

Everyday Lives: Values in Action














Information Sharing and Advisory Committee (ISAC)
Recommendations, Strategies, and Performance Measures



2016

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES

Contents

	Recommendation 1: Assure Effective Communication.....	4
	Recommendation 2: Promote Self-Direction, Choice, and Control	6
	Recommendation 3: Increase Employment	8
	Recommendation 4: Support Families throughout the Lifespan	10
	Recommendation 5: Promote Health, Wellness, and Safety	13
	Recommendation 6: Support People with Complex Needs	16
	Recommendation 7: Develop and Support Qualified Staff	18
	Recommendation 8: Simplify the System	20
	Recommendation 9: Improve Quality	21
	Recommendation 10: Expand Options for Community Living	22
	Recommendation 11: Increase Community Participation	25
	Recommendation 12: Provide Community Services to Everyone.....	28
	Recommendation 13: Evaluate Future Innovations Based on Everyday Lives Principles	35
	Data Sources.....	36

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES

“It is how we are living the vision that matters.”

Savannah Logsdon-Breakstone, ISAC member

INTRODUCTION:

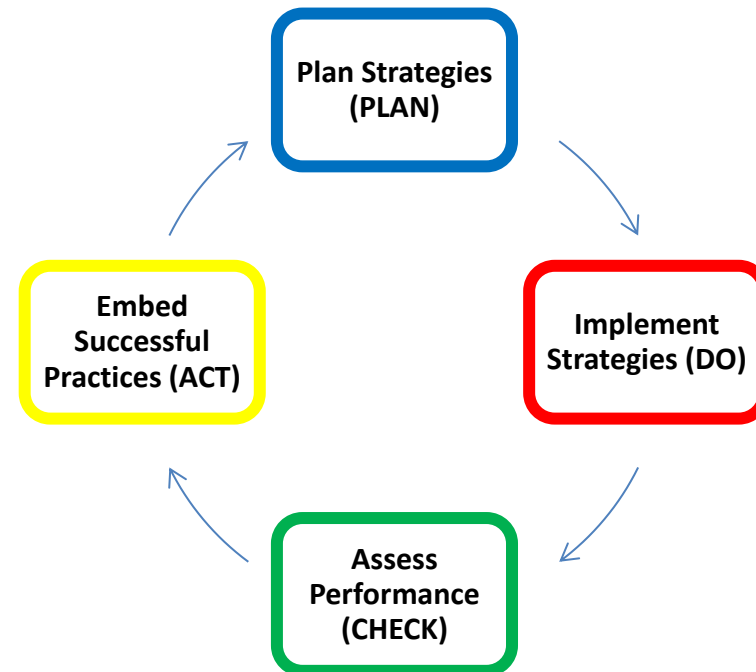
Following the publication of [Everyday Lives: Values in Action](#), the Information Sharing and Advisory Committee (ISAC) has become ODP’s Stakeholder Quality Council. The ISAC has created a detailed series of recommendations, strategies, and performance measures to guide the Office of Developmental Programs (ODP) and gauge its progress in achieving the important goals put forth in *Everyday Lives*. These strategies and recommendations developed by the ISAC are intended to serve as a guide for everyone engaged in developing, providing, and advocating for services in the ODP system: administrative entities, providers, support coordination agencies, advocacy organizations, local quality councils, and all entities involved on the ISAC.

Many of the recommendations and strategies have already been incorporated in draft waiver applications, regulations, policies, the Supporting Families Collaborative, employment initiatives, and training.

As we carry out these recommendations and strategies, we will use the quality improvement framework to gauge our progress and continue to plan improvements in the system. Together we will plan, implement, and assess whether we have achieved the outcomes we intended, make changes as needed, and finally imbed successful practices in the system. This publication offers us a glimpse of where we are today to help us move forward for a better tomorrow.

The ISAC will continue to serve as the entity that provides sustained, shared leadership and a platform for collaborative strategic thinking for the ODP system. Strategies will continue to evolve as counties, support coordinators, service providers, advocates, and others work in partnership to improve services.

Managing for Quality – Planning and implementing strategies, measuring performance, and embedding successful practices



* Note – Data sources identified in performance measures are described on page 35.



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:

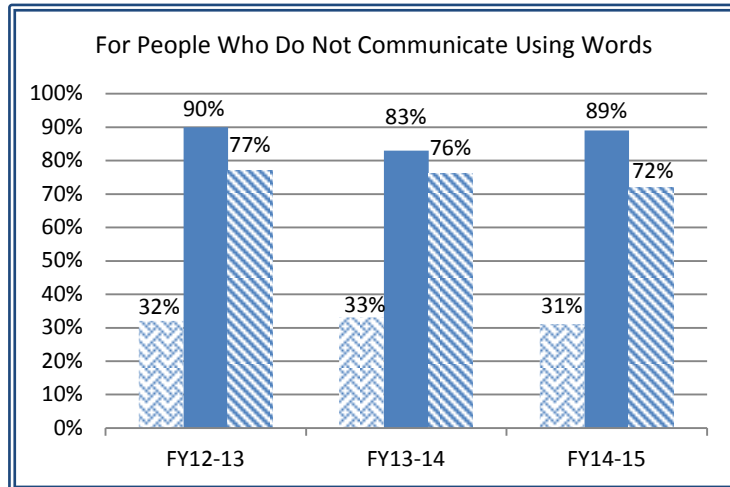
1. Finalize and issue the communication policy bulletin.
 - Establishes that “effective communication is the key to leading self-determined lives, being part of communities, being healthy and safe, and having healthy relationships.”
 - Recognizes the rights of people with communication challenges to receive supports and services to effectively and fully communicate.
 - Describes the communication profile and a communication plan in the ISP.
 - Specifies roles, expectations, training needs, and funding options for supporting effective communication.
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 skilled, specialized clinicians with the expertise to work with people with intellectual disability or autism. The profession is seriously lacking in capacity of speech/language professionals with strong experience with augmentative and alternative communication (AAC).
5. Recognize and accommodate the primary language of individuals, self-advocates, and families; provide materials and translation.

Performance Measures:

(Data Source: Annual Independent Monitoring for Quality (IM4Q) Survey)

1. For people who do not communicate using words, the percent of people with a formal communication system in place, i.e., a formal written plan in place that describes and documents a communication system (e.g., sign language/ASL, a picture board/system such as PECS, a voice-output communication device or iPad, or a combination of methods). A communication profile in the ISP is not sufficient in and of itself.
2. For people with formal communication systems in place, the percent of systems that are in working order and being used.
3. For people with formal communication systems in place, the percent of individuals and self-advocates who report using them across all settings (i.e., you use the system at home, at work, at school, and in your community).

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES



- 1. % with a formal communication system in place
FY12-13 (n=1,822) FY13-14 (n=1,512) FY14-15 (n=1,565)
- 2. % whose formal communication systems are working and used
FY12-13 (n=487) FY13-14 (n=434) FY14-15 (n=421)
- 3. % of formal communication systems used across all settings
FY12-13 (n=475) FY13-14 (n=406) FY14-15 (n=411)

Source: IM4Q Data



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.

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

Strategies:

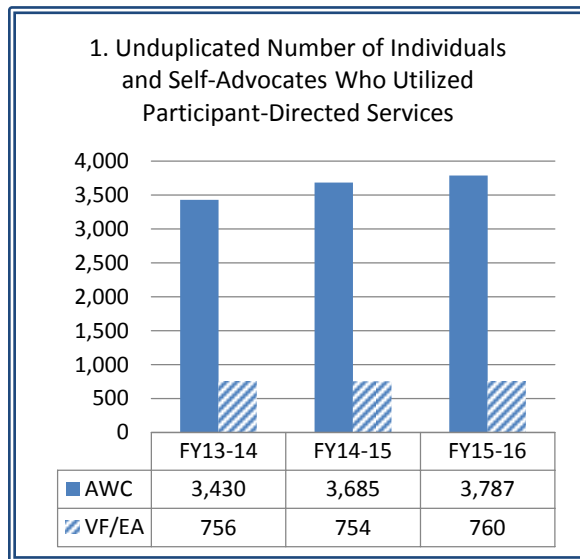
1. Simplify the process for people to direct their services to reduce time and effort needed to use the model.
 - Revise/simplify the PA Guide to Participant-Directed Services (PDS) to make the guide more accessible to people unfamiliar with PDS models.
 - Simplify bulletins and announcements about Vendor/Fiscal 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. Expand the availability of support brokerage services.
 - Clarify that supports broker can be authorized as the only PDS on an individual's ISP.
 - Remove supports broker services from P/FDS capitation to increase service accessibility (Waiver Amendment V).
 - Allow supports broker services for participants in a waiver residential habilitation setting who have a plan to transition to a private residence and to self-direct their services through an AWC or VF/EA FMS when they are in a private residence (Waiver Amendment V).
4. 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.

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES

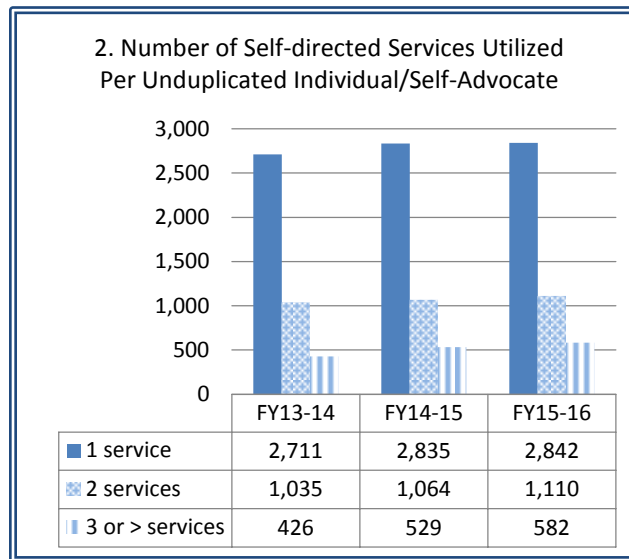
5. Provide training to Agencies with Choice. Provide training to AWCs on operation and ODP recommendations to increase consistency of practice.
6. Provide individuals, self-advocates, and families budget authority. Offer a new service definition, “Participant-Directed Goods and Services,” providing P/FDS Waiver participants \$2,000 per fiscal year to purchase services, equipment, or supplies not otherwise provided through other services offered in this waiver, the Medicaid State Plan, EPSDT or a responsible third-party, such as Medicare or private insurance.

Performance Measures:

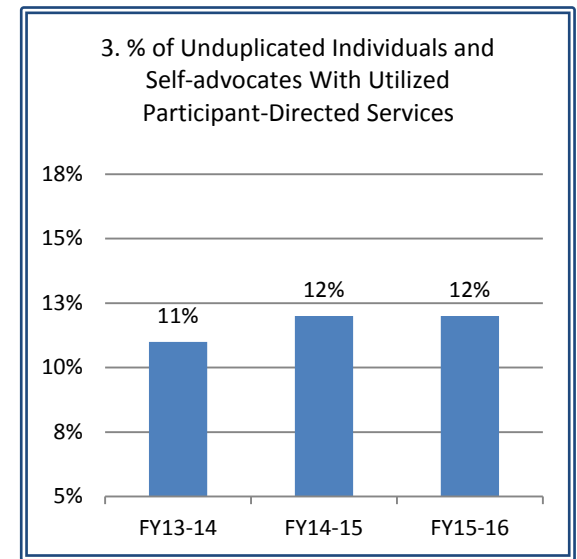
1. Number of individuals and self-advocates who use PDS, by AWC and VF/EA (Source: Home and Community Services Information System (HCSIS)).
2. Number of self-directed services per individual/self-advocate; will include support broker service (Source: HCSIS).
3. Percent of individuals and self-advocates who use participant-directed services, including AWC and VF/EA (Source: HCSIS).
4. Participant satisfaction with ODP’s self-directed services models. (Source: Annual VF/EA and AWC Participant Surveys).



