

Florida Statewide Quality Assurance Program
Delmarva Foundation

Quality Improvement Study
Personal Outcome Measures
Reasons Supports are Not Present

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Agency for Health Care Administration and the
Agency for Persons with Disabilities

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Developmental disabilities may be cognitive, physical, or a combination of both and can result in serious limitations in every day activities of life, including self-care, communication, learning, mobility, or being able to work or live independently. The state of Florida is committed to an aggressive person-centered system of supports and services to help ensure that people living with developmental disabilities are guaranteed the best possible life that is integrated into their respective communities and affords them the opportunities to live and work where they choose. The current state budget recommendations for the Agency for Persons with Disabilities (APD) for fiscal year 2005-2006 would increase funding to \$1.3 billion to provide supports and services to assist persons with developmental disabilities and enhance their ability to live and work as independently as possible in the community. This represents an 11 percent increase over the current year's budget, and roughly a 157 percent increase in funding for persons with developmental disabilities since fiscal year 1998-1999.¹

The number of consumers being fully served in FY 98-99 was 9,219. By April 1, 2005, APD was fully serving 31,256 people with disabilities. Funding for 23,522 of these individuals is provided through the Developmental Disabilities Home and Community Based Services (DD HCBS) Medicaid Waiver. In addition, APD serves 5,478 non-Waiver consumers and 1,784 individuals on the Family and Supported Living HCBS Waiver. There are currently 14,548 people on the waiting list.² Administered by the Florida Agency for Health Care Administration (AHCA), the HCBS Medicaid Waiver is a mechanism to provide services in community-based settings as an alternative to institutional care. The Delmarva Foundation, through a contract with AHCA, provides a program of quality assurance and improvement for persons served through the DD HCBS waiver. This program, the Florida Statewide Quality Assurance Program (FSQAP), has conducted two types of review activities for the first three years of the contract: 1) Provider Performance Reviews to determine provider compliance with the requirements of the Developmental Disabilities HCBS Medicaid Waiver Coverage and Limitations Handbook and: 2) Person-Centered Reviews that monitor the quality of life of individuals receiving services in the program. These review processes have been changed for Year Four of the contract, reflecting an ever-present need to improve the quality of life for the people being served.³

¹ Taken from the Agency for Person's with Disabilities web page:

http://apd.myflorida.com/press_release/govrecbdgt_fy0506/govrecbdgt_fy0506_01182005.shtml

² Information provided by the APD Information Technology department, April 19, 2005.

³ Information on the changes in the processes has been documented in the first Quarterly Report submitted to AHCA, November 2005. Also, see the Delmarva web site for the new protocols and procedures:

<http://www.dfmc-florida.org/index2.htm> .

The DD HCBS program and review processes have initiated a focus on three factors that influence an individual's quality of life—EEE: Education, Exposure and Experience. Consumers must be educated as to their rights and options, they need to be exposed to the availability of various opportunities that support their needs and desires, and they must gain actual experience in varied settings and/or environments. The state is actively promoting a policy to improve and expand supported employment services available to people with developmental disabilities. Helping people gain employment in the community improves their social integration and enhances their sense of personal accomplishment. They gain valuable experiences not only by being employed but also by increasing their social networks and circle of friends. However, people with disabilities often require additional supports to ensure adequate Education, Exposure and Experience in their lives. This study examines the supports provided to consumers of DD HCBS services in order to improve their quality of life. The study is organized into the following sections:

- Personal Outcome Measures
- Sample and Methodology
- Seven POM Areas
- Supports Present by POM Area
- Trends in Demographics
- Supports Not Present for any of the POM Indicators in each Area
- Supports Present for All of the POM Indicators in each Area
- Reason Supports are Not Present
- Three Year Trends
- Conclusions and Recommendations.

Personal Outcome Measures

Each year, Person-Centered Reviews (PCR) of a scientifically selected sample of individuals being served through the DD HCBS Medicaid Waiver program are completed to determine how well the services are meeting the specific needs of the population. The intention of the PCR is to not only ensure that people's individual needs are being met (quality assurance) but to focus on outcomes important to the individual to determine how/if the services are improving their quality of life (quality improvement). A key component of a Person-Centered Review is a consumer interview using the Personal Outcome Measures developed by The Council on Quality and Leadership (The Council).

The Council developed the Personal Outcome Measures (POM) after conducting individual and focus group meetings with over 3,000 individuals with developmental disabilities, chronic mental illness, brain injury and physical challenges.⁴ The 25

⁴ Go to <http://www.dcf.state.fl.us/ddp/ebulletins/071902ebulletin.pdf> and <http://www.wallara.com.au/council/personaloutcomemeasures.htm> for more information on the Council and Personal Outcomes Measures.

Personal Outcomes The Council now uses were identified by the people who were interviewed as most important in their lives.⁵ Principle Component Analysis (Factor Analysis) was used to group the items into seven main POM areas: Identity, Autonomy, Affiliation, Attainment, Safeguards, Rights, and Health and Wellness.⁶

An important component of attaining outcomes for people is the level of support provided to each individual. In fact, the percent of supports present and percent of outcomes met have demonstrated a significant positive correlation.⁷ Therefore, during the interview, trained and reliable interviewers determine not only if outcomes are present for the individual, but also if the supports needed in order to achieve those outcomes are present. Supports are not the “policy, procedure or program” but rather the “specific application of the policy, procedure or program to enable a person to achieve his or her outcome.”⁸ Supports for a person can be provided from a variety of people involved in the person’s life, for example: paid service providers, family members, legal guardians, friends, neighbors, and/or employers. However, in order to make determinations related to supports, the interviewer must know the desired goal for the person.

A good analogy to help explain supports and how consultants determine if supports are present is in planning for a long trip. It may be necessary to make hotel and/or camp site reservations, take the proper clothing, buy maps, map out a route, get traveler’s checks, rent a car, make airline reservations, secure a house sitter and/or pet sitter, develop a budget, stop delivery of the paper, etc. People with disabilities often need supports in order to accomplish these necessary activities that would lead to the desired goal of a successful trip. In addition, if the people providing the supports are unaware of the trip destination, the supports may not achieve a “good” outcome. We may end up in the Bahamas with down jackets and ski boots! It is essential that people providing supports know the desired goal of the individual. Supports provided to consumers are the “intervention point” where district and state staff can most effectively impact the level of outcomes and thereby the quality of life people have. By better understanding the barriers to supports, providers of services and APD can work together to overcome these barriers and move toward quality improvement in terms of outcomes for people being served.

Sample and Methodology

The current study examines supports provided (or not provided) from the results of 6,903 POM interviews conducted with individuals receiving DD Medicaid Waiver services in Florida completed from September 2001 through June 2004—the first three years of the

⁵ Developmental Disabilities Program Office E-Bulletin, Volume 1 No. 8. July 19, 2002.

⁶ The Council on Quality and Leadership in Supports for People with Disabilities, Research Report #2, Construct Validity and Inter-rater Reliability, April 1997.

⁷ Pearson’s $r=.904$, $p<.000$, for the combined years of data: September 2002 – June 2004.

⁸ Taken from the power point presentation “Assessment with the Personal Outcome Measures”, 11-29-04, The Council on Quality and Leadership.

Delmarva/AHCA contract. Delmarva Foundation has collected POM data from a sample of individuals using random probability sampling techniques for each year, sampling without replacement.⁹ An over sample was used to replace individuals if they were unable to be interviewed for various reasons: if they declined to be interviewed, if they were no longer eligible, if the reviewer was unable to locate them or they were deceased.¹⁰ Because this is a difficult to reach population and individuals often decline to be interviewed, not everyone in the sample or over sample was interviewed each year. Results included in this study are based upon the following number of completed reviews (95 percent, 73 percent and 94 percent response rates respectively):

	# Completed	% of sample
• Year 1:	1,530	94.3%
• Year 2:	2,375	74.2%
• Year 3:	2,205	93.4%

The Personal Outcome Measures interview has been used by the Agency for Persons with Disabilities to measure supports provided to persons with developmental disabilities since 1998. Quality Assurance Reviewers (Consultants) with FSQAP conduct the person-centered reviews. They are trained extensively on the review process, the administration of the POM measures, and are found reliable in the use of the POMs by The Council prior to conducting PCRs. In addition, The Council provides on going monitoring and annual reliability for all reviewers.

