

## ISAC Recommendation #4: Support Families throughout the Lifespan



The vast majority of people with disabilities in Pennsylvania live with their families. Families need support in order make an everyday life possible throughout the person's lifetime. Families need information, resources, and training. They need connections with other families and support services. Listening to people with disabilities and their families is key to providing supports that help them achieve an everyday life.

Current Strategy	Accomplishments that support this Strategy	Recommendation for this Strategy (retain, revise, replace)
1. Recognize that family is defined by the person; by who is important to the person. It may include biological and chosen family or staff.	<p>This is the message communicated in all the LifeCourse materials and presentations.</p> <p>Understanding the complexity and context of family for everyone is embedded in the LifeCourse principles.</p> <p>6100 regulations reflect that family is defined by the person (persons designated by the individual).</p>	<p><b>Retain</b></p> <p>Engaging self-advocates, SCOs as well as providers will support this strategy.</p>
2. 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.	<p>The PA Family Network has reached nearly 11,510 through outreach activities, mentoring and workshops throughout Pennsylvania. PAFN has delivered 189 face-to-face workshops with individuals and families presenting LifeCourse curriculum. Outreach and Conference presence and presentations have increased with 9 conference presentations and 146 outreach encounters to date.</p> <p>We have touched more than 291 family units through individualized mentoring. Mentoring is delivered either face-to-face or by phone, addressing specific topics.</p> <p>The PAFN is also in the process of updating the "Gold Book," embedding the LifeCourse language,</p>	<p><b>Retain</b></p> <p>The PA Family Network plays a key role in our approaches to supporting families throughout the lifespan. There is a fidelity that comes from engaging family leadership to support families that is effective and valuable.</p>

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	<p>concepts and principles throughout the resource guide.</p> <p>Waiver changes, Community Safety and Healthy Sexual Relationship workshops developed.</p> <p>PA Family Network is using Instagram, Facebook (including Facebook Live) and Twitter to share information.</p> <p>More State Wide Conference presentations and Expos planned for 2019. Family advisors are co-facilitating Collaborative meetings across the state.</p>	
3. Support the development of regional collaboratives so that communities and all stakeholders experience genuine direction and ownership in local approaches to supporting families of people with autism or intellectual disabilities.	<p>There are currently 27 Regional Collaboratives covering 60 counties. The remaining counties are all in stages of planning around creating their Collaborative participation.</p> <p>Started encouraging regional Collaboratives to engage with the PA Family Network more. Collaboratives are meeting with one another to plan and share information. Strategies around using the LifeCourse principles and tools are a large focus.</p>	<p><b>Revise</b></p> <p>All counties are at some level of participation formally or informally in regards to the Community of Practice. Therefore this strategy should be revised.</p> <p>The strategy should shift to focus on supporting the current work and accomplishments of the Collaboratives while fostering positive information sharing, partnerships and sustainability across the state.</p>

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	Collaboratives are including self-advocates, families, broad community members to be a part of their leadership.	Supporting the infrastructure, free flow of information sharing and collective efforts of the Collaboratives is key to growth and sustainability. The revision should reflect those areas beyond the creation of Regional Collaboratives.  It is suggested that we change the language to be more inclusive of the "All People" not just specifically ID/Autism.
4. Align supports coordination with the LifeCourse Framework so that SCs have the skills and capacity to encourage, explore, and plan with self-advocates and families about their vision of a good life.	All SCOs have had exposure regarding the LifeCourse Framework from regional and central office leads. LifeCourse Framework was built into SC Orientation on MyODP.  Trainings for SCOs have been developed and offered on an ongoing basis. These trainings are being very well received. SCs have been encouraged to use the LifeCourse tools with people and families where they believe there will already be an eagerness, i.e., start "easy" and build on that experience organically. An emphasis is on how the LifeCourse principles and tools are intended to make their work easier, more effective and meaningful for everyone,	<b>Retain</b>  SC Listening Tour and Learning Communities will provide value insight around approaches to this strategy.  Action steps should include ways to support SC's to listen to a family's needs beyond what the system can provide.

