

Everyday Lives: Values in Action

Information Sharing & Advisory
Committee (ISAC)

RECOMMENDATIONS & STRATEGIES



2023

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Recommendation 1: Assure Effective Communication

Every person has an effective way to communicate in order to express choice and ensure his or her health and safety. All forms of communication should consider and include the individual's language preferences and use of current technology.

STRATEGIES for #1

1. Finalize and issue the communication policy bulletin.
 - Define communication:
 - a. It is a right;
 - b. It is expressive and receptive;
 - c. It is a meaningful interaction not just words/signs;
 - d. It is cultural;
 - e. It is foundational to leading a self-determined life, being a part of a community, being healthy and safe, and having healthy relationships;
 - f. It will assert that everyone can communicate in one way or another (such as but not limited to behavior, eye gaze, visual gestural); however, not everyone can communicate effectively and meaningfully.
 - Describe a communication profile and plan;
 - Specify roles and expectations;
 - Include the applicable 6100 regulations.
2. Incorporate a focus on communication in the individual planning process.
3. Identify all possible funding avenues (including private insurance, ACCESS (Medicaid), Medicare, Person/Family Directed Services (P/FDS), waivers, etc.) to support people in exploring effective communication supports. These would include formal assessments to identify needs and appropriate approaches, techniques, devices, updates, and training.
4. Address the lack of Communication Specialists and clinicians, such as speech-language professionals and board-certified behavior analysts, with the expertise in communication to work with individuals with intellectual disabilities or autism.
5. Recognize and accommodate the primary language of individuals, self-advocates, and families; provide materials and translation.

6. Promote generic social change by building capacity in understanding and supporting people with nontraditional communication needs.
7. Track progress by measuring compliance with revised regulations relating to communication.



Recommendation 2: Promote Self-Direction, Choice, and Control

Personal choice and control over all aspects of life must be supported for every person. Choice about where to live, whom to live with, what to do for a living, and how to have fun all are key choices in life, as are seemingly small choices: such as what to eat, what to wear, when to wake up in the morning, and when to go to bed. It is important to be able to trust the people who provide assistance, to feel confident that they respect you and your right to manage your life, and to enjoy each other's company.

Self-direction works when individuals have clear and understandable information, opportunities to exercise choice, and assistance with making decisions when needed. Self-direction is only possible when family, friends, and people who provide supports respect the individual's preferences and their right to make mistakes and facilitate the implementation of the individual's decisions.

STRATEGIES *for* #2

Primary Objective: Greater participant utilization of self-direction opportunities.

1. Simplify the process for people to direct their services to reduce time and effort needed to use the model.
 - Revise/simplify the PA Guide to Participant-Directed Services (PDS) to make the guide more accessible to people unfamiliar with PDS models;
 - Simplify bulletins and announcements about Vendor/Fiscal Employer Agent (VF/EA) and Agency with Choice (AWC) to establish clear and consistent expectations for VF/EA and AWC performance;
 - Clarify the documentation required to comply with state and federal regulations regarding PDS services.

2. Provide information and education about self-direction to individuals, self-advocates, families, supports coordinators, and providers.
 - Provide training to participants, common-law employers, supports service workers, and natural supports on real world methods to manage the self-direction process in the VF/EA and AWC models through the PA Family Network and Self-Advocates United as 1;
 - Conduct targeted outreach to AEs/SCOs with low participation in PDS to encourage increased use of PDS;
 - Support the PA Family Network to educate families about the self-direction option.
3. Assure the availability of fiscal intermediary services. Permit more than one AWC to operate within a county/AE, allowing greater access to AWC services and expanded participant choice.
4. Provide training to Agencies with Choice on operation and ODP recommendations to increase consistency of practice.
5. Ensure personal choice and control over all aspects of life are supported for every person.
 - Apply the “Individual Rights” sections of Chapter 6100 to support choice and control over all aspects of individuals’ everyday lives;
 - Use data analytics to track and measure results, and to help support the provision of technical assistance and training.
6. Build capacity in understanding and supporting people with nontraditional communication needs with an emphasis on self-direction, choice, and control.
 - Communicate expectations regarding the link between effective communication and the ability to control one’s own life.



Recommendation 3: Increase Employment

Employment is a centerpiece of adulthood and must be available for every person.

The benefits of employment for people with disabilities are significant and are the same as for people without disabilities.