Source: 9/30/16 HCSIS Data



Source: 9/30/16 HCSIS Data
Includes AWC and VF/EA Services



Source: 9/30/16 HCSIS Data
Includes AWC and VF/EA Services; Individuals enrolled in Consolidated & P/FDS Waivers, and Base Program



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.

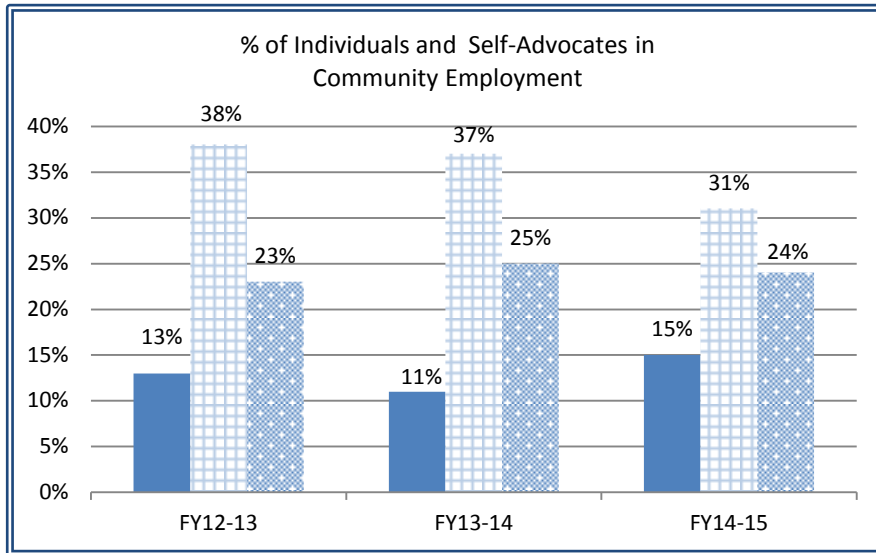
Strategies:

1. Inform families about employment opportunities when their children are young; inform self-advocates as they approach the age of transition.
2. Build an Employment First assumption in all supports coordination planning activities, including the ISP redesign and training.
3. Provide training and ongoing technical assistance to service providers and supports coordinators.
4. Establish a baseline number of people receiving employment services and those employed; routinely publish data on work and wages.
5. Connect OVR Workforce Development information system and ODP information system (HCSIS) to enable the departments to share information.
6. Support provider transformation to employment services.
7. Facilitate public-private partnerships and local interagency coalitions to support employment opportunities and encourage innovation.
8. Add benefits counseling to inform individuals, self-advocates, and families about options to work without losing benefits including the ABLE Act and Medicaid buy-in.
9. Promote and increase government hiring of people with disabilities.
10. Offer P/FDS waiver services to high school seniors interested in work and who transition into competitive, integrated jobs.
11. Support the growth and advancement of post-secondary education programs.
12. Create service definitions and rates to incentivize providers and support individuals, self-advocates, and families.

Performance Measures:

1. Percent of people who have a paid job in the community (Source: Annual Adult Consumer National Core Indicators (NCI) Survey).
2. Percent of people who would like a paid job in the community (Source: Annual Adult Consumer NCI Survey).
3. Percent of people who want to work who have employment as a goal in their ISPs (Source: Annual Adult Consumer NCI Survey).
4. Number of people with authorized employment services (Source: HCSIS).
5. Number of people receiving employment services (Source: PROMISe™).
6. Number of waiver participants in a competitive, integrated job (Source: HCSIS/updated ISP monitoring; collected beginning November 2016).

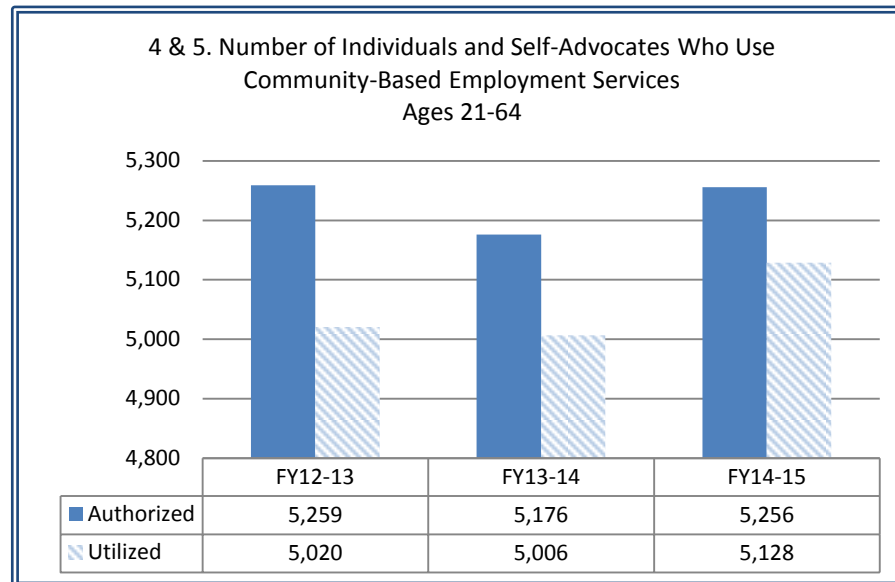
EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES



Source: NCI PA Adult Consumer Survey Data

- 1. % who have a paid job in the community
FY12-13 (n= 1,244) FY13-14 (n=619) FY14-15 (n=624)
- 2. % who would like a paid job in the community
FY12-13 (n=479) FY13-14 (n=275) FY14-15 (n=275)
- 3. % who want to work and have an employment goal in their ISPs
FY12-13 (n=1,308) FY13-14 (n =610) FY14-15 (n=633)

A community-based setting is a place where most people do not have disabilities. Examples of a paid job in a community-based setting include supported employment, competitive employment, enclave, or work crew.



Sources: Authorized community-based employment services: **HCSIS on 8/31/2016**. Utilization data: **PROMISE™ paid claims as of 9/26/2016** and may not be complete. All ODP waiver and Base programs are included.

Notes: Unduplicated people ages 21-64 during each fiscal year. Community-Based Employment Services includes Supported Employment and Transitional Work Services. Job Finding and Job Assessment as separate services are also included for Adult Autism Waiver.



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:

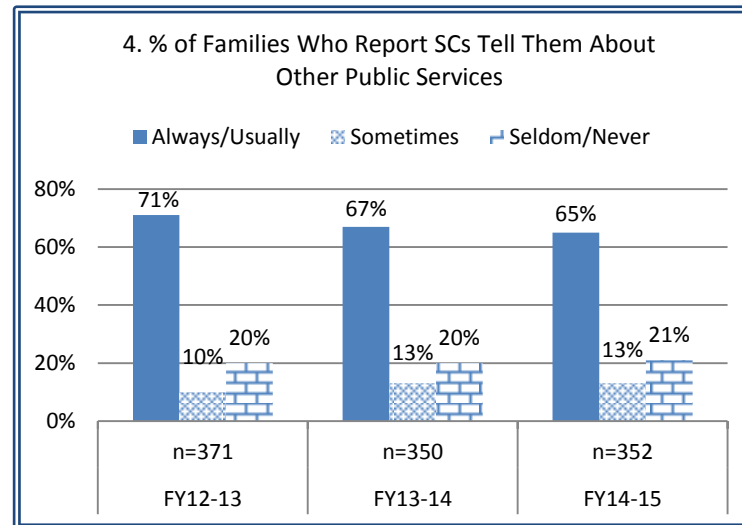
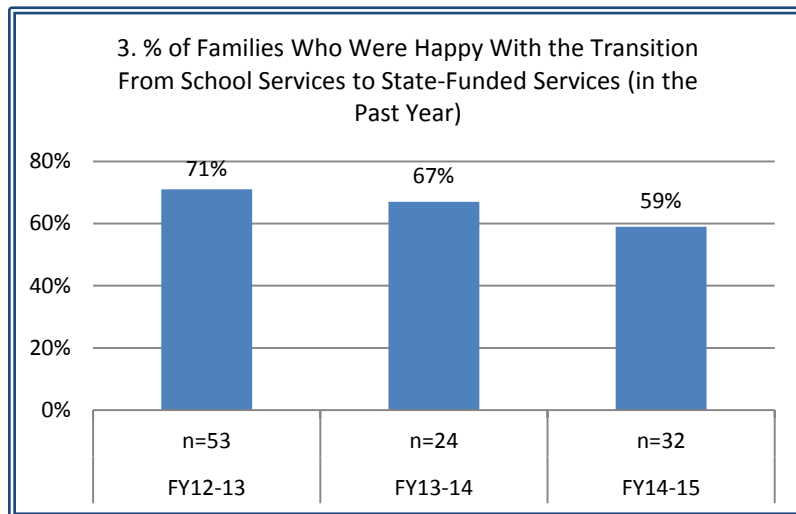
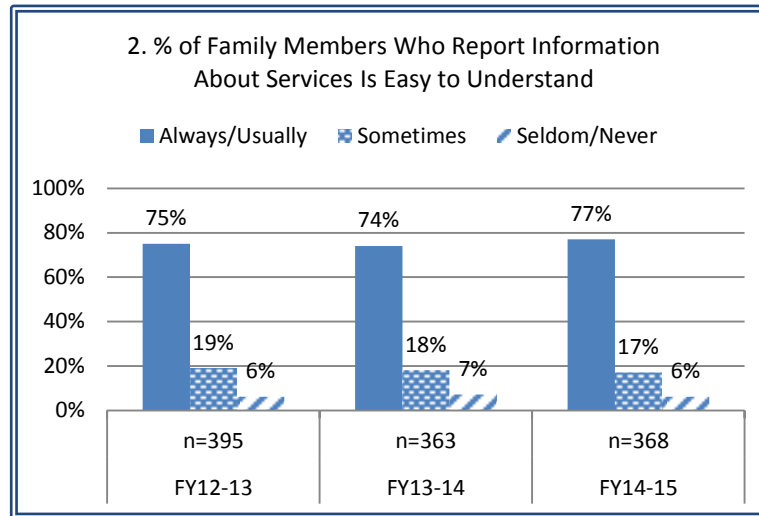
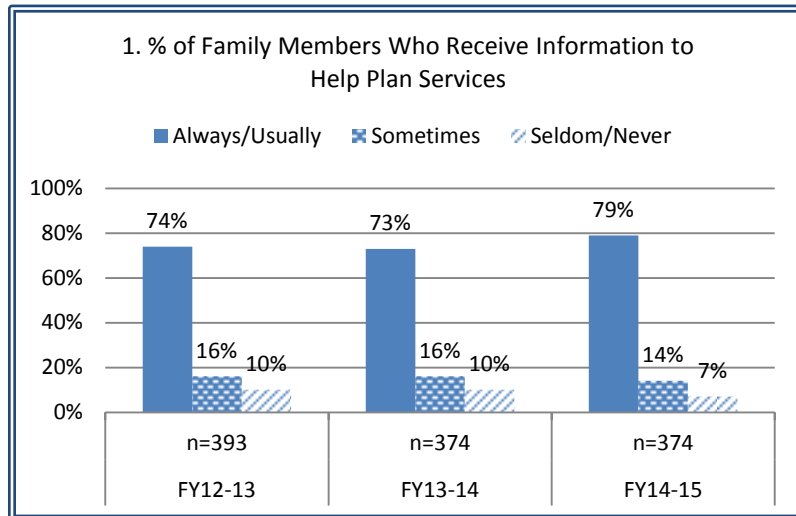
1. Recognize that family is defined by the person; by who is important to the person. It may include biological and chosen family or staff.
2. Support the work of the PA Family Network to reach families with a consistent message of the importance of family expectations of a good life for family members and opportunities for discovery and navigation of support/service systems and community-based resources.
3. Support the 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.
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. 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.
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.