As noted earlier, there are 25 Personal Outcome Measures. They are grouped into seven POM areas: Identity, Autonomy, Affiliation, Attainment, Safeguards, Rights, and Health and Wellness. After an extensive interview process, the reviewer scores the outcome and supports for each POM as Present (Met) or Not Present (Not Met). If supports are Not Present for any of the 25 POM items, the reviewer indicates the reason the support was Not Present. To provide a method for aggregating and analyzing reasons supports are not being provided, staff from the APD state office identified a series of pre-populated reasons for interviewers to use when the supports were not present for the individual.¹¹ These pre-populated reasons were revised and incorporated into the PCR application used by the FSQAP. For this study, we have grouped these reasons into several categories within each POM area, and analyzed the percent of times they have been utilized over the years. The reasons logically sorted into several broad categorical definitions. Words in bold lettering are used to identify the categories on the following graphs:¹²

⁹ Because the probability of selection varies from year to year, inferential statistics, for example determining if results vary significantly from year to year, will require adjustments be made when calculating standard errors.

¹⁰ See the Florida Statewide Quality Assurance Program Annual Reports, 2001-2002, 2002-2003, and 2003-2004 for details on the samples. Individuals in the Longitudinal Panel study are excluded from this study.

¹¹ APD staff interviewed reviewers extensively to determine the reasons most often cited, and from this information developed a list of pre-populated reasons more conducive to analytic analysis.

¹² See Appendix A for a detailed list.

- A lack of **knowledge** or awareness of preferences, goals, needs, achievements, rights, medical necessities or other relevant issues;
- Some awareness of the need for supports but little or **no effort** made to provide them;
- Supports are limited or **barriers** are present and not being addressed;
- An insufficient amount or a total **lack of support** is indicated;
- A lack of appropriate **training**;
- Needs and preferences are identified but supports are **not provided** to address them;
- Supports are provided but they are not achieving **outcomes** for the individual.

When comparing these categories it is important to understand that comparisons can be meaningful when looking *within* POM areas. For example, a trend analysis over the three years comparing the percent of times a lack of **knowledge** was cited as a reason supports within the area of Identity were Not Present is meaningful. However, because the reasons vary somewhat *between* POM areas, comparisons across the areas should be minimized. Therefore, it is not appropriate to compare the percent of times a lack of **knowledge** was used as a reason supports for Identity were Not Present to the percent of times a lack of **knowledge** was used as a reason when supports were Not Present for Autonomy.

Seven POM Areas

Identity

A strong sense of identity is something important to all people. Choosing our own personal goals, where and with whom we live and where we work are freedoms we all need to enjoy. As we formulate goals for ourselves and decide on our choice of employment and living environment, we learn more about who we are and what we want out of life. We also learn more about who we are or want to be and build our own identity through our interactions with other close and intimate friends. Our definitions of satisfaction show the different ways we express our individual identity. Six Personal Outcome items used to measure Identity give us a sense of how people express themselves as unique individuals and are as follows:

- People choose personal goals;
- People choose where and with whom they live;
- People choose where they work;
- People have intimate relationships;
- People are satisfied with services;
- People are satisfied with their personal life situations.

A key component demonstrating that individualized supports are present for Identity is whether the people providing supports know the person and learn their preferences for each. Once choices have been made by the person, these should be respected and

supported by the supports and services to assist the person in obtaining their choices and preferences.

Autonomy

To live autonomously is to have authority and control over our lives. To have autonomy is to have the power and the authority to determine and enforce the rules and policies that govern us and to feel we have some control over our physical environment, daily schedule, our needs for privacy, and control over privileged and personal information. We decide whom we will allow into our personal space. Autonomy is a sense of independence. This is a goal most people embrace. Four Personal Outcomes measure if people have autonomy in their lives:

- People choose their daily routine;
- People have time, space and opportunity for privacy;
- People decide when to share personal information;
- People use their environments.

It is important for supports to recognize each person's own preferences in the area of Autonomy. Like Identity, these preferences and choices must be respected. For example, in order for supports to be considered Present for "people use their environment", people providing supports must know how the individuals access their environment or how they would like to access their environment, and make an effort to allow that to happen. However, the outcome may not be met if the access is still somehow denied.

Affiliation

Affiliation describes our connections to others, our degree of integration into the community. Because "social integration" is such a vague and ambiguous term, it has been used to represent a wide variety of concerns. As popularly used, the term carries with it ideas of justice, equality, material well being and democratic freedom, and it also implies harmonious interaction and solidarity at all levels of society. The opposite of social integration is the exclusion of certain groups from mainstream society. That exclusion affects not only the excluded group but also limits the awareness of others. Exposure to different cultures, ethnic backgrounds, family types, the elderly, the young, the developmentally disabled and, in short, people with various social roles helps improve our awareness of options that might be available to us as well as our tolerance and acceptance of those different, in some way, from us. Living in an integrated environment, or Affiliation, is therefore important to many people. Affiliation is measured with six Personal Outcomes:

- People live in integrated environments;
- People participate in the life of the community;
- People interact with other members of the community;
- People perform different social roles;
- People have friends;
- People are respected.

People with supports present in their lives for the Affiliation domain have expanded their community experiences and become a part of their community. They are supported to continue to learn about their community. They are respected because people listen to them and respond to their wishes. This includes listening to the type and level of community interaction they chose and responding with supports needed to reach those goals.

Attainment

Attainment is a measure of how people define success in both personal and social terms. In some instances, people define goals and services in very personal terms. At other times, services and goals can reflect commitment to a group of people, an association, a cause, and even a sense of community. People find some degree of individual motivation with successful accomplishments. This motivation is individually defined and varies from person to person. Time frames, types, and levels of support, and the person's definition of success influence the choice of individual goals, services and supports.¹³ Attainment is measured with only two Personal Outcomes:

- People choose services;
- People realize personal goals.

The primary area of support for both of these Personal Outcomes to be Present, is for people providing supports to be aware of what is important to the person. Solicitation of preferences, options and supporting choices are key supports needed for the Personal Outcome of “chooses services” to have supports Present. In order for Supports to be Present for “people realize personal goals” accomplishments must be identified and celebrated.

Safeguards

The remaining three POM areas are defined by The Council as Foundational Outcomes. These are the basic outcomes to which all people should be entitled and are the indicators of Safeguards, Rights and Health/Wellness. As the term implies, Safeguards help us feel secure and safe. Being near close family members and friends, knowing they are there to help and support us, gives us a safe and secure feeling. With the support of those close to us who are as concerned for our well being as we are, we may garner a sense of protection and strength. Where Affiliation implies a connection to the community, implicit to feeling safe is a connection to intimate friends and family members. The Safeguards domain is measured with two Personal Outcomes (two of the seven Foundational Outcomes):

- People are connected to natural support networks;
- People are safe.

¹³ Personal Outcome Measures 2000 Edition, The Council on Quality and Leadership. Go to <http://www.ncor.org/frame3.htm> for more information.

Supports for this domain must identify the person's natural support network and safety needs. Once this is done, supports should then provide the necessary provisions needed and requested by the person.

Rights

People with developmental disabilities have the same rights as any other citizens. People need to be encouraged to identify which rights are most important to them and the organization should help assure the person is able to fully exercise those rights. The process extends beyond removing barriers to ensuring people actually experience what they have a right to experience. Two Personal Outcomes (two of the seven Foundational Outcomes) are used to measure an individual's rights:

- People exercise rights;
- People are treated fairly.

The three Es play an integral part for this domain. Without education, exposure and experience to rights, how do individuals know the rights they have or which rights are actually important to them? Which of their rights are being violated and how do individuals know they are being treated unfairly if they are not educated in these areas? Finally, how will individuals know which rights they want to fully exercise? By providing supports related to EEE, the person has an increased ability to answer each of these. Supports can assist individuals in maintaining their rights and ensure they are being treated fairly.