STRATEGIES for #3

1. Inform families about employment opportunities when their children are young; inform self-advocates as they approach the age of transition.
2. Strengthen state and local interagency collaboration to support individuals and self-advocates to transition into competitive integrated employment upon graduation.
3. Support individuals receiving subminimum wage to gain competitive-integrated employment.
4. Support families before, during, and after an individual's transition to competitive-integrated employment.
5. Build an Employment First assumption in all supports coordination planning activities, including ISP redesign and training.
6. Provide training and ongoing technical assistance to service providers and supports coordinators.
7. Routinely publish data on employment services, work, and wages.
8. Connect OVR Workforce Development information system and ODP information system (HCSIS) to enable the departments to share information.
9. Support provider transformation to employment services.
10. Facilitate public-private partnerships and local interagency coalitions to support employment opportunities and encourage innovation.
11. Build provider capacity for the benefits counseling service. Provide training and technical assistance to supports coordinators to increase awareness of how benefits counseling might inform individuals, self-advocates, and families about options to work without losing benefits.
12. Promote and increase county and state government hiring of people with disabilities.
13. Support the growth and advancement of post-secondary education programs.



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 to 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.

STRATEGIES for #4

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.
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.
3. Support the continued growth of regional collaboratives, through the Community of Practice, so that communities and all stakeholders experience genuine direction and ownership in local approaches to ensure equal access and support of individuals and families.
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.
5. Amend the ISP to address families' needs, including challenges a family faces, the vision for the individual, and extended family information.
6. Develop materials that lead families to information, connections, opportunities, supports, and resources needed to build everyday lives for all.
7. Strategize multiple ways to disseminate information to families. Communication avenues include counties, providers, email distribution lists, school districts, advocacy organizations, social media, and traditional media at the local and state level.

8. Focus on the engagement of cross-systems partners in the Community of Practice 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, supports, and services throughout the lifespan is essential.
9. For people who are waiting for supports and services, utilize the supports coordination service, Targeted Support Management, to support community navigation through the LifeCourse Framework and tools for planning, connecting with other families, and finding information and resources within their communities.



Recommendation 5: Promote Health, Wellness, and Safety

Promote physical and mental health, wellness, and personal safety for every individual and his or her family. Promoting physical and mental health means providing information about health and wellness, emotional support, and encouragement. Tools that help every individual adopt a healthy lifestyle — including good nutrition, healthy diets, physical activity, and strategies to reduce and manage stress and protect oneself from all types of abuse and exploitation — must be provided.

STRATEGIES for #5

Overarching plan to meet above recommendation: Develop and implement a comprehensive program of wellness opportunities for people with IDD and autism. Areas including diet/nutrition; physical activities; emotional wellness; sexuality and healthy relationships; wellness as related to aging; safety and drugs and alcohol. To support the utilization of health, wellness and safety opportunities, increased health literacy will be promoted. Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

1. Direct people to existing resources with information on healthy living.
 - Create a resource guide with available resources by region, and post online;
 - Provide outreach and education for Supports Coordinators on these topics to promote incorporation into the ISP;
 - Continue to promote waiver services among professionals to become eligible providers for available waiver services for wellness;
 - Promote health literacy to increase individuals' capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.
2. Increase the use of Mental Health First Aid (MHFA) among stakeholders across the state.

3. Update, disseminate, and provide training on sexuality guidelines.
 - Identify experts in the field in PA available to support individuals and families with recommendations and strategies.
4. Incorporate a focus on health and wellness into the individual planning process.
 - Use the Health Risk Screening Tool (HRST) to inform individual planning;
 - Offer training on the Fatal Four to broader audiences in both live and on-line formats.
5. Health Care Quality Units will develop outreach to promote wellness to individuals and self-advocates living with families, including people on the waiting list, engaging partners including ASERT, SAPNA, the PA Family Network, and Temple.
6. Broaden the use of physical and behavioral health data to understand health, wellness and safety needs and risks, and to inform ODP planning and direction of supports such as waiver development, HCQU and ASERT activities.



Recommendation 6: Support People with Complex Needs

People with disabilities who have both physical and behavioral health needs receive the medical treatment and supports needed throughout their lifespan. People are more able to live an everyday life when individuals, families, and providers plan and prepare to provide and modify supports as needs and challenges change. Opportunities for a full community life are dependent on adequate supports and the commitment to build capacity within the larger human service delivery system.