Performance Measures:

(Source: Annual NCI Adult Family Survey)

1. Percent of family members who receive enough information that helps them participate in planning services for their family.
2. Percent of family members who report that the information received is easy to understand.
3. Percent of family members who report being happy with the transition process (if their family member transitioned from school services to state-funded services in the past year).
4. Does the Supports Coordinator tell you about other public services for which your family is eligible (food stamps, supplemental security income (SSI), housing subsidies, etc.)?

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES



Source: NCI PA Adult Family Survey Data



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:

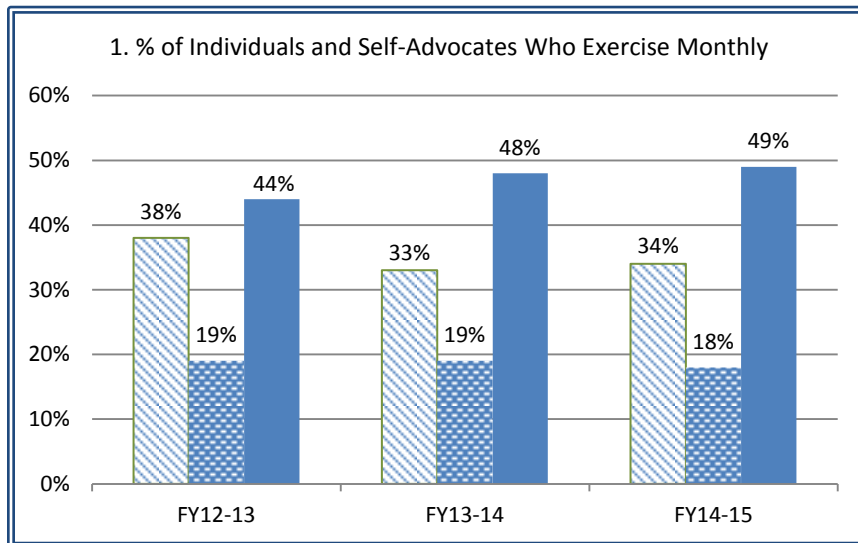
Overarching plan to meet above recommendation: Develop and implement a comprehensive program of wellness opportunities for people with IDD and autism. Areas including: diet/nutrition; physical activities; emotional wellness; sexuality and healthy relationships; wellness as related to aging; safety and drugs and alcohol.

1. Direct people to existing resources with information on healthy living.
2. Increase the use of Mental Health First Aid (MHFA) among stakeholders.
3. Update, disseminate, and provide training on sexuality guidelines.
4. Incorporate a focus on health and wellness into the individual planning process.
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.




Performance Measures:

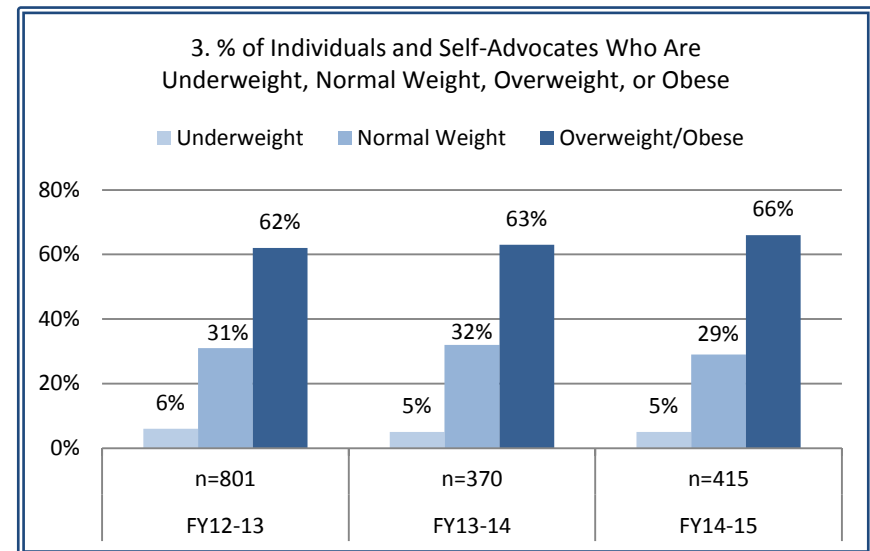
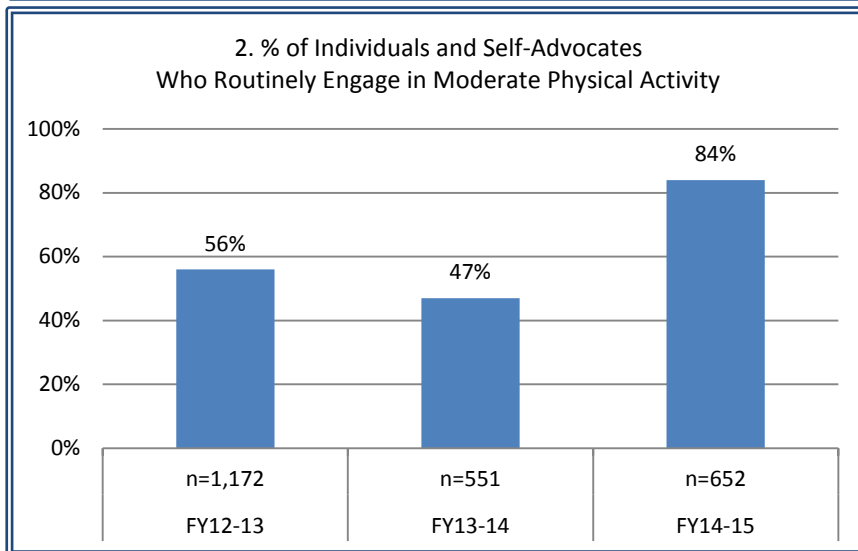
1. Regarding monthly exercise, percent of individuals who report they:
 - Never go out for exercise.
 - Exercise less than weekly.
 - Exercise once a week.
 - Exercise more than once a week (Source: Annual IM4Q Survey).
2. Percent of individuals who are underweight, normal weight, overweight, and obese (Source: Annual NCI Survey).
3. Percent of individuals with medical, dental, and eye exams in the past year (Source – NCI Adult Consumer Survey Data).
4. Number of persons receiving MHFA trainings and number of participants. Track role of participants. (Source: MHFA Enrollment Form Data).
5. Updated sexuality guidelines distributed.

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES



Source: IM4Q Data

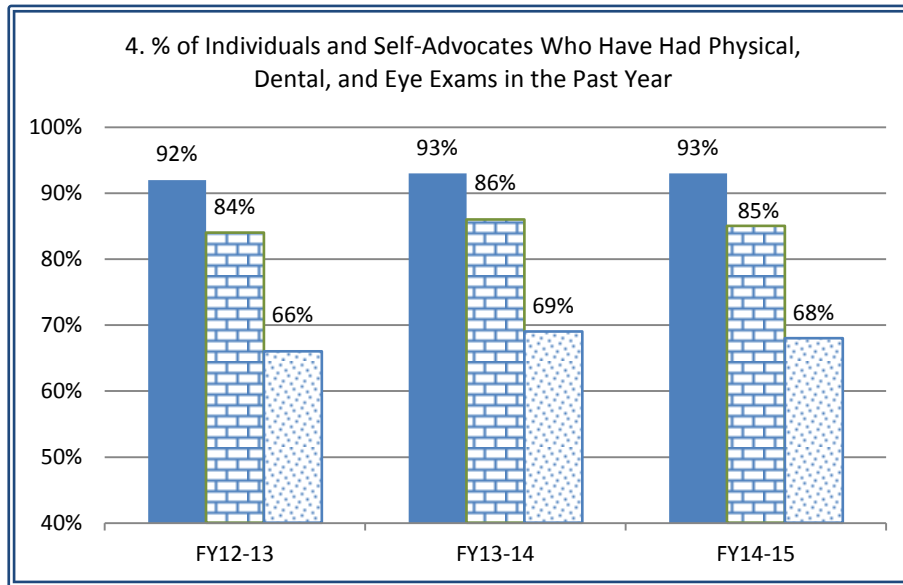
-  % who never go out for exercise
FY12-13 (n= 5,506) FY13-14 (n=4,735) FY14-15 (n=4,865)
-  % who exercise once/week or less
FY12-13 (n=5,506) FY13-14 (n=4,735) FY14-15 (n=4,865)
-  % who exercise more than once/week
FY12-13 (n=5,506) FY13-14 (n=4,735) FY14-15 (n=4,865)



Source: NCI PA Adult Consumer Survey Data

Notes – Moderate physical activity is an activity that causes some increase in breathing or heart rate. Examples include: brisk walking, swimming, bicycling, cleaning, and gardening.

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES



- % who had a physical exam in the past year
FY12-13 (n=1,295) FY13-14 (n=603) FY14-15 (n=644)
- ⊕ % who had a dental exam in the past year
FY12-13 (n= 1,127) FY13-14 (n=527) FY14-15 (n=573)
- ⊙ % who had an eye exam or vision screening in the past year
FY12-13 (n=1,021) FY13-14 (n =483) FY14-15 (n=540)

Source: NCI PA Adult Consumer Survey Data



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 lifespans. 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.

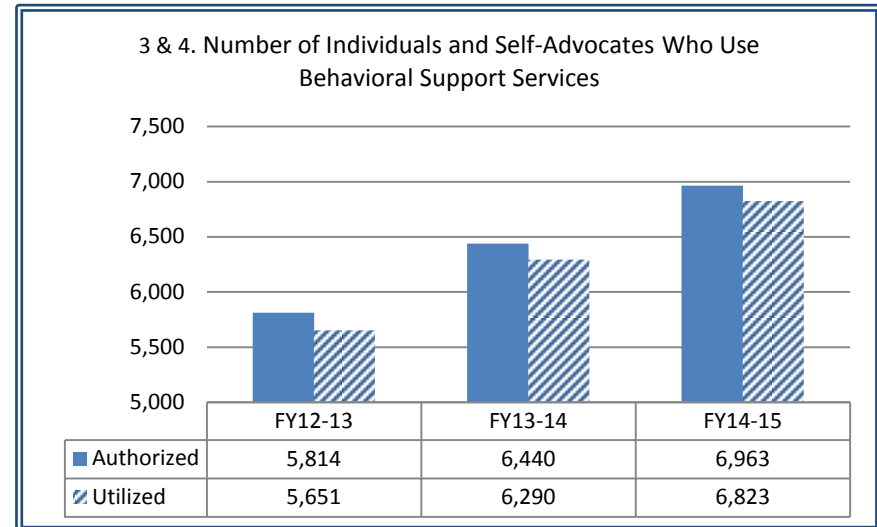
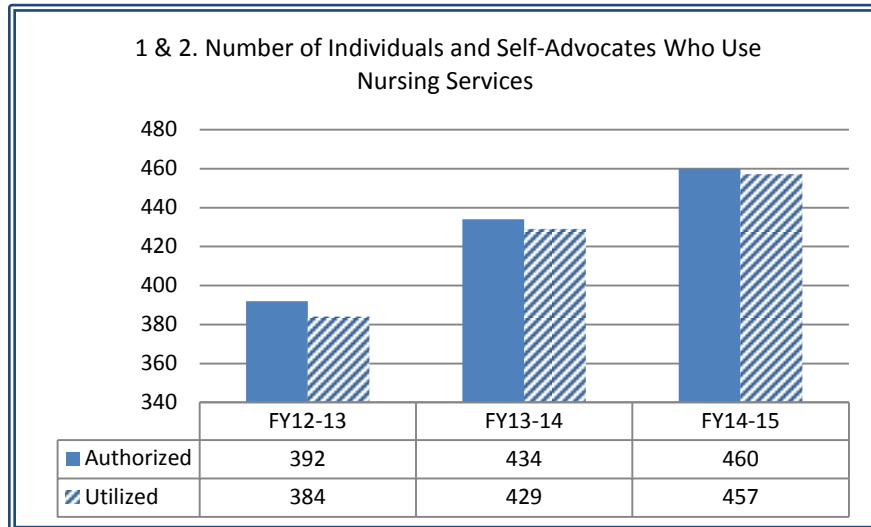
Strategies:

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. A dual diagnosis training curriculum will be made available online. Currently the Health Care Quality Units and ODP provide training in established dual diagnosis curriculum. An online format will provide greater access for users and will be more convenient in time and pace of the information.