Health and Wellness

Having the best possible Health and Wellness is a basic human need and right. Services and supports that address physical and mental health needs must be designed to ensure that individuals attain the best possible health, within the confines of each person's unique situation. Health and Wellness encompasses the last three Foundational Outcomes that address best possible health, freedom from abuse and neglect, and continuity and security. Abuse and neglect directly effects both physical and mental health. Action must be taken immediately when allegations of or any indication of either of these is identified. Continuity of care is an important aspect of one's overall health and wellbeing. Changing a primary care physician disrupts the continuity of medical care for all people and can be psychologically and emotionally difficult. Having a care giver or physician with an individual over a prolonged period of time can help promote a sense of comfort and security that leads to better health outcomes. Health and Wellness is measured with the final three Foundational Outcomes:

- People have the best possible health;
- People are free from abuse and neglect;
- People experience continuity and security.

Supports for the Health and Wellness domain center around knowing the person's specific needs and concerns. Once these are determined, based upon the person's

preferences, supports are able to promote, attain and maintain the health and wellness of the person.

Supports Present by POM Area

The data in Table 1 present the percent of supports that were present in each POM area for individuals interviewed between July 2001 and June 2004. In general, the percent of supports present has decreased over the three year period, from 59.5 percent to 48.5 percent. When comparing across POM areas is it important to remember that a different number of indicators (POM questions) is used for each area. Therefore, for example, by missing one support for Rights an individual would achieve 50 percent Present. However, missing one support for Identity, an individual would achieve 83 percent Present.

Safeguards (two indicators) has consistently demonstrated the highest percent of Supports Present each year. However, the percent Present has decreased from Year One to Year Three, more than for any other area, with the exception of Health and Wellness. Affiliation and Attainment consistently show the lowest percent Present each year.

**Table 1: Percent Supports Present
by POM Area**
July 2001 - June 2004

POM Area	Year 1	Year 2	Year 3
Identity	56.6%	53.8%	47.9%
Autonomy	66.4%	59.0%	53.0%
Affiliation	48.5%	42.6%	38.3%
Attainment	44.1%	40.6%	36.7%
Safeguards	83.4%	75.3%	69.5%
Rights	57.6%	51.2%	49.6%
Health/Wellness	73.6%	64.4%	57.1%
Total	59.5%	53.7%	48.5%

Trends by Demographics

Data on the Outcomes and Supports for the DD HCBS Waiver population are presented in the Annual and Quarterly reports submitted to AHCA and APD. However, the focus in those reports is generally on the percent of Outcomes Met, as this is the final outcome of interest in determining how well the system’s providers are achieving results for the individuals being served. Here we present a brief summary of the Supports Present for

the districts, various age groups, type of disability, and residential status.¹⁴ The Supports are essential in achieving results for the individual and, as mentioned previously, an “intervention point” where providers, families, the district and the state can initiate positive change in the system.

Table 2 displays the number of interviews and percent of Supports Present on the POM measures by district for each of the first three years of the contract.¹⁵ On average, the percent of Supports Present varies from 69.4 percent in District 1 to 41.6 percent in District 8. While a general downward trend exists across the three years, some variation among the districts is likely due to small sample sizes.

Table 2: Individuals with Supports Present by District
July 2002 - June 2004

District	Number of Interviews			Percent Present			
	Year 1	Year 2	Year 3	Year 1	Year 2	Year 3	Total
1	84	86	144	75.0%	61.0%	71.2%	69.4%
2	134	219	189	81.2%	51.8%	45.9%	57.0%
3	107	150	90	52.8%	46.8%	40.6%	47.1%
4	82	221	173	56.6%	52.5%	50.2%	52.4%
7	152	180	179	66.7%	59.0%	50.2%	58.2%
8	71	81	110	48.2%	39.5%	38.8%	41.6%
9	60	140	159	62.9%	52.1%	42.2%	49.5%
10	143	198	192	57.1%	60.5%	61.8%	60.1%
11	176	272	241	61.4%	60.7%	56.6%	59.4%
12	20	71	71	63.4%	76.1%	43.3%	60.1%
13	85	120	94	54.8%	49.2%	43.9%	49.1%
14	52	83	76	51.2%	52.2%	42.7%	48.6%
15	41	58	62	72.6%	47.3%	43.7%	52.4%
23	323	496	425	48.5%	49.0%	39.9%	45.8%
Total	1,530	2,375	2,205	59.5%	53.7%	48.5%	53.3%

The following table shows the percent of Supports Present by Age Group from July 2002 through June 2004. On average, the youngest portion of the DD HCBS Waiver population is most likely to have supports present (62.3%) while people age 45 to 64 are least likely (48.7%). Estimates presented for the elderly population, age 65 and over, are based on small sample sizes and are therefore somewhat unstable. The proportion of supports school age children receive is ten percentage points higher than for any other age group, receiving supports while still in the school systems. We know that supports

¹⁴ See Attachment 1 for a detail of the number of POM interviews by district, age group and home type each year.

¹⁵ In order to produce stable estimates of the Supports Present, each district requires a sample size of at least 67 individuals. With this sample size the estimates are accurate with 90 percent confidence, ± 10 percentage points. It is important to note here that for districts 9, 12, and 14 in Year 1 and District 15 in all three years, the sample size is less than 67 and the estimates are therefore somewhat unreliable. Trends must be interpreted cautiously.

have shown a positive and statistically significant association with Outcomes for individuals.¹⁶ Therefore, these results clearly support the need for further efforts to increase supported employment services and services that support independence to better assist the developmentally disabled in their transition from school to becoming independent working adults.

Table 2: Percent Supports Present by Age Group
July 2002 - June 2005

Age Group	Number of Interviews			Percent Present			
	Year 1	Year 2	Year 3	Year 1	Year 2	Year 3	Total
0 - 17	281	346	286	68.1%	60.8%	58.5%	62.3%
18 - 21	123	185	146	57.2%	52.2%	47.5%	52.1%
22 - 25	151	237	199	56.8%	53.1%	49.6%	52.9%
26 - 44	624	1,045	1,024	59.4%	53.9%	47.7%	52.8%
45 - 64	318	504	507	55.2%	48.8%	44.5%	48.7%
65+	33	58	43	51.0%	57.6%	45.0%	51.9%
Total	1,530	2,375	2,205	59.5%	53.7%	48.5%	53.3%

Where people live appears to determine the quantity of supports present for them. Supports are greatest among people living independently or in supported living environments (Table 3). This pattern is consistent across all three years. These could be supports provided through the DD HCBS Waiver program or natural support systems that are more likely to be in place in family rather than group home settings. The *Group Homes* category includes people living in small and large group homes as well as a few individuals in residential treatment facilities (30 individuals over three years). In Home includes a few people living in Foster Care, a total of 73 for three years.

Table 3: Percent Supports Present by Residential Status
July 2002 - June 2004

Residence	Number of Interviews			Percent Present			
	Year 1	Year 2	Year 3	Year 1	Year 2	Year 3	Total
In Home	811	1,181	1,108	63.6%	57.1%	52.4%	57.1%
Ind/Sup Living	222	299	352	68.9%	63.4%	58.8%	62.9%
Group Homes	457	696	689	47.1%	44.7%	37.0%	42.4%
Unknown	40	199	56	64.7%	50.5%	46.6%	51.7%
Total	1,530	2,375	2,205	59.5%	53.7%	48.5%	53.3%

¹⁶ Florida Statewide Quality Assurance Program: Annual Report 2203 - 2004. Submitted to AHCA by the Delmarva Foundation, October 2004.

Because the number of people in the sample served under the DD HCBS Waiver program with certain disabilities is quite small each year, little information has been provided by type of disability. However, using a three year average gives us a sufficient number of cases within each category to begin to present some meaningful comparisons.¹⁷

Table 5: Percent Supports Present by Disability

July 2001 - June 2004

Disability	Number of POM Interviews	Percent Supports Present
Mental Retardation	5,008	51.6%
Cerebral Palsy	476	61.7%
Autism	220	62.1%
Spina Bifida	125	69.2%
Other/Unknown	281	54.9%
Total	6,110	53.6%

As indicated in Table 5, supports are least likely to be present for people with mental retardation and more likely to be present for people with Spina Bifida, Cerebral Palsy or Autism. This is likely due in part to the fact that individuals with Mental Retardation are less likely to live in family homes or in independent or supported living environments. On average over the three years, 62.7 percent of individuals interviewed with mental retardation as their primary disability lived in family homes or independent/supported living settings. By comparison, the proportion of people with Cerebral Palsy, Autism or Spina Bifida in these environments is 81.5 percent, 80.5 percent and 90.4 percent respectively.