STRATEGIES for #6

1. Develop Capacity Building Institute (CBI). ODP will, in collaboration with the Office of Mental Health and Substance Abuse Services, will establish a training opportunity for members of the IDD and mental health fields to better serve individuals and self-advocates with IDD and autism in addition to mental health needs.
2. Improved support for individuals and self-advocates with complex medical needs. ODP will develop in coordination with the HCQUs and ASERTs increased access to information and guidance for individuals and self-advocates with new onset or longstanding complex medical health needs.
3. Improved used of data. Use data related to individuals with complex medical needs, complex dental needs or complex mental health needs to inform ODP policy and program design. This data will enhance the development of:
 - Training and education.
 - Strategies to target identified health risks.
 - Improved capacity.
4. Promote to use of online dual diagnosis training curriculum. New providers are required to complete the dual diagnosis training curriculum.
5. Dual Diagnosis Conference – Implemented 2017. Next Dual Diagnosis Conference is scheduled for August 2019 in Altoona, PA. Since the first conference in 2017, each conference has met expectation for capacity.

6. Develop online training modules for Functional Behavioral Assessment. These modules are being developed as a coordinated effort between BAS and ASERT but will be of use in support of any individual served by ODP. This will promote a more standardized approach to the FBA and will allow for a greater number of individuals to build competency in this area.
7. Professional Conference Series – Initiated 2017. Specialized opportunities for clinicians in practice and in training, including but not limited to psychiatrists, psychiatric residents, Nurse Practitioners, Licensed Social Workers, Behavior Specialists, DSPs, transition coordinators and educational coordinators, offering enhanced exposure to and education about the needs of individuals with I/DD and MH diagnoses and networking with other professionals & clinicians.
8. ODP will explore ways to promote interest in and competencies for providing nursing services for individuals with I/DD and autism.



Recommendation 7: Develop and Support Qualified Staff

People with disabilities receiving services benefit when staff who support them are well trained. Values, ethics, and person-centered decision-making can be learned and used in daily practice through mentorship and training. Providing professional training that strengthens relationships and partnerships between individuals, families, and Direct Support Professionals (DSPs) will improve the quality of support.

STRATEGIES for #7

1. Adopt the Direct Work Force Core Competencies, which were developed by the Centers for Medicare and Medicaid Services (CMS) as an expectation.
 - a. To further this actively support and promote the Core Competencies through the following:
 - Policy Bulletins;
 - Training: As a part of this, conduct a review of MyODP.org for existing course content pertaining to Core Competencies to identify areas where augmentation of course material is needed, and to help identify and promote the use of this existing material;
 - Other Outreach.
 - b. Incentivize Core Competencies by:
 - Identifying if there are any providers who have adjusted pay scales to promote/incentivize completion of Core Competencies;
 - Reviewing the payment models of other states to report on how Core Competencies are incentivized elsewhere;
 - Utilizing Residential Services Learning Collaborative (RSLC) meetings to provide information on creative incentive methods.
 - c. Engage families and individuals in the discussion of Core Competencies to include:
 - An explanation of the Core Competencies;
 - Conveying ODP's expectations regarding the implementation of Core Competencies.
 - Facilitating a discussion as to whether or not Core Competencies should be tied to pay.

2. Discuss opportunities to promote additional credentialing and competencies.
3. Maintain and encourage significant DSP participation at RSLC meetings.
4. ODP will establish and implement credentialed training programs based on standard curriculum and testing in an attempt to maintain and develop qualified staff, decrease the rate of turnover, and promote staff retention and provider capacity. This strategy will include training for DSPs as well as other professionals, such as Benefits Counselors.
5. Build incentives into the reimbursement system to promote staff credentials, encourage professional growth and development, and adopt incentive-based training and credentialing. This includes:
 - Reviewing other states' models, where success has been achieved, to learn from those who have attempted and have identified hurdles to progress;
 - Obtaining consultation from The National Alliance for Direct Support Professionals (NADSP) as a mean of considering their extensive credentialing system.
6. Promote the use of and improve the usability and functionality of MyODP.org, to include allowing for greater access, upgrading the Learning Management System (LMS) software, and promoting the College of Direct Support and other courses available via the site.