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	<p>particularly in terms of reframing conversations and changing expectations for Everyday Lives.</p> <p>LifeCourse training is now built into the SC Orientation curriculum. Some SCOs have intended to use the LifeCourse to create organizational changes as a part of how their organization will do business. We have provided many of the SCOs and their support coordinators with a more comprehensive hands on training on the LifeCourse with applied learning models.</p>	
5. Amend the ISP to address families' needs including, challenges a family faces, the vision for the individual, and extended family information.	ISP Manual: We continue to be involved in this process and are helping to craft the language that accomplishes this critical message.	<b>Retain</b> Recommend that it should still be stated as a strategy under Recommendation #8
6. Develop materials that lead families to: information, connections, opportunities, supports, and resources needed to build everyday lives for all.	<p>Regional Collaboratives are making community mapping a key part of their strategies at the local level.</p> <p>The LifeCourse materials are designed to lead families to discover integrated supports through their relationship and community-based resources and are available in English and Spanish.</p> <p>The PA Family Network is beginning to build local family networks through their face-to-face</p>	<b>Retain</b>

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	<p>workshops and outreach. We are also providing trainings on the LifeCourse to cross system providers and entities across the state to make the information available to all people. There is a strong focus on the three buckets concept throughout all touchpoints with the community.</p> <p>We continue to incorporate the LifeCourse philosophy into Target Support Management (TSM).</p> <p>PA Family Network as well Regional Collaboratives are using social media to provide materials and resources.</p> <p>MyODP</p> <p>Transition focused Web collaborations are expanding our reach, resources and information sharing with the broader community.</p>	
7. Strategize multiple ways to disseminate information to families. Communication avenues include counties, providers, email distribution lists, school districts, advocacy	Regional Collaboratives are building this capacity at varying paces. Key to their work is bringing broad representation into their stakeholder groups; including school districts, providers, advocacy groups and generic community partners	<p><b>Retain</b></p> <p>Along with Strategy #6, disseminating information at all levels is a priority. Listening</p>

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organizations, social media, and traditional media at the local and state level.	<p>(such as parks and rec., clubs, businesses, churches, etc.) Presentations are continuing to be requested by provider groups and others.</p> <p>The PA Family Network has established a Facebook page and a Twitter account to reach families, along with an electronic newsletter.</p> <p>Families are also receiving information through registering with myODP.org.</p> <p>A Family Listening Tour occurred in 2018 with Deputy Secretary, Kristin Ahrens.</p>	tours provided insight into the ways that we can support this strategy.
8. Collaborate across systems to encourage positive expectations of meaningful lives, to realize the role of all systems in supporting families within this vision, and to make it as easy as possible for families to receive the information, supports and services they need throughout the lifespan. Include the school systems and medical community as pivotal messengers.	<p>Include the school systems and medical community as pivotal partners in reaching the "ALL". Regional Collaboratives have been inviting their human services partners to the table, such as EI, MH, and C&amp;Y. An exciting piece is that OCDEL is incorporating LifeCourse principles, strategies and trainings into their work. The HCQUs have been very engaged and supportive.</p> <p>More opportunities are being explored to further collaborate across systems so that families hear a consistent message of encouragement to have high expectations for full community involvement</p>	<p><b>Revise</b></p> <p>It is recommended that the last sentence of the current strategy, "Include the school systems and medical community as pivotal messengers" be removed. Cross system collaboration is a global focus and therefore we should focus this strategy to be inclusive of all systems and community partners at all levels. While the school system and medical community are pivotal messengers, keeping this strategy more global allows ownership</p>

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	<p>by all. We will again reach out to the Department of Education to explore collaboration. Several School Districts have hosted family workshops and staff trainings around Charting the LifeCourse. School personnel across the state have joined several Regional Collaboratives as well. Districts are reaching out for training around the LifeCourse Framework for classroom use and transition planning.</p> <p>We continue to explore any opportunity to share the COP with our human services partners, OCDEL, OVR, Department of Education and OMHSAS.</p>	and development of stronger community and cross system partnerships.
9. For people who are waiting for supports and services, develop a supports coordination service and funding for planning, connecting with other families, and finding information and resources within their communities.	<p>Several regional Collaboratives are intending to use Intake as an opportunity to introduce families to LifeCourse at the front door.</p> <p>A pilot was started in Lackawanna with their SCO to create a designated role of "Community Specialist" that utilizes TSM funding and incorporates the LifeCourse Framework into supporting families.</p>	<p><b>Revise</b></p> <p>The development of TSM funding fulfilled a large part of this strategy, however a revision to focus on the importance of providing the connections to other families, finding information and community resources should be reflected in the revised strategy as an ongoing need for families.</p>

New Strategies and/or Strategies that have been implemented but were not included in the original 2016 list

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