¹⁷ The samples have not been weighted to account for variance in the probability of selection each year. Because the samples have been drawn without replacement the probability of being in the sample each year increases. However, because the base population is approximately 23,500, this difference will have only a small effect on statistical outcomes.

Supports Not Present for any of the POM Indicators in each Area

As demonstrated in the previous section, each of the POM areas is measured with a different number of POM item (indicators). Identity and Affiliation have six indicators, Autonomy has four, Health and Wellness uses three, and the remaining three areas (Attainment, Rights, and Safeguards) each have only two indicators to measure the outcome. Scoring Not Present on two indicators for Rights indicates that none is Present while scoring Not Present on two indicators for Identity does not. Therefore, to compare across the POM areas, we present information in this section by displaying the areas with four to six indicators in one figure and areas with only two or three indicators in a second figure.

Figure 1 below shows the percent of individuals with supports Not Present on any of the indicators for the POM areas of Identity, Autonomy and Affiliation. We see a steady increase over the three year period, with the greatest difference in Autonomy, showing a 115 percent increase from 7.8 to almost 16.9 percent of people interviewed having supports Not Present in this area. Affiliation, our ability to help people integrate into the community, has the greatest proportion of people with all supports Not Present (among these three areas), up to over 24 percent by the 12 month period ending June 30, 2004, representing a 57 percent increase since Year One. This is, of course, an essential component to a Home and Community Based Services program, providing supports so people can live in integrated environments, perform different social roles and participate in the life of the community.

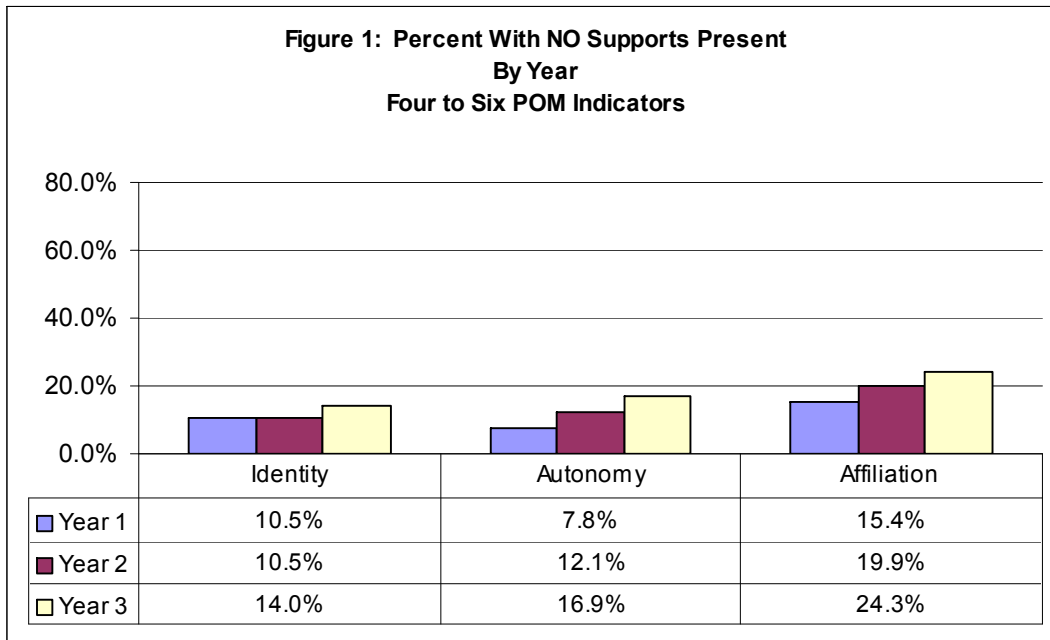
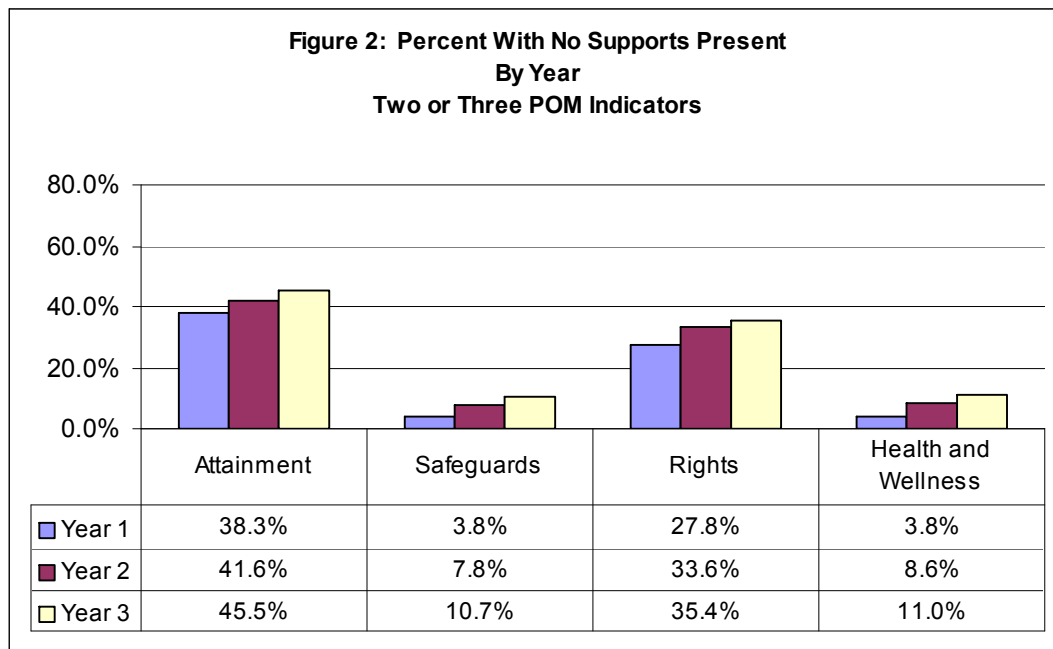


Figure 2 displays the proportion of individuals from the samples each year with supports Not Present for the POM areas of Attainment, Safeguards, Rights and Health and Wellness. These areas are measured with only two or three (Health and Wellness) POM items. Again, there is a demonstrated increase each year. The greatest increases over the three year period are in the areas of Safeguards and Health and Wellness, but the data show that 45.5 percent of interviewed individuals during the third year had all supports Not Present in the area of Attainment. Apparently, the individuals receiving services on the DD Waiver program are seriously lacking in supports that help enable them to choose their own services or to realize their own personal goals. Supports that help enable people to exercise their rights and also to ensure people are treated fairly (Rights) are also deficient, with over 35 percent of individuals in Year Three indicating supports were Not Present in these areas.

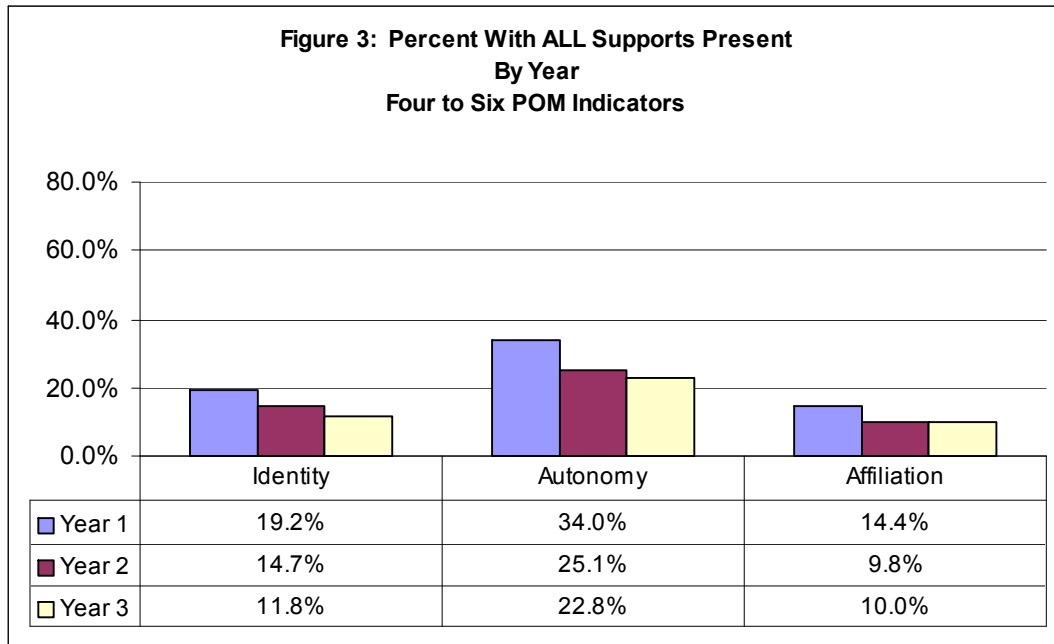


Although there is some variation, it appears that for these seven areas on average, there was a greater increase in the proportion of individuals with supports Not Present from Year One to Year Two, than from Year Two to Year Three. Perhaps this trend is leveling off somewhat.