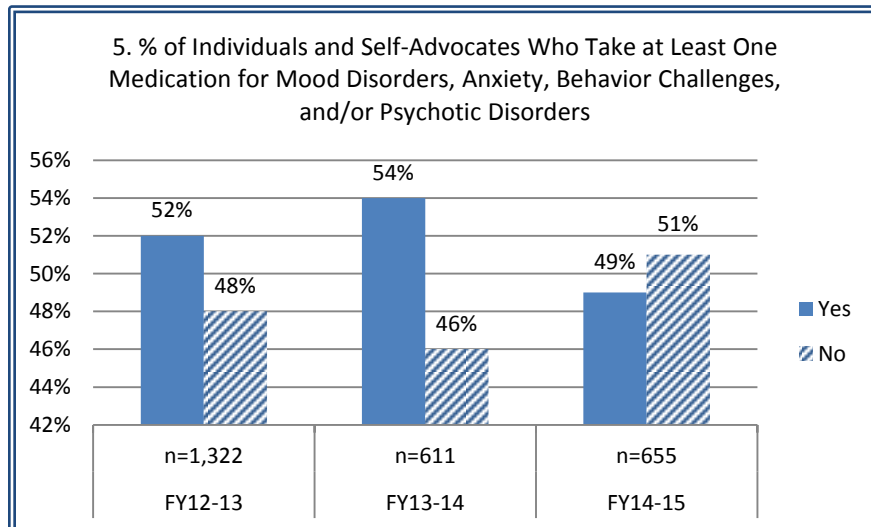
Performance Measures:

1. Number of people with authorized nursing services (Source: HCSIS).
2. Number of people who use nursing services (Source: PROMISe™).
3. Number of people with authorized behavioral support services (Source: HCSIS).
4. Number of people who use behavioral support services (Source: PROMISe™).
5. Number and percent of people who take at least one medication for mood disorders, anxiety, behavior challenges, and/or psychotic disorders (Source: NCI PA Adult Consumer Survey).
6. Number of people by role and county trained through the Capacity Building Institute (Source: MYODP.org).
7. Assessment of knowledge/skills of CBI attendees (Source: MYODP.org).
8. Number of people trained in Mental Health First Aid as part of the Capacity Building Institute.
9. Number of people trained and number of sessions completed (total, per county, per provider, family supports) in the dual diagnosis curriculum (Source: MYODP.org).

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES



Sources: Authorized Nursing Services and Behavioral Support Services: People enrolled in ID Waivers and Base; **9/30/16 HCSIS Data**. Utilization data: **PROMISE™ paid claims as of 10/10/2016** and may not be complete.



Source: NCI PA Adult Consumer Survey Data

Notes - In 2012-2013 and 2013-2014 NCI Surveys, % of people who take at least one medication for mood disorders, anxiety, behavior challenges, and/or psychotic disorders was measured. In 2015, the measurement did not include medications for behavior challenges.



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 will improve the quality of support.

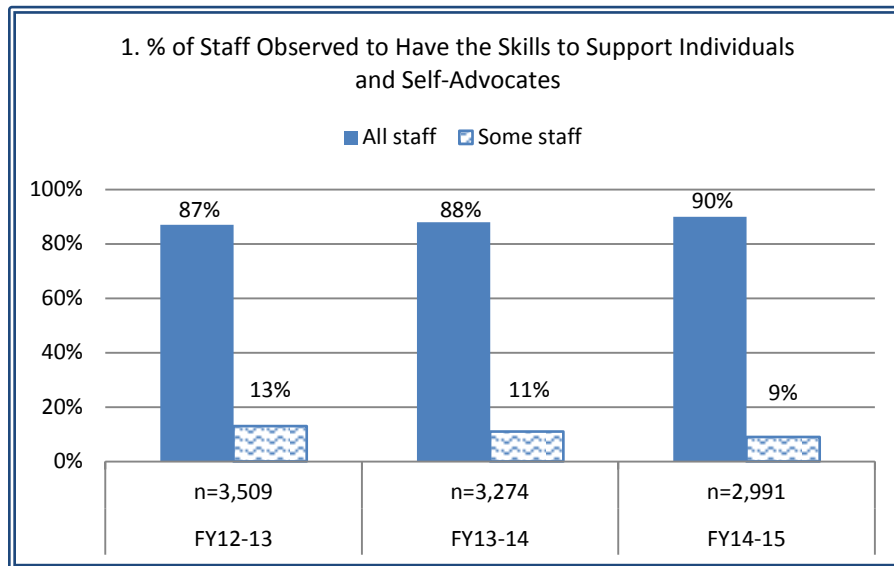
Strategies:

1. Adopt and promote through policy bulletins and training, the Direct Work Force core competencies developed by the Center for Medicare and Medicaid Services (CMS). Competencies areas are:
 - Communication
 - Person-Centered Practices
 - Evaluation and Observation
 - Crisis Prevention and Intervention
 - Safety
 - Professionalism and Ethics
 - Empowerment and Advocacy
 - Health and Wellness
 - Community Living Skills and Supports
 - Community Inclusion and Networking
 - Cultural Competency
 - Education, Training and Self-Determination
2. Engage families regarding the application of core competencies by staff who support their family member.
3. ODP will establish and implement credentialed training programs based on standard curriculum and testing.
4. Build incentives into the reimbursement system to promote staff credentials, encourage professional growth and development, and adopt incentive-based training and credentialing.
5. Promote the use of the College of Direct Support and MYODP.org.

Performance Measures:

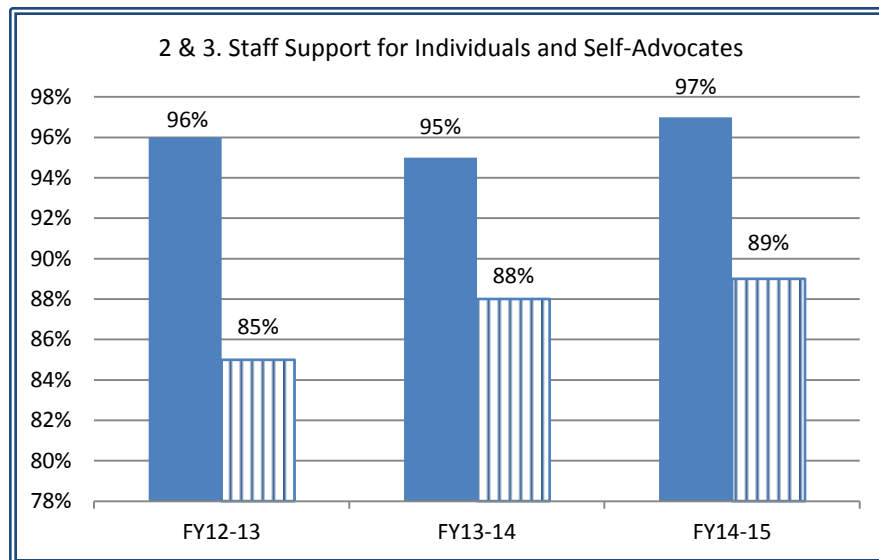
1. Percent of staff observed to have the skills needed to support the individuals (Source: Annual IM4Q Survey).
2. Percent of staff observed who treat individuals with dignity and respect (Source: Annual IM4Q Survey).
3. Percent of staff observed who recognize individuals in ways that promote independence (Source: Annual IM4Q Survey).
4. Number of people (statewide) who meet credentialing requirements by program (Source: MYODP.org).
5. Total # of enrolled agencies who utilize College of Direct Support and MYODP websites.
6. Total # of people who have completed courses through the CDS and MYODP (combined) websites.
7. Total # of people trained by the Health Care Quality Units.
8. Total # of people trained by the ASERTs.

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES



Source: IM4Q Data

Note: Independent Monitoring Teams answered questions on staff support for individuals and self-advocates after having spent time with the person and the staff who support them.



Source: IM4Q Data

- % of staff observed who treat individuals and self-advocates with dignity and respect
FY12-13 (n=3,434) FY13-14 (n=3,331) FY14-15 (n=3,137)
- ▨ % of staff observed who recognize individuals and self-advocates in ways that promote independence
FY12-13 (n=3,518) FY13-14 (n=3,166) FY14-15 (n=2,860)



Recommendation 8: Simplify the System

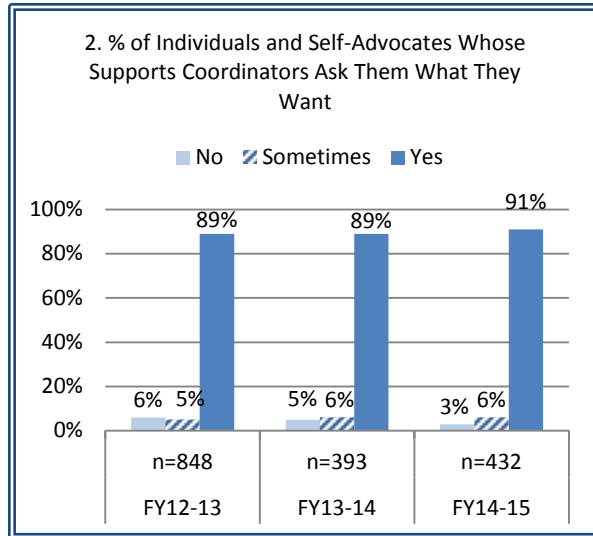
The system of supports and funding of those supports must be as straightforward and uncomplicated as possible. This will allow for greater understanding and use of the system by everyone — most importantly the individual needing and receiving supports.

Strategies:

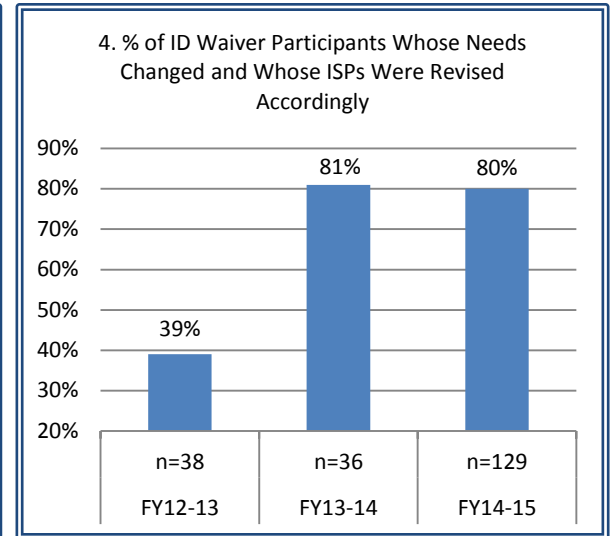
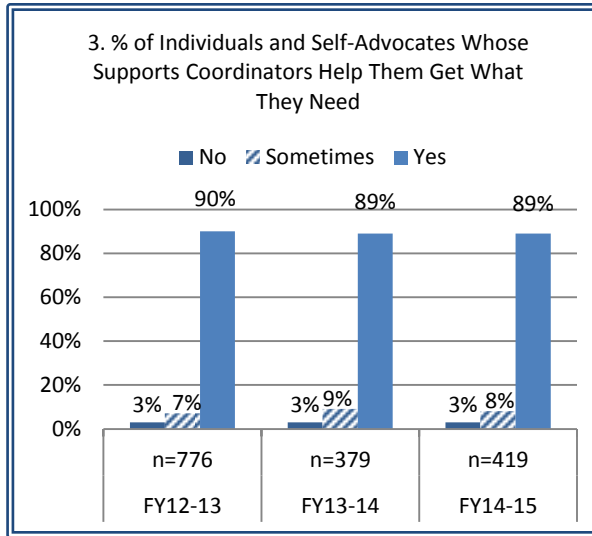
1. Redesign the ISP process and format to reduce the time, simplify the document and increase the positive experience of individuals, self-advocates and families, and all stakeholders.
2. Provide a user-friendly useful planning tool and document that increases flexibility and ease of access for the individual,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

Performance Measures:

1. Evaluate the redesign of the ISP process and format for: reduction in time that SC spends on administrative tasks, reduction in the number of pages in the ISP, and increase time spent with individuals, self-advocates, and families in person centered planning.
2. Percent of respondents who report their supports coordinator asks them what they want (Source: Annual Adult Consumer NCI Survey).
3. Percent of respondents who report their supports coordinator helps them get what they need (Source: Annual Adult Consumer NCI Survey).
4. Percent of people in the Consolidated and P/FDS waivers who had a change in need and had the plan updated (ODP monitoring of ID waivers).