Recommendation 8: Simplify the System

The system of supports and funding of those supports must be as straightforward and uncomplicated as possible. This will allow for greater understanding and use of the system by everyone — most importantly the individual needing and receiving supports.

STRATEGIES *for* #8

1. Redesign the ISP process and format to reduce the time, simplify the document and increase the positive experience of individuals, self-advocates and families, and all stakeholders.
2. Provide a user-friendly useful planning tool and document that increases flexibility and ease of access for the individual, self-advocate, family, and supporters to manage services and supports.



Recommendation 9: Improve Quality

Together we must plan and deliver services and supports that adhere to our values, measure person-centered outcomes, and continuously improve an individual's quality of life. All stakeholders must be engaged in the process of measuring how well services assist people in achieving an everyday life.

STRATEGIES for #9

1. Maintain the Information Sharing and Advisory Committee (ISAC) as ODP's Stakeholder Quality Council, the entity that creates a detailed series of recommendations, strategies, and performance measures to guide the Office of Developmental Programs (ODP) and gauge its progress in achieving the important goals put forth in Everyday Lives. The ISAC will continue to use the quality improvement framework to plan and implement improvements, assess whether we achieve outcomes as intended, make changes as needed, and embed successful practices in the system.
2. Continue to offer ODP's Quality Management (QM) Certification Curriculum to build system capacity in applying quality management principles and practices across the system.
3. Develop and disseminate an ODP annual report to show the implementation of approved recommendations and strategies across the system.
4. Create a provider profile to assist individuals, self-advocates, families, and supporters to make informed choices about providers and services.
5. Develop, implement, and maintain Quality Assessment and Improvement (QA&I) process as ODP's annual monitoring of the system's performance in supporting individuals and families.



Recommendation 10: Expand Options for Community

Living

Expand the range of housing options in the community so all people can live where and with whom they want to live. Listening to people with disabilities and their families, providers, and Support Coordinators will help people locate affordable and accessible housing, find house

mates, and identify housing resources/supports and other government benefits that, when blended with natural supports, will promote an everyday life.

STRATEGIES *for* #10

1. Review the Housing Transition and Tenancy services to determine if it is meeting the needs of individuals.
2. Develop a training for SCOs, AEs and providers on the Housing Transition and Tenancy service.
 - The training should include more information on the financial impact.
 - Provide training to on the varied options for community living.
3. Expand understanding of what is possible.
 - Promote development and distribution of education/training/technical assistance to individuals and self-advocates to increase knowledge of options and ability to make informed choices.
 - Ensure development and distribution of education/training/technical assistance for families through the Supporting Families initiative. This should include planning for the future so that families can explore what is possible. The education should include items like ABLE accounts, sustaining housing, and community support.
 - Evaluate and improve the education and support for individuals to budget for their housing needs.
4. Expand the Life Sharing service to allow for the enrollment of birth families as Life Sharing providers.
 - Begin to develop material to help SCs and families understand the benefit to delivering this service.
 - Hold listening session with life sharing providers and individuals and their families to brainstorm on how to expand the supports.
5. Continue to develop supported living service availability that enable individuals and self-advocates to live in their own homes with the support of an agency available to provide guidance and assistance as needed.

- Continue to promote this service as an alternative to residential habilitation.
 - Develop more specific material to help SCs explain the benefit of the services to individuals and families.
6. Expand choice of options to include creative housing alternatives.
 - Continue to work on developing more integrated options that support the Everyday Lives (EDL) philosophy.
 7. Support the development of safe and affordable housing options that meet the individual's and self-advocates personal preferences.
 - Work with the providers of the Housing transition and pre-tenancy service to identify options that support individual preference.
 8. Provide access to home modifications, transportation, and assistive technology to support people to live in their homes.
 - Continue to help SCs and providers learn how to access technology to promote independence.



Recommendation 11: Increase Community Participation

Being involved in community life creates opportunities for new experiences and interests, the potential to develop friendships, and the ability to make a contribution to the community. An inter-dependent life, where people with and without disabilities are connected, enriches all of our lives.