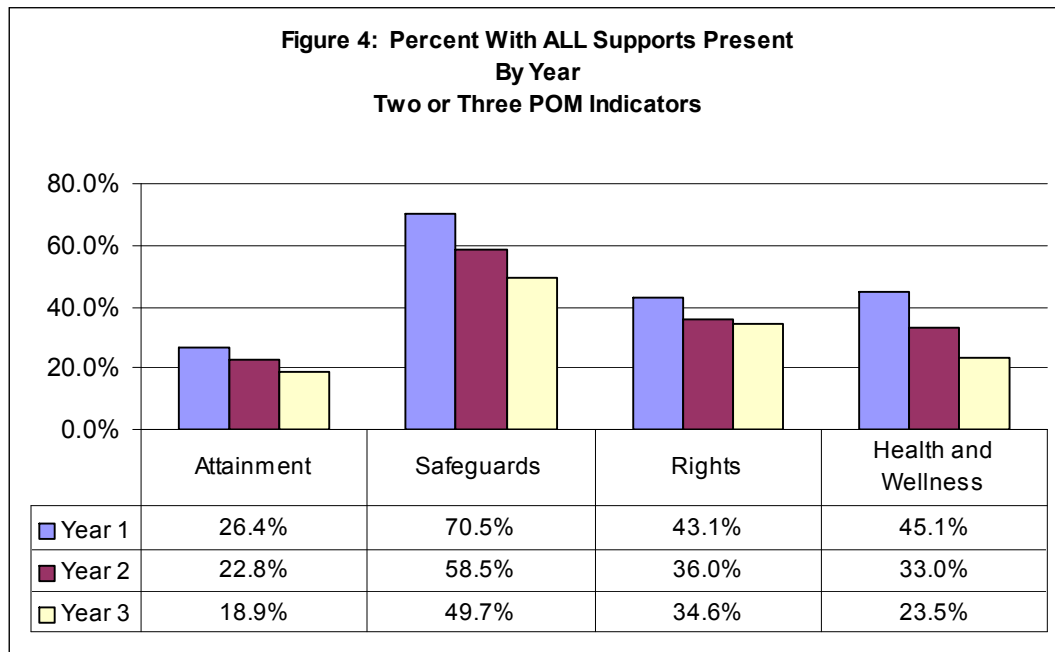
Supports Present for All the POM Indicators for Each Area

The opposite, and more positive aspect is the percent of people with all the supports Present on the indicators within each POM area. For Identity, Autonomy and Affiliation, areas with four to six POM indicators, the percent of individuals with all of the supports Present in Year Three ranges from 10.0 percent for Affiliation to 22.8 percent for Autonomy (Figure 3). In general, there has been a decline in the percent of individuals with all the supports present within these POM areas.

While Autonomy has the greatest percent decrease over the three year period, individuals are still more likely to have all supports Present for this than for Identity or Affiliation. As indicated above where supports were Not Present, most of the decline on this measure reflecting that all supports were Present occurred from Year One to Year Two. Perhaps this trend has also leveled off and may improve over Year Four (July 2004 – June 2005) in these areas.



For the remaining POM areas that have only two or three indicators each, Attainment, Safeguards, Rights, and Health and Wellness, there has been a consistent decline in the percent of individuals with all supports Present over the three years. In the area of Safeguards, indicating if people are connected to natural supports and if people are safe, nearly 50 percent of the individuals interviewed in Year Three had all the supports present. Therefore, while this has decreased from over 70 percent in Year One, the proportion of individuals with all Safeguard supports Present remains fairly high.



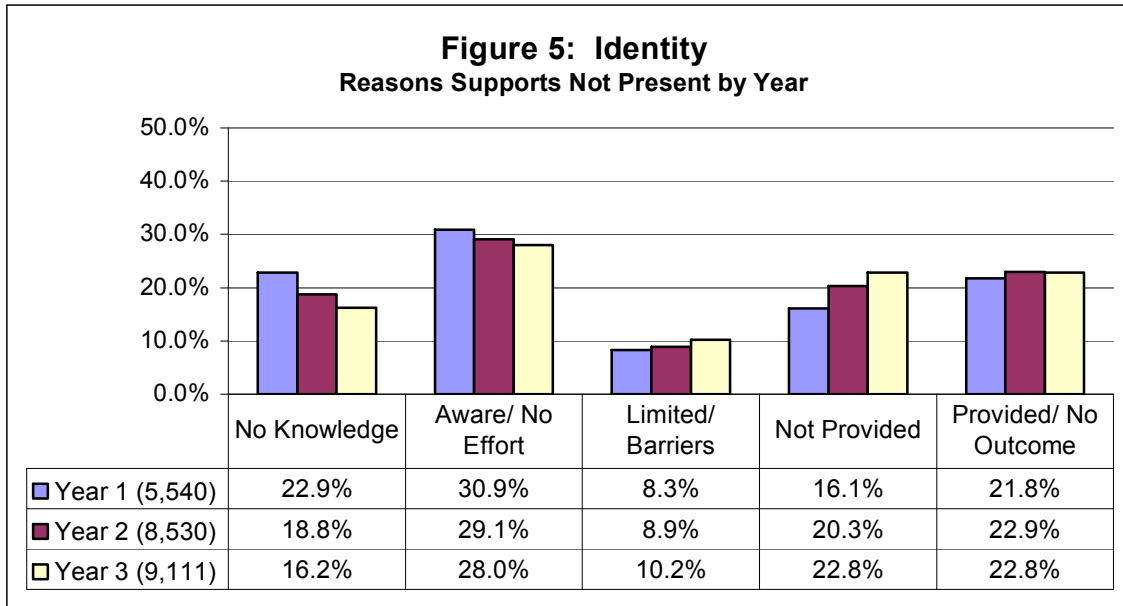
Reason Supports are Not Present¹⁸

Identity

The six personal outcome items used to measure the POM area of Identity give us a sense of how people express themselves as unique individuals. The Reasons supports were Not Present in this area are grouped into five categories: 1) there is **no knowledge** or awareness of the individual’s personal goals, interests or preferences and no effort or a limited amount of effort is evident to enable the individual to obtain the knowledge; 2) the provider has some awareness of the preferences and desires of the individual but **no effort** is evident that all preferences or options are explored; 3) supports are **limited or barriers** are present; 4) needs are identified but supports/services are **not provided**; and,

¹⁸ See Appendix A for a list of all the groups of reasons within each POM area.

5) supports are provided but they are not adequately meeting the intended *outcome*. The percent for each category for three years is presented in Figure 5.