Source: NCI PA Adult Consumer Survey Data



Source: Annual ODP Monitoring of ID Waivers



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:

1. Finalize and disseminate ODP's updated Quality Management (QM) Strategy Bulletin.
 - Communicates ODP's mission, vision, and values.
 - Establishes the purpose of Quality Management in ODP.
 - Describes ODP's QM structure, processes, and tools.
 - Defines expected quality outcomes based on ODP's *Everyday Lives* and the Home and Community Based Services (HCBS) Quality Framework.
 - Outlines roles and responsibilities for ODP and stakeholders to maintain and improve quality.
 - Establishes the ISAC as ODP's stakeholder Quality Council.
 - Establishes *ODP's QM Certification Curriculum* as part of building system capacity in applying quality management principles and practices across the systems.
2. Develop and disseminate an ODP annual report to show the implementation of approved recommendations and strategies across the system.
3. Create a provider profile to assist individuals, self-advocates, and families to make informed choices about providers and services.

Performance Measures:

1. ODP's QM Strategy Bulletin is updated and disseminated.
2. Number of ODP and stakeholder staff who achieve ODP QM Certified status (Source: MYODP.org).
3. ODP develops and distributes an annual report.
4. ODP develops and maintains an online provider profile.
5. ODP, in collaboration with the ISAC, uses all available data and identifies the need for new data collection to measure and improve performance.



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:

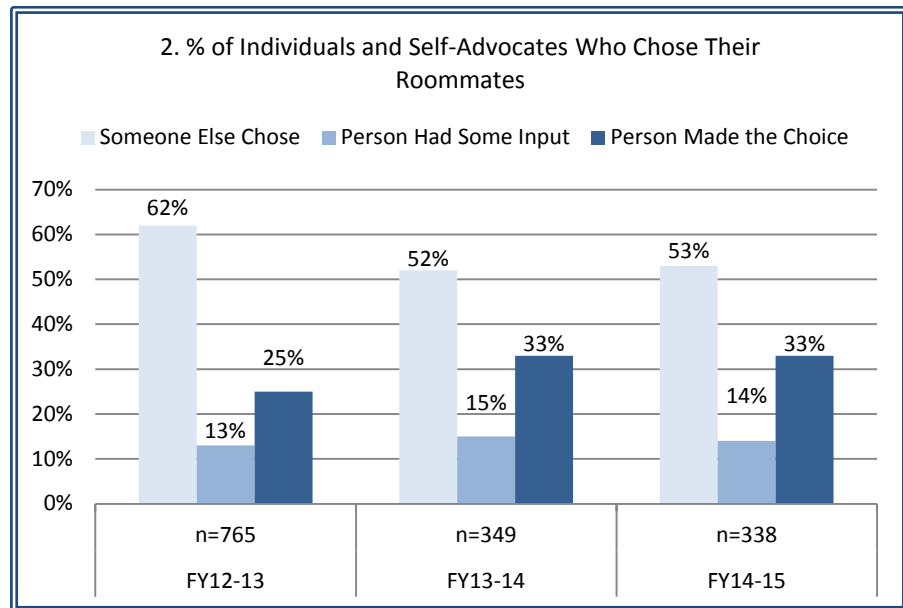
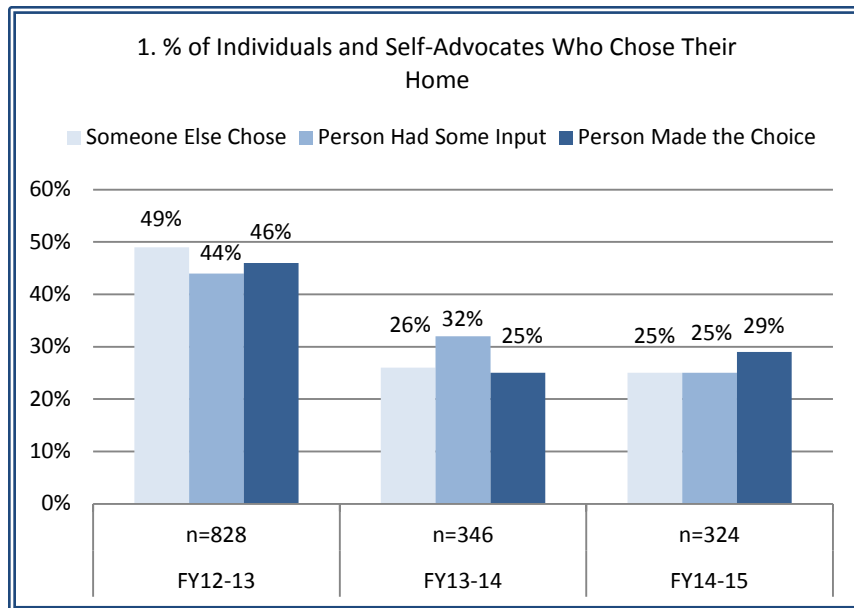
- Establish a housing transition and tenancy sustaining service definition: Direct services provided to assist individuals and self-advocates with planning, locating, and maintaining a home of their own. Services include:
 - assessing the individual's community living skills and housing needs;
 - assistance with:
 - locating housing;
 - applying for housing vouchers/applications;
 - finding and establishing a relationship with a housemate;
 - financial planning and education family including special needs trusts and ABLE accounts;
 - communicating with landlords;
 - arranging for home modifications and repairs; consider warranty periods;
 - making security payments and monthly payments;
 - purchasing necessary home security devices;
 - obtaining and using assistive technology;
 - coordinating the move;
 - arranging support services;
 - securing government benefits, household furnishings, and utility assistance; and
 - providing training on tenant rights, empowerment, advocacy, and how to be a good tenant.
- 2. 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.
- 3. Expand Lifesharing to allow for the enrollment of birth families as life sharing providers.
- 4. Develop a supported living option that enables individuals and self-advocates to live in their own homes with the support of an agency available to provide guidance and assistance as needed.
- 5. Provide training to Supports Coordinators on the varied options for community living.
- 6. Expand choice of options to include creative housing alternatives.

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES

7. Support the development of safe and affordable housing options that meet the individual’s and self-advocates personal preferences.
8. Provide access to home modifications, transportation, and assistive technology to support people to live in their homes.

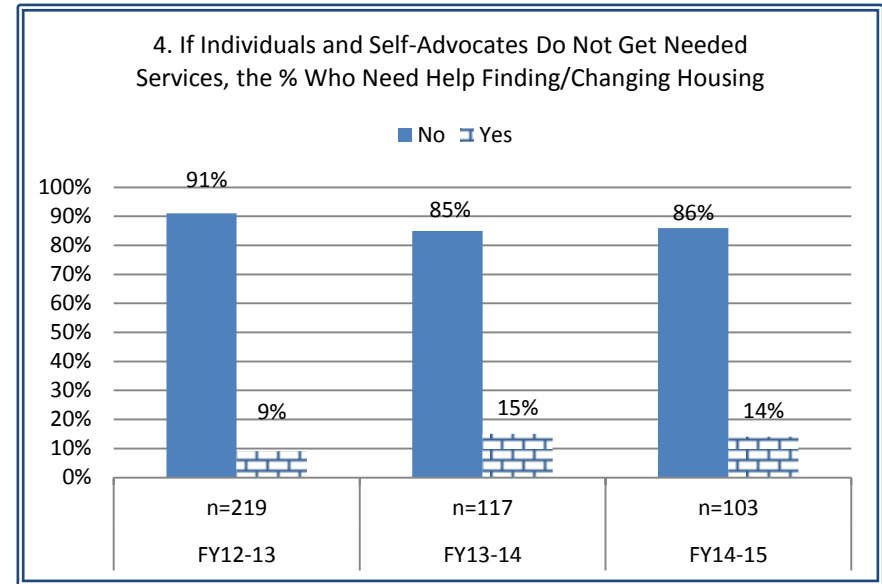
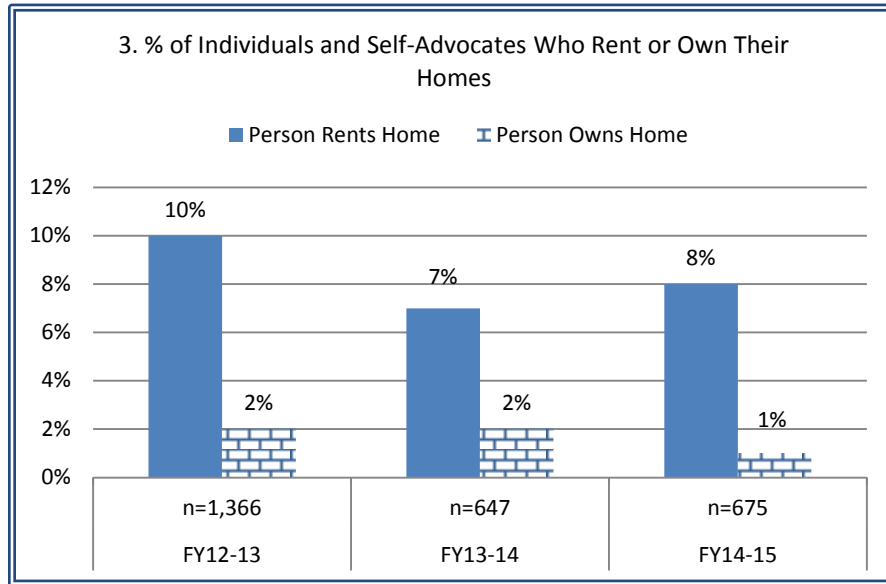
Performance Measures:

1. Percent of people who choose their home (Source: Annual NCI Adult Consumer Survey).
2. Percent of people who choose their roommate (Source: Annual NCI Adult Consumer Survey).
3. Percent of people who rent or own their homes (Source: Annual NCI Adult Consumer Survey).
4. If people don’t get needed services, the percent whose unmet need is in the area of finding/changing housing (Source: Annual NCI Survey).
5. Number of people with authorized housing transition and tenancy sustaining services (Source: HCSIS).
6. Number of people receiving housing transition and tenancy sustaining services (Source: PROMISE).



Source: NCI PA Adult Consumer Survey Data Individuals and self-advocates and/or their families or supporters reported they chose or had some input in choosing where they live and their roommates, or that they chose to live alone.

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES



Source: NCI PA Adult Consumer Survey Data



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:

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. Establish 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. Redesign day programs (adult day habilitation and prevocational services) to limit separation from the community, encourage employment and community participation, and to provide the support people need to be in their communities, from transportation to skill building.
4. Provide training to SCs and all stakeholders on facilitating and supporting individuals to become more involved in community life.
5. Develop and disseminate new ideas and approaches on how to provide creative solutions to transportation barriers.

