA?
- \* additional "moving forward" ideas

https://mofamily.org/green-folder-resources/ - share with AEs and SCOs to demonstrate a format/template

Kinconnector/Refugee families/Aging Caring programs - Counties & Providers to know about them so that we're all pointing families in the same direction

#### What I Don't Want

List the things you don't want or what is NOT a "good life"

Parents to get to a crisis point/shut down point; be at a loss of what to do or think that they just can't do it.

Families to have application processes for multiple systems that are cumbersome on the family.











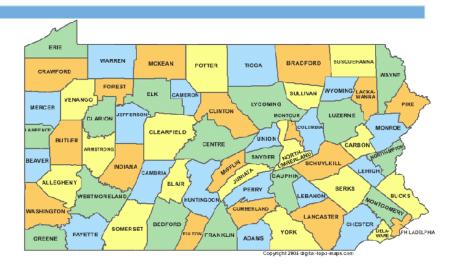
Developed by the Charting the LifeCourse Nexus - LifeCourseTools.com

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# Strategy 1: Regional Activities



- Administrative Entities (AEs) in the Southeast Region review LifeCourse tools with individuals and families at intake meetings.
- Bradford/Sullivan AE in the Northeast Region hired a staff member who meets with newly enrolled individuals and families to discuss Charting the LifeCourse. This staff member completes LifeCourse tools with individuals and provides a one-page summary to the Supports Coordination Organization (SCO) at the time of registration.
- Centre County AE created a <u>LifeCourse Intake Family</u> <u>Guidebook</u>.
- Three AEs in the Western Region include Family Liaison positions to have a stronger focus on what families need and build local engagement and capacity.





Support the work of the PA Family Network to reach families with a consistent message of the importance of family expectations of a good life for family members and opportunities for discovery and navigation of support/service systems and community-based resources.



# InVEST Project | Department of Labor and Industry | Commonwealth of Pennsylvania

- 55 active participants in mentoring.
- Family advisors actively engaged with 155 individuals and families in the community.
- Family advisors are actively engaging with 35, 14c programs throughout the state.
- Bringing on a Spanish Speaking Family Advisor 5 participants Spanish speaking.



Support the continued growth of regional collaboratives, through the Community of Practice (CoP), so that communities and all stakeholders experience genuine direction and ownership in local approaches to ensure equal access and support of individuals and families.

# Take a look! Hosting a 2025 Hybrid Summit







Align supports coordination with the CtLC framework so that Supports Coordinators (SCs) have the skills and

capacity to encourage, explore, and plan with individuals and families about their vision of a good life and achieve short and long-term goals towards that vision of an everyday life now and in the future.

## Strategy 4: Quarterly Sessions through ODP



### **Charting the LifeCourse: Applying Principles and Using Tools to Support a Good Life**



"I learned new tools I can use in my monitoring sessions. I understand better how to incorporate it into my consumer lives."

"How visually seeing a person's domains can help guide them. Also, how the tool can be used to help others understand your client's desires and what they want others to understand about them."

## Strategy 4: Continued Activities to Help Reach This Vision



# Supporting Families Supports Coordination Innovation Workgroup publishes resources



### for SCs!

### **Community Engagement**

Throughout the past year, the Supporting Families' Supports Coordination Innovation Workgroup has been sharing ideas to help SCs fill their buckets to better help them support individuals and families. This resource is guided by the Charting the LifeCourse framework and is the first in a series responding to SCs as they support individuals with Intellectual Disabilities, autism, children with medical complexities, and their families.

Supports Coordinators asked for resources to increase access to the community. Being engaged in the community makes people feel connected and safe. Consider the strategies below to support community involvement and relationship-building skills, essential to engaging with neighbors, businesses, service providers, faith-based organizations, and outlets for leisure activities.





Focus on the engagement of cross-systems partners to build capacity across fields (e.g., medical, hospital social workers, etc.) in the CoP for Supporting Families to recognize their roles in supporting families to have strong visions and high expectations. The value their roles play in improving access for families to needed information, connection to other families, simplifying the processes of accessing supports, and services throughout the lifespan is essential.



# InVEST & Pathways to Partnership

- Intro to Charting the LifeCourse
- Charting the LifeCourse Person Centered Fundamentals
   Series
- Charting the LifeCourse (CtLC) Ambassador Series





People with disabilities who are parents, or who are planning to become parents, should be supported to plan for their needs as a family. Support should include planning with the SC. The Office of Developmental Programs (ODP) will develop concrete expectations for how to support parents with disabilities and those who plan to become parents. Individuals will have the support they need to explore family planning.

# Strategy 9: New Activities to Help Reach This Vision



### **Pregnancy & Postpartum Questions to Help Guide Conversations**

**Employment Example** What kind of time off and benefits are available to me to

have my baby including health savings or employee

assistance programs?

Individual and Family Life Example

What extended family members, friends, and neighbors can

help support me?

Personal Safety Example What technology for myself, the baby, or our vehicle will help

me go where I need to go?

**Legal & Financial Example**What are my parental rights?

### **Strategy 9: Technical Assistance with National CoP**



### **National Projects**

- National Research Center for Parents with <u>Disabilities | The Heller School</u> <u>(brandeis.edu)</u>
  - ACL Funded
- Through the Looking Glass

### **National Resources**

- Sex Education for people with disabilities
  - Sex Ed for Individuals with I/DD (ncil.org)
- Planning
  - The Arc's Center for Future Planning (<u>The Arc's Center for Future Planning</u>), also has a "Build your plan" interactive feature:
     <u>Future Planning (thearc.org)</u> not specific to parenthood, but general future planning that includes healthy relationships.

# Healthy Sexuality Training: ELEVATUS



- Beginning FY22-23, ODP, the Dept of Health, and PA Dept of Education have collaborated to fund opportunities for key stakeholders to be trained in the Elevatus <u>Curriculum: Sexuality Education for</u> <u>People with Developmental Disabilities - Elevatus Training</u>.
- Curriculum fully incorporates disability rights, independent living, and self advocacy.
- Places emphasis on the individual being a sexual self-advocate.
- Created by not only professionals in the field but also by individuals with developmental disabilities.
- Instruction of curriculum co-facilitated by an individual from the Intellectual and Developmental Disabilities (I/DD) population.
- The curriculum is an evidence-informed program guided by theories and practices that have a
  history of demonstrating positive results, including: Sexual Script Theory, Self Determination
  Theory, Social Learning Theory, and Social Impact Theory.



**Audience:** People who work with individuals with I/DD and want to lead sexuality education classes, staff training, or parent workshops.

- There were 161 training slots available across 3 Commonwealth agencies over a three-year period (FY 22-23 through FY 24-25).
- ODP has 57 Certified Healthy Sexuality educators.



LEADERS IN SEXUALITY AND DEVELOPMENTAL DISABILITY

# **Developmental Disabilities and Sexuality 101**



An Engaging Self-Study, Online Course to Help Staff Work One-on-One With This Sensitive Topic

- Welcome Module-Getting Started
- Module One: Getting Back to Basics
- Module Two: Sexuality 101



# ISAC Feedback & Suggestions





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