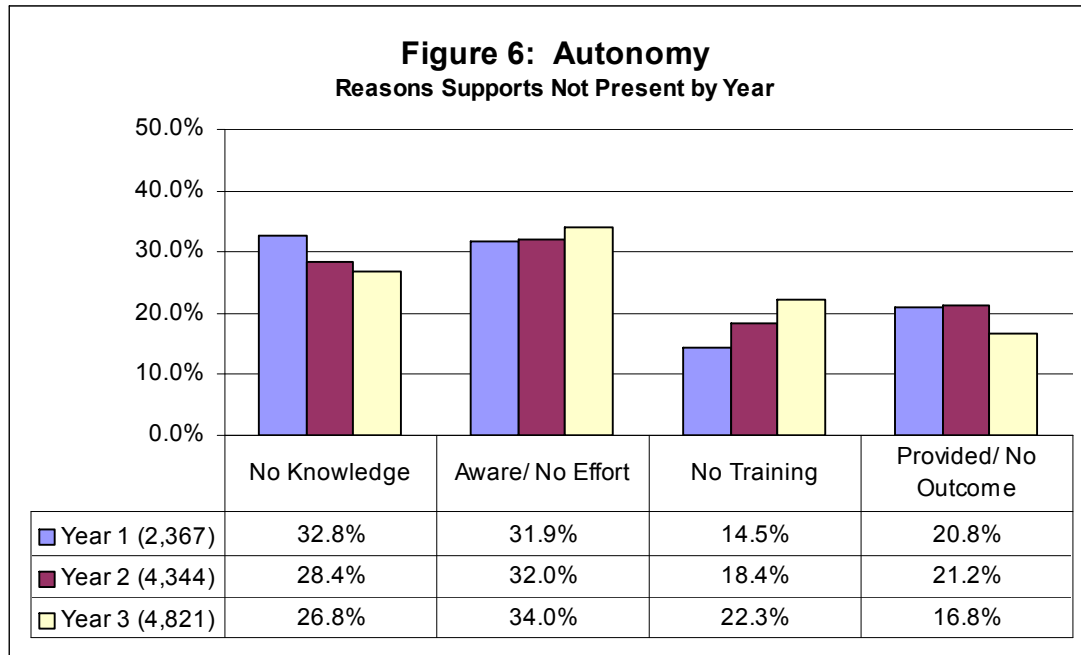


The reasons most frequently cited each year indicate the provider has some awareness of individuals’ preferences and life situations but not all options are explored to increase awareness in these areas (Aware/No Effort). Most frequently noted in this category, over the three year period, is that not all the options for the individuals are explored, assumptions are made that individuals are happy or they “like” their current situation, and that stronger efforts to learn and to communicate are needed. Some improvement is evident in the area of the provider’s knowledge or awareness of the individual’s needs and preferences (No Knowledge). This has proportionately declined since Year One. The categories of reasons that have increased proportionately each year pertain to a limited number of supports or the presence of barriers that are not addressed, and needs that are identified but supports are not present to address them. Overall, the three most frequently cited comments in the area of Identity over the three year period indicate that varied experiences are not provided for the individuals (2,396); that all options are not explored (1,980); and that supports need to be stronger (1,333).

Autonomy

Autonomy is a sense of independence. There are four categories for reasons supports were Not Present in the POM area of Autonomy: 1) there is *no knowledge* or awareness of the individuals preferences or desires; 2) there is some awareness of preferences or needs but little or *no effort* is made to address them; 3) there is a lack of appropriate *training*; and, 4) supports are provided for the individual but they are not meeting *outcomes* for that person (Figure 6). The most frequently noted comment over the three year period informs us “training is not addressed” (1,975). This indicates a lack of

training for the individuals to enable them to identify ways to increase autonomy in their lives. This category as a whole (No Training) has increased proportionately over the years.¹⁹



The percentage of reasons that indicates “awareness is present but no effort is made to address needs”, has remained relatively high, comprising 32 to 34 percent of all the reasons each year. Comments inform us the provider often assumes certain “limits are OK” (1,899), or that “preferences are assumed without exploration” (549), or providers are not providing modifications as needed (630). On the other hand, the proportion of comments reflecting a lack of knowledge about preferences and desires has decreased from close to 33 percent to just under 27 percent. When the supports were provided but the outcomes were not yet met, the most frequently noted reason was that “personal information is shared without the individual’s consent”.

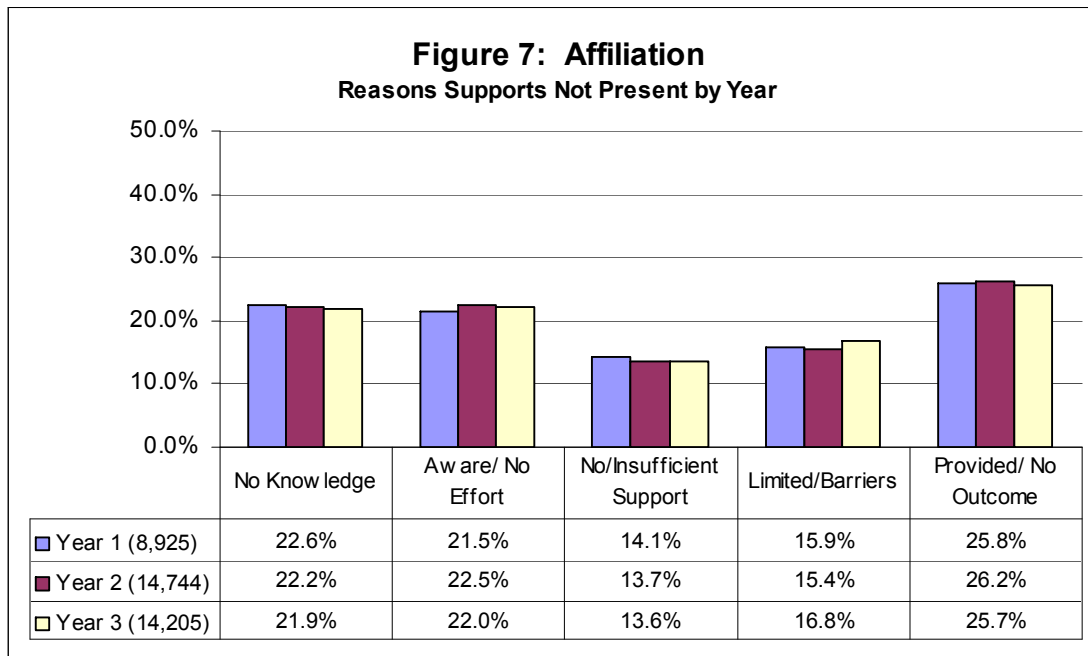
Affiliation

Affiliation describes our connections to others, our degree of integration into the community. The POM area of affiliation has, over the three years reported on in this report, a greater number of reasons supports were Not Present than any of the other areas. In total, 37,874 reasons were listed indicating why a support was Not Present. This reflects a significant need to explore interventions that will aid in the integration of the population into the community. There are five categories of reasons for this area: 1) there is *no knowledge* or awareness of the individuals’ preferences or desires; 2) there is

¹⁹ There are only two reasons in the No Training category. Therefore, even though “training not addressed” is cited more often than any other reason, the category as a whole is not proportionately as large as the other categories.

some awareness of preferences or needs but little or *no effort* is made to support them, no plans are apparent that support the needs of the individual, and opportunities are not explored; 3) there are no supports evident or the supports are *insufficient*, generally noting staff, education, transportation, counseling and/or training shortages/needs; 4) supports are *limited* or *barriers* are noted; and, 5) supports may be provided but they are not yet achieving *outcomes* for the individual.

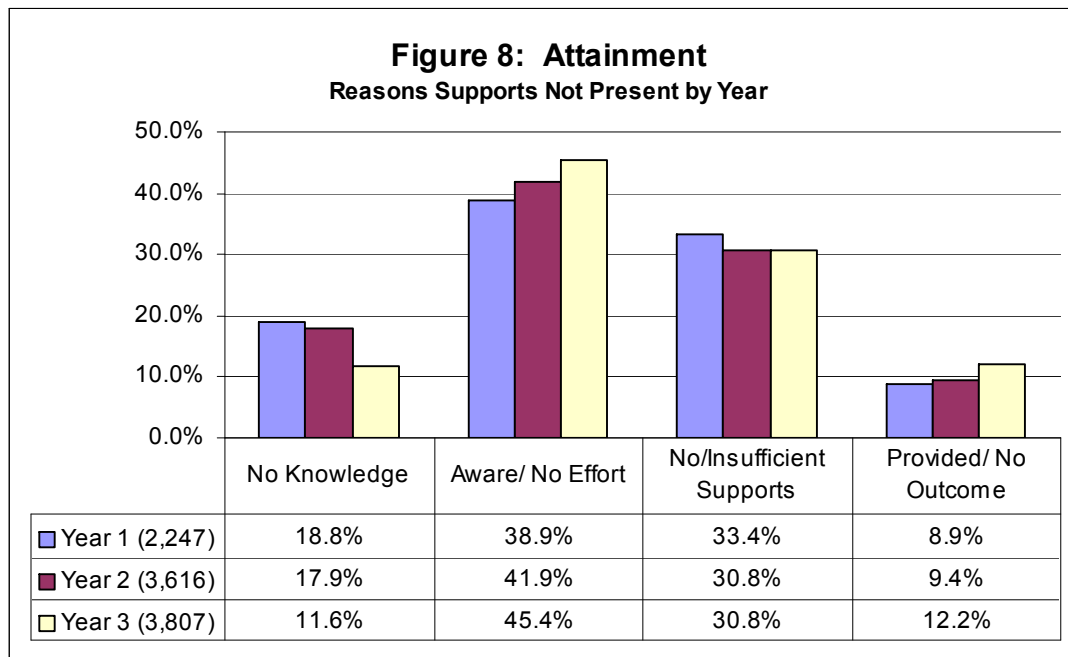
As demonstrated in Figure 7, these categories have remained fairly consistent over the first three years of this contract. The category most likely to be cited indicates that supports are provided but they are not meeting outcomes. Reasons supports are Not Present in this category reflect that “more experiences need to be supported”, that “supports need to enhance quality”, the “focus of the supports tends to be on deficits rather than achievements”, and that “supports and individual desires differ”. The latter reason cited may also reflect a lack of knowledge of the consumer’s preferences and desires, or an inability or unwillingness to address them.