Performance Measures:

1. Use claims and encounters data for pre-vocational, day habilitation, and community participation support to track whether community-based services are increasing and facility-based services are decreasing over time (Source: PROMISE™).
2. Number and percent of people with weekly participation (Source: Annual IM4Q Survey).
 - a. Visit friends, relatives and neighbors
 - b. Go to restaurant
 - c. Go to worship
3. Percent of people who have friends (Source: Annual NCI Adult Consumer Survey).
4. Percent of respondents who said their relative had enough opportunities to participate in activities in the community (Source: Annual Family/Friend/Guardian IM4Q Survey).
5. Percent of respondents who said their relative seemed to have the opportunity to learn new things (Source: Annual Family/Friend/Guardian IM4Q Survey).
6. Use data from ODP monitoring of providers to evaluate community participation and inclusion in physical locations including work and home.

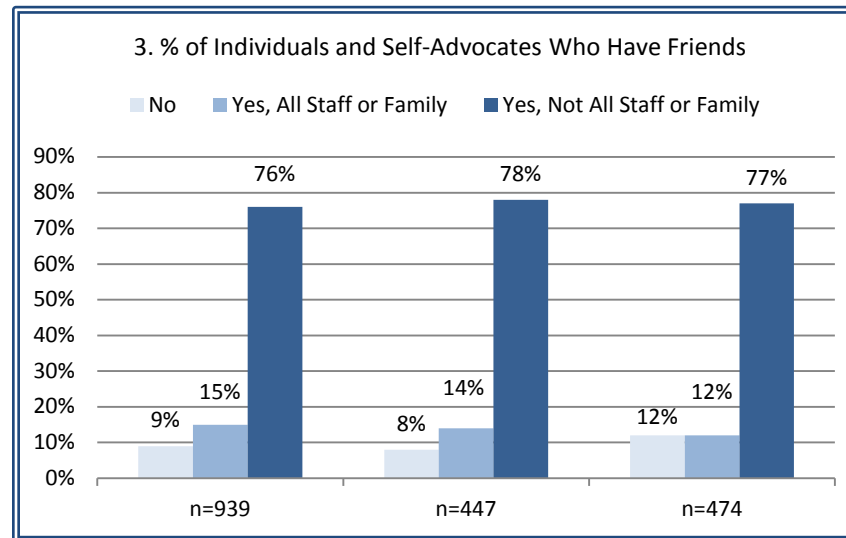
EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES

2. Weekly Participation in Community Activities Harris Poll Comparisons					
	Harris 2010: People Without Disabilities	Harris 2010: People With Disabilities	Independent Monitoring 2013	Independent Monitoring 2014	Independent Monitoring 2015
Visit with friends, relatives, and neighbors	65%	54%	54% (n=5,485)	51% (n=4,938)	50% (n=4,949)
Go to restaurant	41%	20%	43% (n=5,456)	44% (n=4,960)	43% (n=4,956)
Go to worship	28%	24%	27% (n=5,318)	27% (n=4,661)	28% (n=4,765)

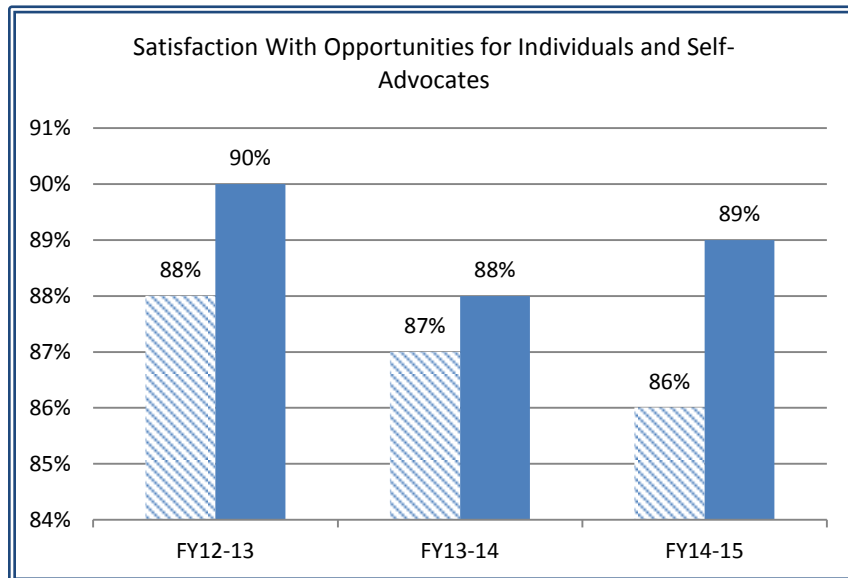
Source: IM4Q Data

Notes: In May and June 2010, the National Organization on Disability commissioned Harris Interactive, Inc. to conduct a national phone survey to examine and compare the quality of life and standard of living for people with and people without disabilities. In the table above, the frequency of weekly community participation reported by individuals in the IM4Q sample is compared to the frequency reported by those in this national sample. Pennsylvanians with disabilities in IM4Q and individuals with disabilities are nearly equally likely to visit with friends, relatives and neighbors, while people without disabilities are about 10% more likely to visit with friends, relatives and neighbors. Pennsylvanians with disabilities in IM4Q were slightly more than twice as likely to go to a restaurant weekly as people with disabilities in the Harris Poll, and also slightly more likely than people without disabilities in the Harris Poll. Pennsylvanians with disabilities in IM4Q are more likely to go to places of worship weekly than people with disabilities in the Harris Poll.



EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES



Source: NCI Adult Consumer Survey Data



Source: Family/Friend/GuardianIM4Q Survey

- 
 4. % of respondents who said individuals and self-advocates have enough opportunities to participate in activities in the community
 FY12-13 (n=1,992) FY13-14 (n=1,671) FY14-15 (n=1,834)
- 
 5. % of respondents who said individuals and self-advocates have the opportunity to learn new things
 FY12-13 (n=1,939) FY13-14 (n=1,628) FY14-15 (n=1,802)



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:

1. Individuals, self-advocates, and families with intellectual disability or autism should receive: supports coordination service; information about local resources and services (e.g. OVR, Medicaid, aging, housing supports, income supports); 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 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 for incorporating publically funded services to support an 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:

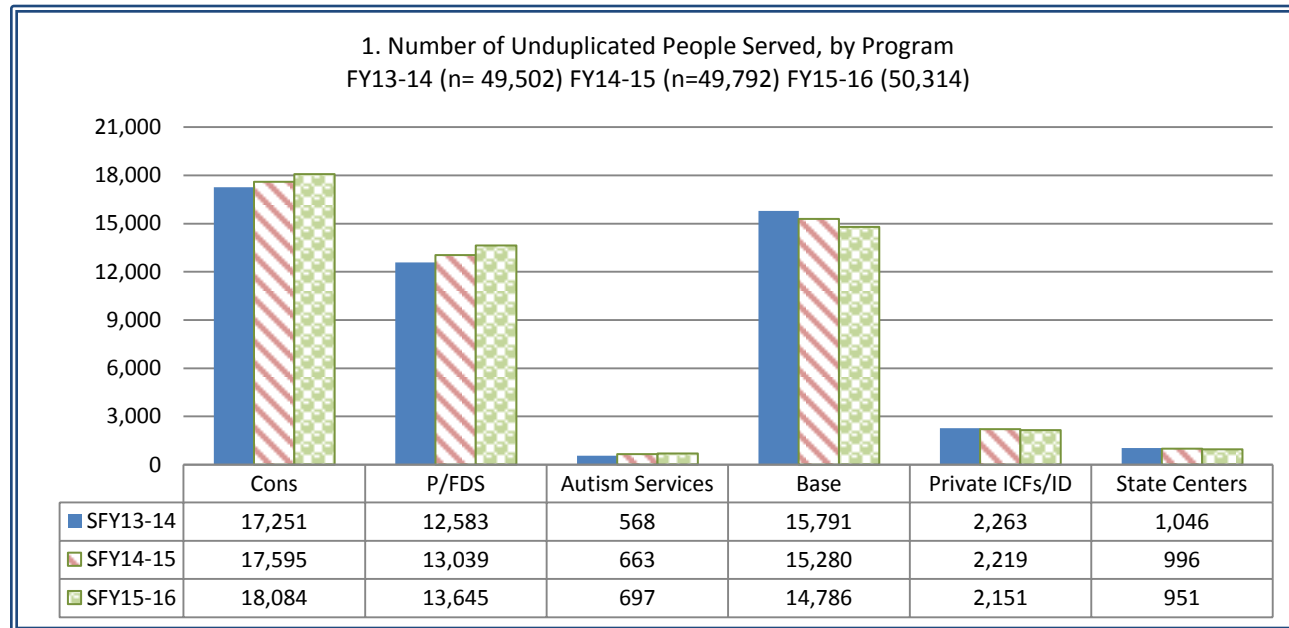
- a. High school graduates to begin services 30 days prior to graduation.
 - b. People on the emergency list who have a caregiver over the age of 60.
 - c. People who have caregivers who are unable to take care of their family member due to illness or an unanticipated life situation.
3. Improve the Prioritization of Urgency of Need for Services (PUNS) instrument and process to more accurately identify individuals with ID or autism in need of supports and services and the types of services needed. The work should be done with the advice of a stakeholder work group.
 4. All individuals waiting for services will have their eligibility for ODP Medicaid waivers determined.
 5. ODP will provide instruction to professionals in the criminal justice system to minimize arrest.
 6. ODP will issue an annual report on progress in addressing the waiting list.

Performance Measures:

1. Number of unduplicated people served, by program, by fiscal year, during the course of the year (Sources: HCSIS, PROMISE™).
2. Number of people newly enrolled (Source: Enterprise Data Warehouse (EDW), HCSIS):
 - a. From the ID waiting list, by category, (Emergency, Critical, Planning), by age.
 - b. From the interest list, by category, (Priority 1, Priority 2), by age.
 - c. From the ID waiting list, by category, by some ODP-funded services and no ODP-funded services.
 - d. From the ID waiting list, with caregivers over the age of 60.