STRATEGIES *for* #11

1. Train direct care provider staff, supervisors, and managers in Person Centered Thinking and Planning to assist people to identify new experiences, promote engagement in new activities, and make new connections that are important to them.
2. Continue the statewide practice of community participation that facilitates valued and active participation in a broad range of integrated activities that build on the person's interests, preferences, and strengths while reflecting the person's desires for employment, community involvement, and membership.
3. Provide peer to peer education for people with disabilities who might be considering increasing how much time they are supported in the community versus an adult training or prevocational facility.
4. Establish technical assistance teams to focus on provider readiness to support expanding the individual's connections to the community. The TA teams will include individuals with lived experiences and expertise in the LifeCourse framework, employment, transportation and community mapping to develop plans that meet the individual's choice, preferences and goals. The PA Support Broker Network will also be available for consultation with providers seeking to improve community mapping and enhancement of community supports.
5. Develop and provide training to SCs on facilitating planning, discussion and effective monitoring to support individuals to become more involved in community life.
6. Develop and disseminate new ideas and approaches on how to provide creative solutions to transportation barriers.

7. Analyze data to identify providers that are meeting goals for CPS, to learn and share best practices with facility-based CPS providers through training and technical assistance.



Recommendation 12: Provide Community Services to Everyone

People with disabilities — whether living on their own, with families, or in institutions — are waiting for community services. The goal is to build a system having the capacity to provide services in a timely fashion for all people who need supports.

STRATEGIES for #12

1. Individuals, self-advocates with intellectual disabilities or autism, and families should receive supports coordination service; information about local resources and services (e.g., OVR, Medicaid, aging, housing supports, income supports and victim services); information to connect with family and self-advocacy support organizations; and Family Support Service (FSS) using Base and block grant funding.

Supports coordination should provide individuals, self-advocates, and families with tools and support to create a vision of an everyday life that:

- a. Considers factors and local community resources in an everyday life: daily and community living, social and spirituality, healthy lifestyles, security, and advocacy;
 - b. Builds on the personal strengths, interests, relationships, resources, and opportunities within the person's and family's lives; and
 - c. Serves as the overall framework to provide publicly funded services which align with everyday life.
2. Expand service system capacity to be able to provide employment services, in home supports and community participation services to individuals and self-advocates with intellectual disabilities or autism within 90 days of their eligibility determination.

In the process of building capacity, prioritize and reserve capacity for:

- a. High school graduates to begin services 30 days prior to graduation;
- b. People who have caregivers who are unable to take care of their family member due to illness, aging, or an unanticipated life situation;
- c. PUNS and/or any other emergency.

3. Conduct ongoing training on the Prioritization of Urgency of Need for Services (PUNS) instrument:
 - a. For individuals, families, SC and AEs;
 - b. For SCs on facilitating discussion to inform the PUNS.
4. ODP will provide training and technical assistance to law enforcement and criminal justice systems regarding intellectual disability and autism on available supports and services in order to:
 - a. Promote diversion for people with intellectual disabilities or autism who are arrested;
 - b. Improve supports to victims of crimes with intellectual disabilities or autism.
5. Develop expertise within AEs and SCOs and provide training for AEs and SCOs to navigate the criminal justice system to support diversion and improve outcomes for those who are arrested.
6. ODP will issue an annual report on progress in addressing the waiting list.
7. Provide outreach and communication to autism community about the expanded eligibility in ODP Programs.



Recommendation 13: Evaluate Future Innovations Based on Everyday Lives Principles

Future consideration of service models and reimbursement strategies must be based on the principles of person-centered planning, individual choice, control over who provides services and where, and access to/full engagement in community life. Innovative approaches should be evaluated based on the recommendations of *Everyday Lives*, including employment, recognizing, and supporting the role of families, and meeting the diverse needs of all individuals. Stakeholders should be fully engaged in designing, implementing and monitoring the outcomes and effectiveness of innovative service models and service delivery systems.



Recommendation 14: Promote Racial Equity (New)

Communities are richer, more just, and stronger when we honor and respect the whole of racial diversity. Access to a quality, person-centered, culturally competent system of supports and funding must be equally available regardless of race. Services must include planning over a life span and address racial disparities, including disparate outcomes. The duty to ensure that racial diversity is promoted and supported, at all levels within the services system, must be embraced.

STRATEGIES *for* #14

1. Consistently include breakdowns by race in data analysis and reporting and incorporate in Quality Management (QM) plans.
2. Develop and provide peer training for self-advocates on racial bias and racial equity.
3. Support organizations with tools to improve racial equity performance and ensure increasing levels of racial diversity and inclusion, across all levels of the organization, as part of their quality management strategy.