The most frequently cited reasons for a lack of supports in achieving Autonomy are that “more experiences need to be supported” (2,473), that “all opportunities are not explored” (2,274), and that “needs are not addressed or are not identified” (2,101). It is also apparent from the data that desired interactions and preferences are not explored or assessed, there is a lack of support enhancing quality of life issues, there are often staffing and transportation limitations, and *there were 1,254 citations over the three years indicating there were no plans to support integrated employment*. Given the state of Florida’s current emphasis on providing Supported Employment for persons with developmental disabilities, this is a significant find.

Attainment

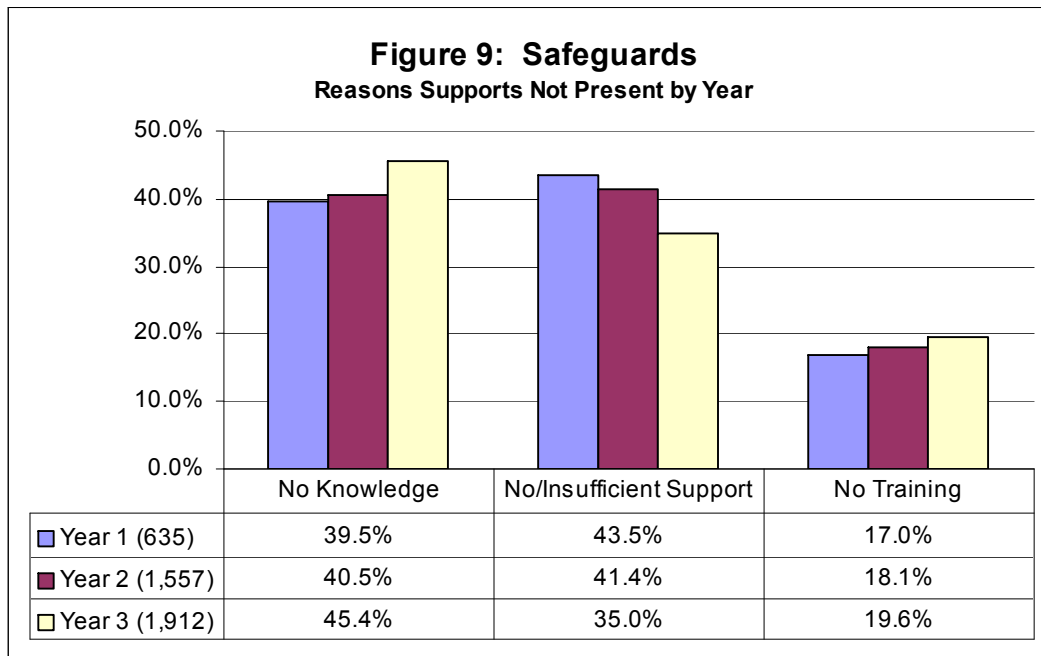
Attainment is a measure of how people define success in both personal and social terms. Reasons supports are Not Present in this area fall into four categories: 1) *No knowledge* or awareness of the individual’s specific achievements; 2) the providers have some *awareness* of the preferences and achievements of the individual but supports are not present; 3) there are no supports or they are *insufficient* to address needs; and, 4) supports are provided but they are not meeting *outcomes*. The second category has consistently shown the highest proportion within this POM area, representing over 45 percent of all the reasons in Year Three (Figure 8). The most frequently cited reasons refer to choices for the individual: family and staff continue to make choices or the choices for the individual are made for the convenience of others.



In the category indicating insufficient supports are present, a lack of supports enhancing individual choice is also apparent. Organizations are not always working to increase the choices individuals have (1,269) and organizations do not always educate the person on available choices (2,080). Also of interest is that 955 times the reason cited indicated “supports are not focused on outcomes important to the person”. The processes initiated in Year Four of the contract are designed to help providers listen to and focus on outcomes that are chosen by and important to the individual.

Safeguards

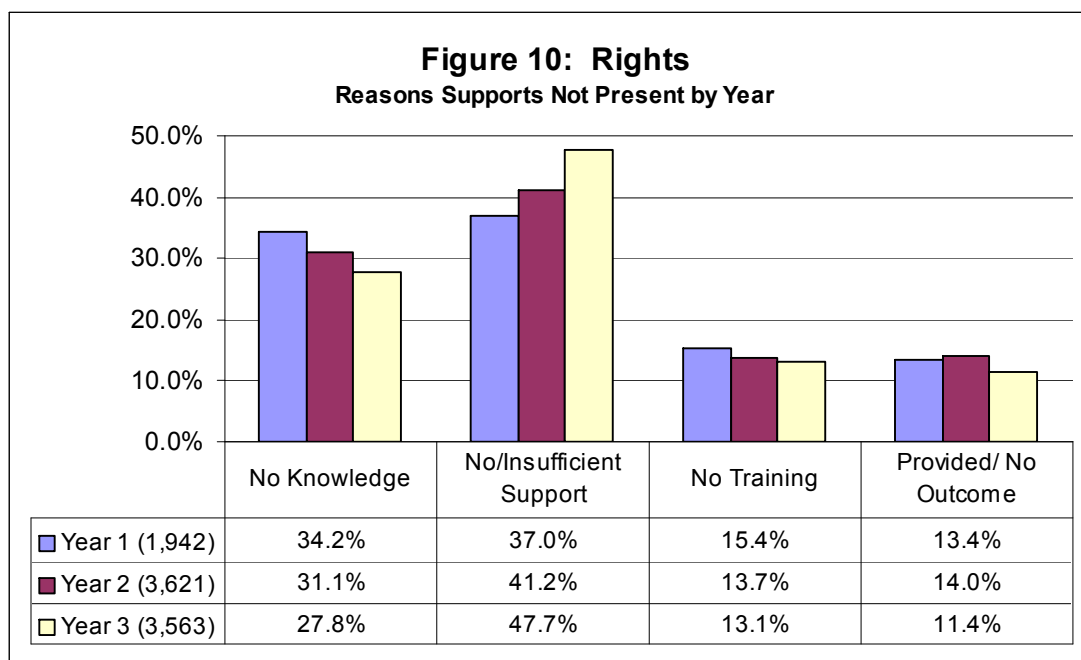
The right to feel safe and secure at work and at home is basic to all of us. This is an area where all supports are more likely to be present than for the other POM areas, as indicated in the previous section. The POM indicators for Safeguards are the first of the seven Foundational Outcomes. The reasons support are Not Present fall into three categories: 1) providers have *no knowledge* of family, safety issues or the importance of safety to the individual; 2) no supports or *insufficient* supports are provided; and, 3) there is a lack of appropriate *training* to help the individual communicate or learn, for example, basic fire safety protocol. When supports are Not Present within this POM area, it is most likely due to the fact that not all safety issues are identified (937) or if identified they are not adequately addressed (849). The data also indicate that at times necessary training is not provided regarding basic fire safety or the use of the phone. In a world of telecommunications, lacking basic telephone skills can impact connections not only to family and natural supports but also to other community programs. In fact, the data suggest there is not enough training in the community.