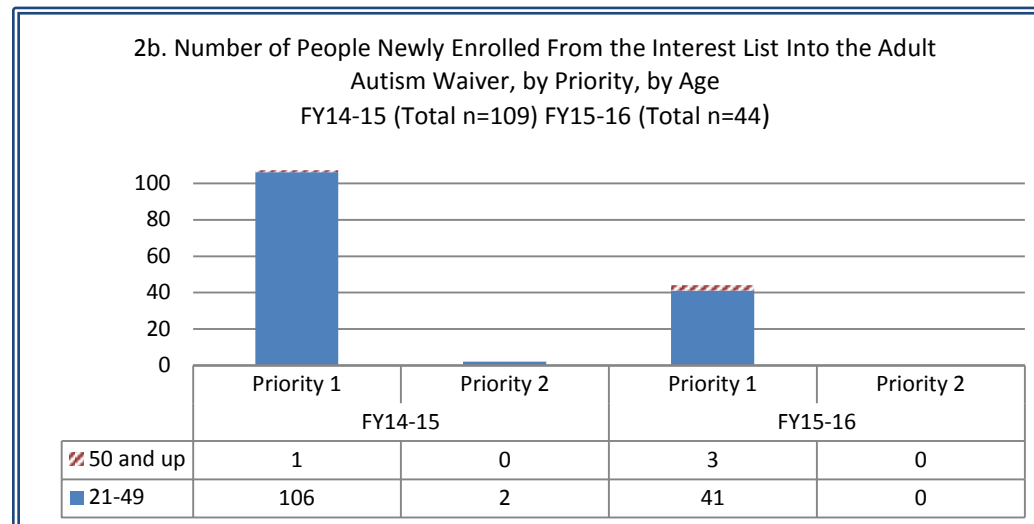
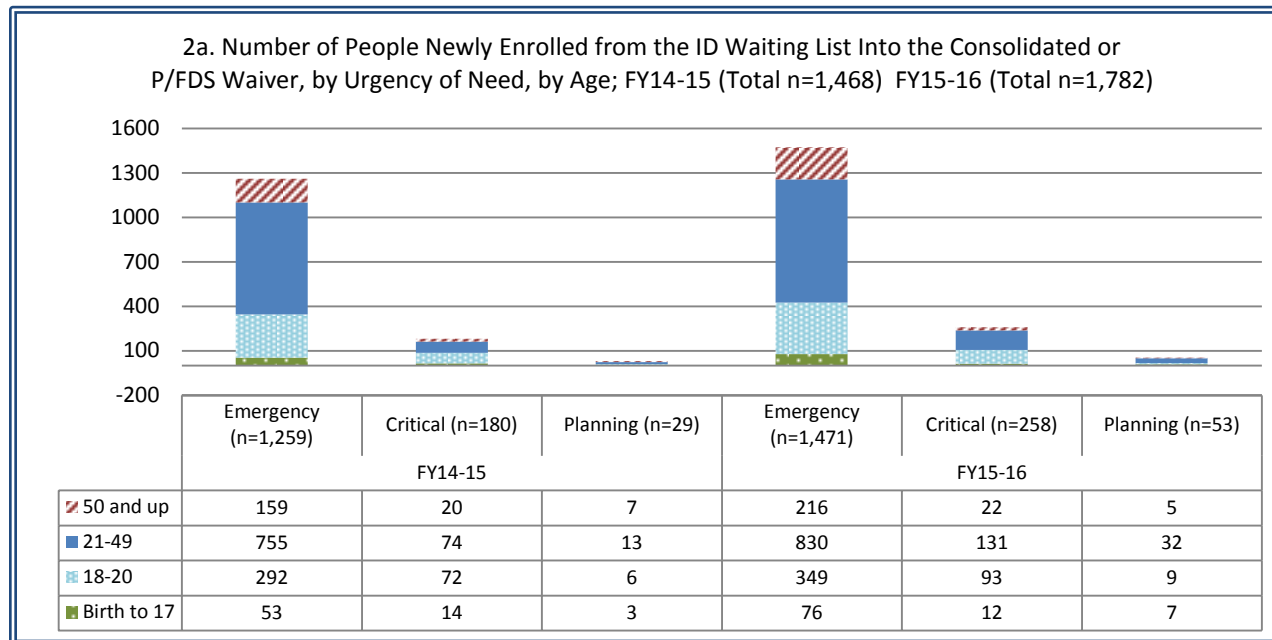
EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES

- e. From the ID waiting list, by program enrolled in – Cons, P/FDS, Autism Programs, Private ICF/ID, Base.
 - f. From the interest list, by program enrolled in – Cons, P/FDS, Autism Programs, Private ICF/ID, Base.
 - g. The amount of time each person waited for services prior to enrollment (by categories, 1 yr., 3 yrs., 5 yrs. or more; by people with services and people without services).
3. The number of people waiting for services:
- a. On the ID waiting list, by category, by some ODP-funded services and no ODP-funded services (Source: PUNS Reports).
 - b. On the ID waiting list, by category, by age (Source: PUNS Reports):
 - Birth – day before the 18th birthday
 - 18 – the day before the 21st birthday
 - 21- the day before the 50th birthday
 - 50 and above
 - c. On the Autism Services interest list, with no services and with services (Source: Adult Autism Waiver Interest List).
4. Number of people moving from state-operated facilities, Private ICFs/ID, state hospitals, and nursing homes (Sources: HCSIS, PROMISE™).

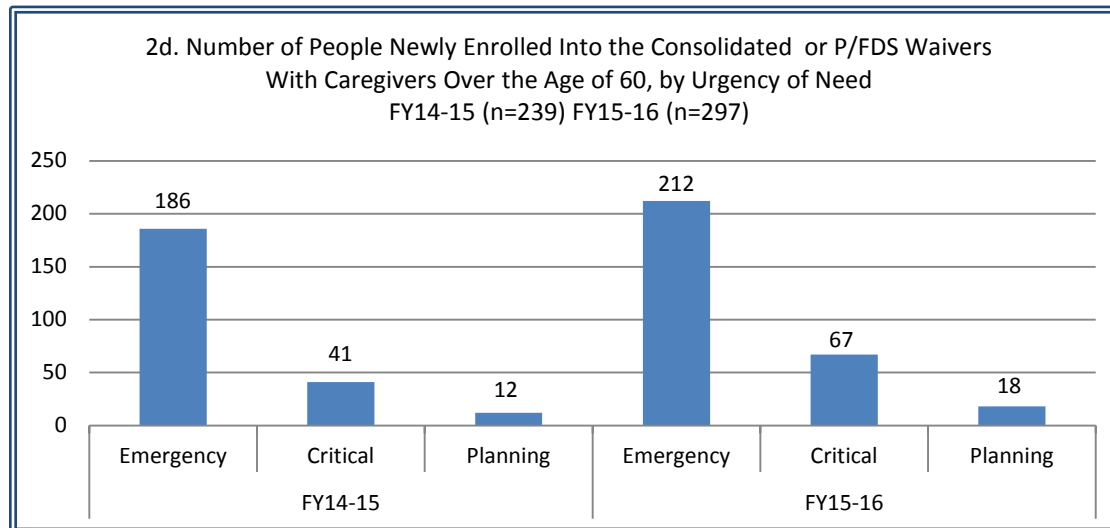
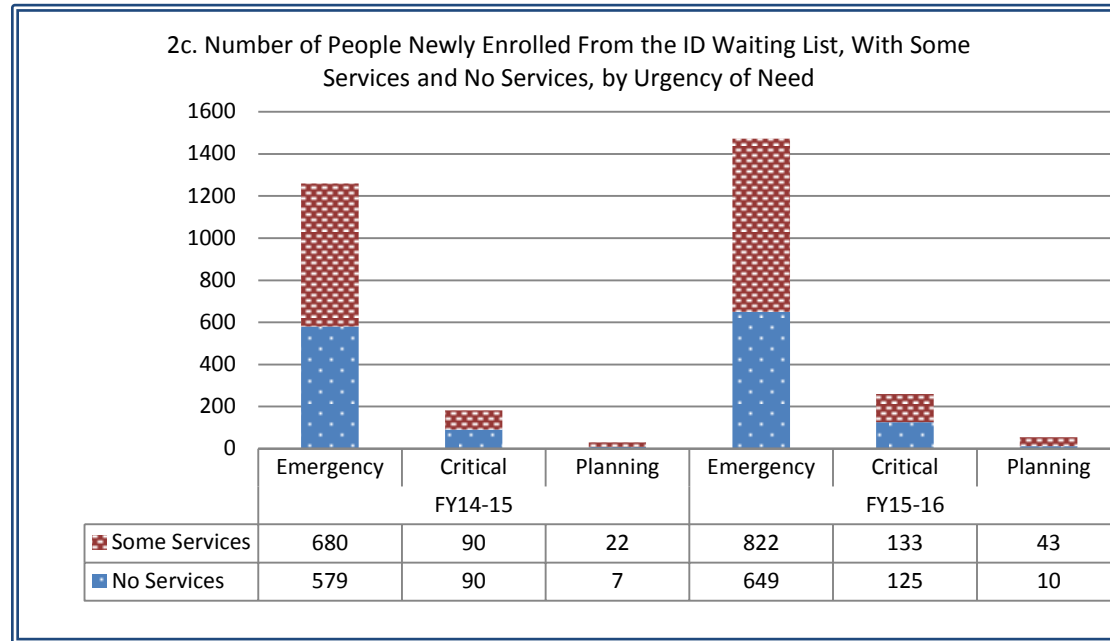


Sources: Consolidated, P/FDS, Base, and Autism Services (AAW and ACAP): Data in **HCSIS** as of 08/31/16, data extracted 09/21/16; Private ICFs/ID and State Centers: Data in **PROMISE™** as of 10/03/16, data extracted 10/12/16

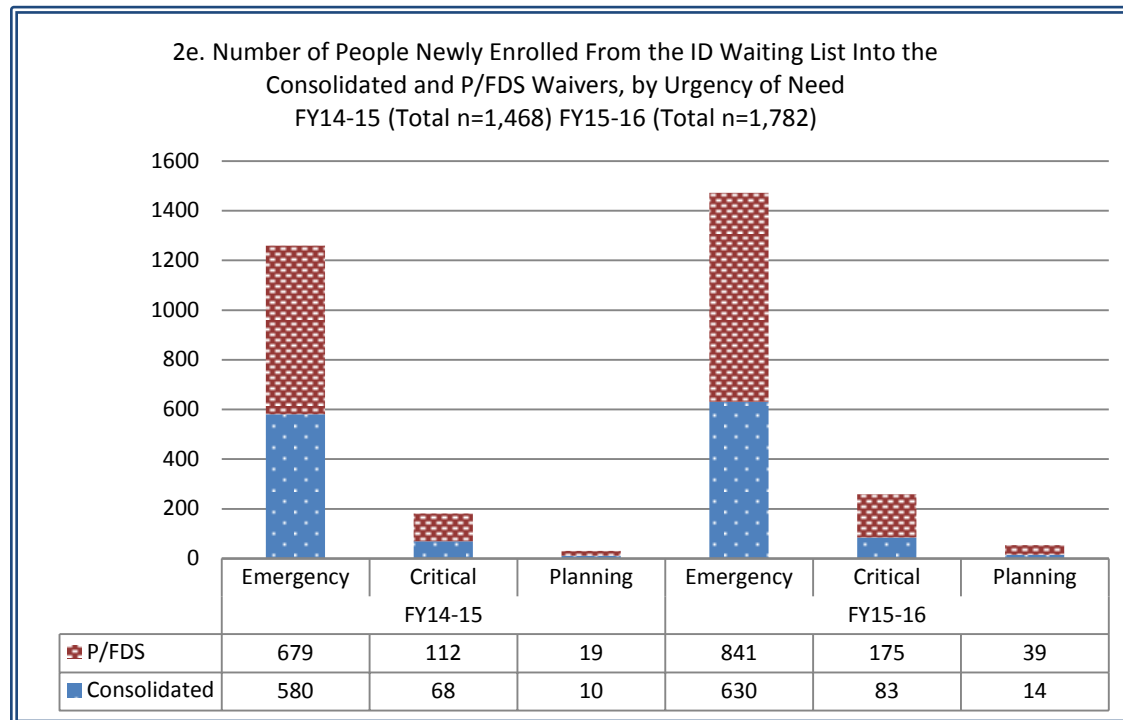
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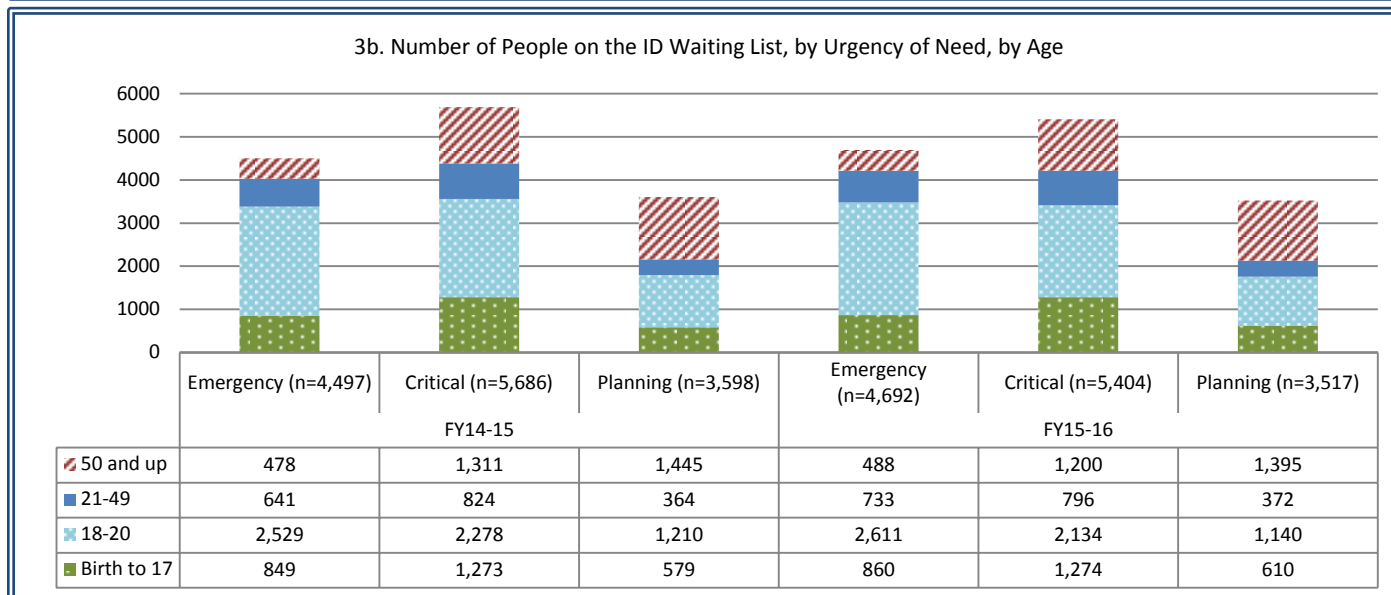
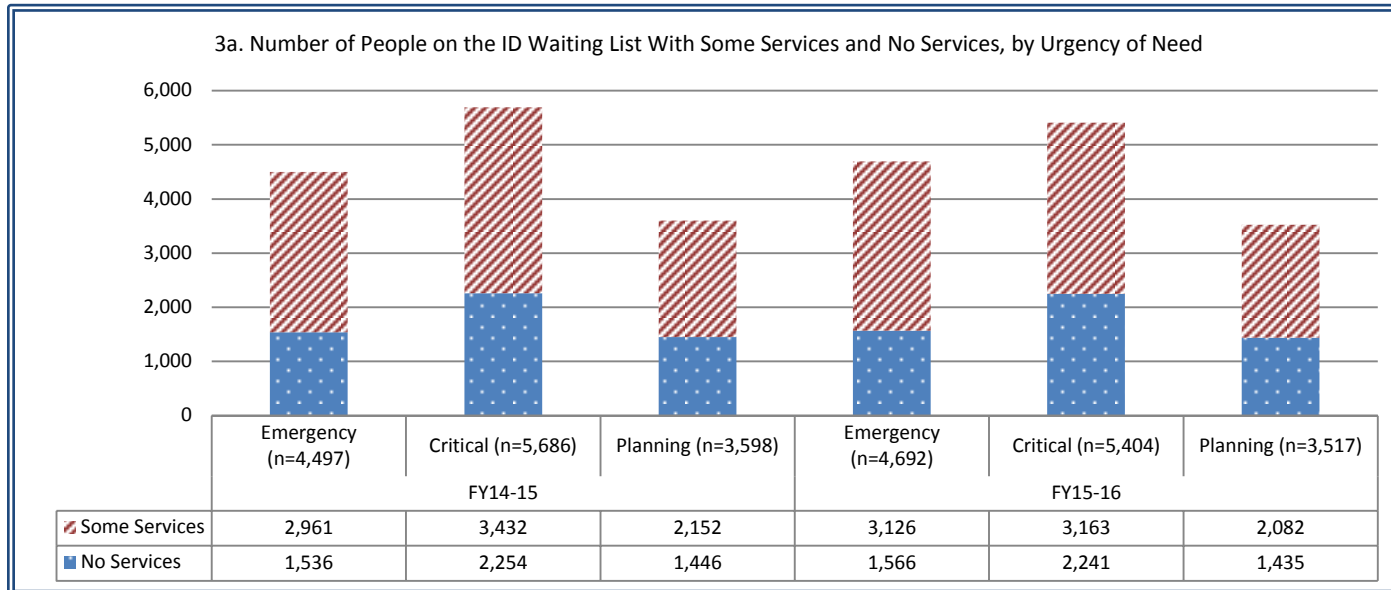


EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES



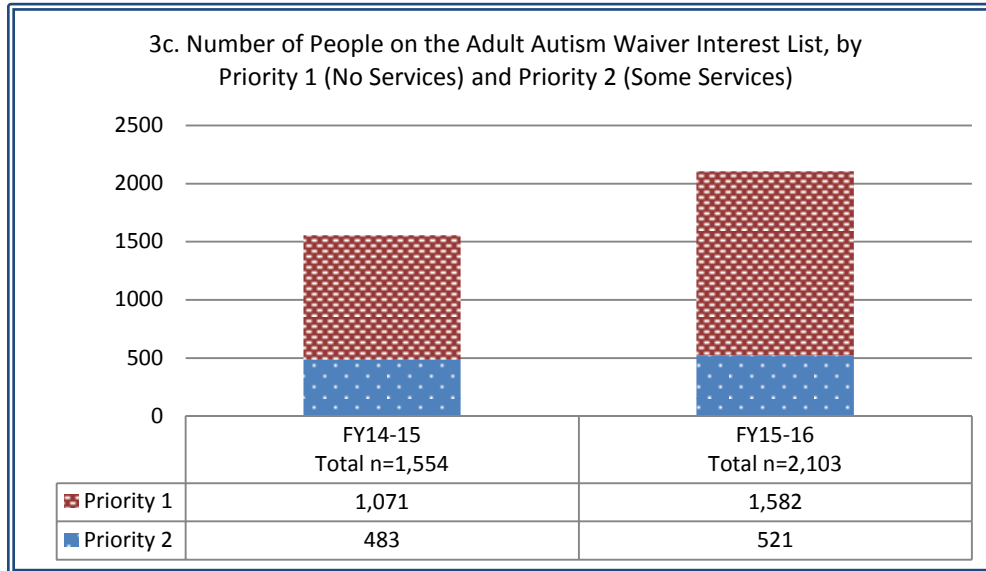
Sources: 2a, 2c, 2d, 2e: **Enterprise Data Warehouse (EDW), HCSIS**, as of 9/30/16. 2b: **HCSIS System Report**, for FY14-15, as of 7/12/15; for FY15-16, as of 8/21/16. 2e: Waiver/Program is as of the last day of the month of the person's last PUNS.

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES

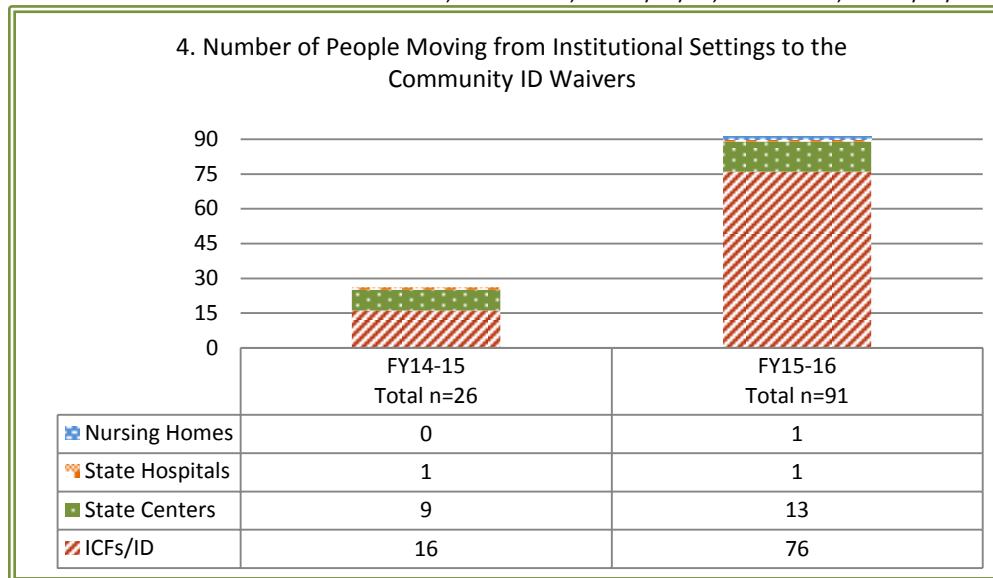


Source: PUNS Reports, for FY14-15, as of 6/30/15; for FY15-16, as of 6/30/16.

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES



Source: *Adult Autism Waiver Interest List*, for FY14-15, as of 7/12/15; for FY15-16, as of 8/21/16.



Sources: *EDW, HCSIS* as of 9/30/16; *PROMISE™* as of 10/3/16



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.

Principles:

Consideration of new service delivery systems or payment models such as managed care, accountable care organizations, medical homes** or pay for performance must include the following:

1. Adherence to the values and principles of *Everyday Lives*.
2. Engagement of stakeholders, including individuals and self-advocates with disabilities, family members, county governments, providers, and advocates in designing, implementing and monitoring the outcomes.
3. Recognition that payment models assume that individuals and self-advocates with intellectual disability and autism require supports across the lifespan, that their needs are not episodic or time-limited, but are on-going and ever changing throughout life. Investment in skill development and job placement and training may not realize savings for a number of years into the future.
4. Recognition that while individuals and self-advocates with intellectual disability or autism have medical, mental health, and dental needs that require medical services, the goal of home and community based services is to enable people to live and engage in community life.
5. Incorporation of the Federal Home and Community Based Services rule, which requires person-centered planning, individual choice and control over who provides services and where, and supports access to the greater community and full engagement in community life.
6. Adoption of a performance evaluation system founded in the principles of *Everyday Lives* and the Home and Community Based Services Rule.
7. Recognition that most individuals and self-advocates with intellectual disability or autism are supported by their families throughout life. An effective service system respects the valued role of families and understands that supporting families is critical to achieving good outcomes for individuals and self-advocates with disabilities.

*** Note: A typical description of a medical home is: a model or philosophy of primary care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety.*

EVERYDAY LIVES 2016 – RECOMMENDATIONS, STRATEGIES AND PERFORMANCE MEASURES

Data Sources

[College of Direct Support](#) - national, web-based learning system designed for people who support individuals with intellectual/developmental disabilities that the commonwealth has used since 2003.

[Home and Community Services Information System \(HCSIS\)](#) - web-based application that supports the Department of Human Services, including ODP, AEs, Supports Coordinators (SCs) and providers in the administration of federal and state-funded home and community-based programs.

[Independent Monitoring for Quality \(IM4Q\)](#) - people with disabilities, family members, and support professionals in Pennsylvania are interviewed by the IM4Q project to learn about the overall quality of life for people who receive support through ODP.

[MYODP.org](#) - the Office of Developmental Programs' online Training and Resource Center.

[National Core Indicators \(NCI\)](#) - supports member agencies to gather a standard set of performance and outcome measures used to track their own performance over time, to compare results across states, and to establish national benchmarks. NCI includes an Adult Consumer Survey and Adult Family Survey.

ODP Monitoring of Waivers: Participant Record Review - ODP evaluates the experience of waiver participants annually to document system performance, remediate any individual problems found, identify opportunities for systemic improvement, and develop and implement quality improvement plans. Performance data and follow-up are submitted to CMS as evidence of the state's quality oversight of its waiver programs.

[Provider Reimbursement and Operations Management Information System \(PROMISe™\)](#) - Pennsylvania's CMS-certified Medicaid Management Information System (MMIS) and HIPAA-compliant claims processing and financial management information system.

Vendor Fiscal/Employer Agent (VF/EA) and Agency with Choice (AWC) Participant Satisfaction Surveys – VF/EA vendor and AWCs are required to complete an annual satisfaction survey to measure the quality of services rendered to participants in each of these programs.