Rights

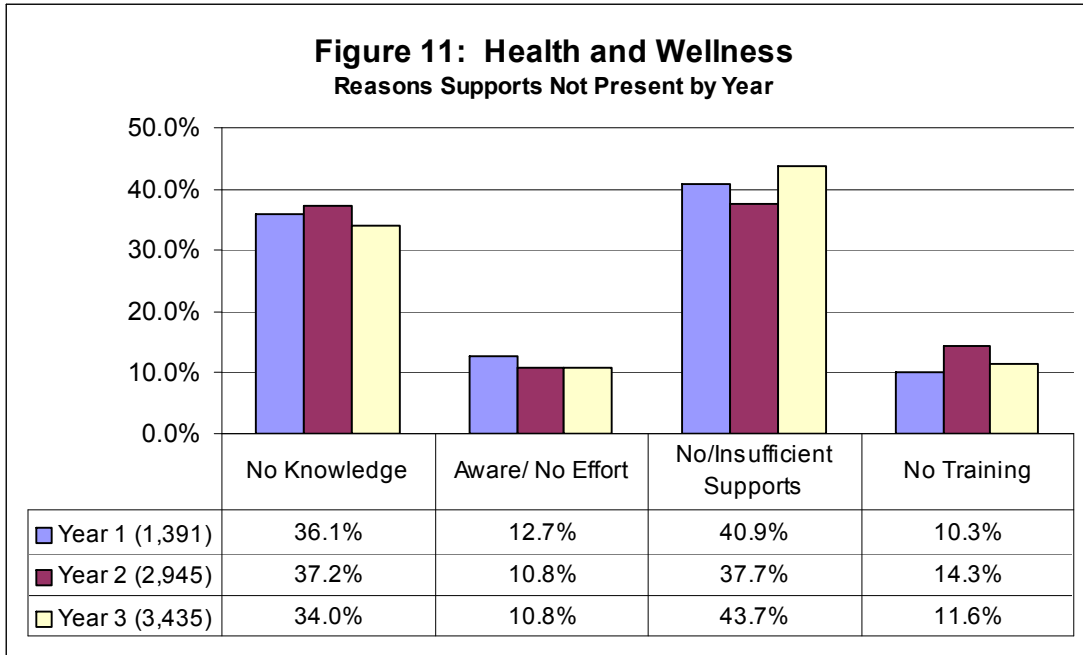
People with developmental disabilities have the same rights as any other citizens. It is essential that supports be in place to ensure they attain these rights. When supports are Not Present they fall into one of the following four categories: 1) there is *no knowledge* of important rights; 2) no supports are provided or they are *insufficient*; 3) there is no rights *training*; and 4) supports may be provided but they are not achieving *outcomes* for the individual.

Over the three years, the reasons supports for Rights are Not Present are most often due to a lack of supports or “insufficient supports for the needs of the individual”, representing almost 48 percent of the reasons in this POM area (Figure 10). There is evidence of limited attempts to maximize personal control and limited to no personal advocacy support. In addition, due process is not always supported, a right for all citizens. A person’s fair treatment issues are not always solicited, and procedures for addressing concerns are not always effective. Over the three year period, 1,259 people interviewed were noted as having no Rights training. When outcomes are not met, it is most often because “procedures for addressing concerns are not effective.” Therefore, systems are in place to provide support, but they are not yet effective. The new Delmarva consultative review processes specifically address this scenario.



Health and Wellness

The last POM area, Health and Wellness, encompasses the last three Foundational Outcomes that address best possible health, freedom from abuse and neglect, and continuity and security. The reasons supports are Not Present in Health and Wellness are: 1) having **no knowledge** or awareness of rights, fair treatment or restoration of competency; 2) No or **insufficient** supports are provided; 3) there is no Rights **training**; and, 4) supports are provided but people are not achieving **outcomes** (Figure 11).



The most frequently cited reasons over the three year period are that support was not provided to promote personal control for the individual (1,409) and the necessary (medical) appointments had not always been scheduled (1,312). The data also indicate there are often medical awareness issues, the organization does not always know the person’s needs or desires, and the possibility of being provided with insurance is often not explored. In 961 instances over the three years, it was noted that either training for protection or choice was not apparent, or that training was simply not addressed at all.

Three Year Trends

Some of the reasons supports are Not Present are the same or very similar across the POM areas. For example, under Identity “Preferences unknown by Support Coordinator” and “Preferences unknown by supports” are both options that are utilized in the drop down menu. In addition, “Preferences unknown” is used for Autonomy and “Support Coordinator unaware of role preferences” for Affiliation. By combining these and other reasons that are similar across all of the POM areas, we can examine in general how the reasons have trended over the three years.

As indicated in Table 5, there has been little movement among the “top ten” reasons supports are Not Present for individuals on the DD Medicaid Waiver. Knowing an individual’s preferences, exploring and/or addressing preferences, exploring all options or opportunities, and transportation issues have ranked in the top four each year. Other reasons cited indicate individuals need supports to help them obtain more experiences and that varied experiences are not always provided. Issues surrounding choice are also apparent in that family and staff continue to make choices for individuals.

Table 6: Reasons Supports Not Present

Rank by Year

Reason Given for Support Not Present	Rank		
	Year 1	Year 2	Year 3
Preferences Unknown	1	2	3
Transportation Needed or is Limited	2	4	4
All Options/Opportunities Not Explored	3	1	1
Preferences Not Explored or Not Addressed	4	3	2
More Experiences Need to be Supported	5	5	8
Varied Experiences Not Provided	6	6	10
Staff Limitations	7	7	5
No or Limited Effort to Learn/Communicate	8	18	20
Supports Unaware of Specific Achievement	9	13	31
Family/Staff Continue to Make Choices	10	8	9
Needs Not Addressed/Unidentified	12	9	7
Training Not Addressed	21	10	6

Issues surrounding training of providers have been documented in other reports submitted to AHCA and APD.²⁰ A Reason often given by the reviewers every year for the lack of support indicates training is needed for the provider or the consumer. This has moved up in rank each year. In addition, the reason cited in Table 5 (Training Not Addressed) is only one option from the drop down menu.²¹ Others that refer to training problems are also quite prevalent including: “More training needed for organization”, “Staff training needed”, “No training to express desire for privacy”, “No communication training/phone”, “Not providing enough fire training”, and “Not providing necessary training”. Some of these indicate the provider needs more training to provide the proper supports and others that the consumers are not properly trained to help them become more independent or to help them with safety issues.

Conclusion and Recommendations

Previous reports on the Personal Outcome Measures for the DD HCBS population in Florida have indicated a slow decline in the number of outcomes that have met the criteria for that particular item. At the same time, the number of Supports Present has also decreased over the years. A primary focus for people on the DD HCBS Waiver program is to enhance consumer’s lives through Education, Exposure and Experience to

²⁰ See Florida Statewide Quality Assurance Program: Provider Performance Reviews, An Analysis of Desk Review Results: Delmarva Foundation, June, 2004.

²¹ In other words, several of the other categories are a combination of different similar reasons but this one is a “stand alone” reason.

various opportunities and options available to them. The presence of natural and provider supports are essential in accomplishing this for persons with developmental disabilities. In this study we have looked more closely at the reasons supports have not been present for individuals on the DD Waiver Program.

In general, children, people in independent or supported living or in a family home are more likely to have a higher percent of Supports Present than adults or people living in Group Homes. While people with Mental Retardation as their primary disability are less likely to have Supports Present, this might be due in part to the fact that they are also more likely to live in Group Homes. Natural support systems are more likely to be present for people living in family homes or in supported living environments than group homes.

Recommendation: Further study should be conducted to help determine if people with a certain type of disability, i.e., mental retardation, are more or less likely to have effective support systems, controlling for other factors such as where the person is living.

Within every POM area, the percent of people interviewed with no Supports Present has increased since the first year of the contract. At the same time, the percent with all the Supports Present for the indicators that were used to measure the concept has decreased. Among the Foundational Outcomes (Safeguards, Rights, and Health and Wellness), Safeguards is the best performer, with close to 50 percent of individuals having supports present for all (both) POM items in Year Three. Individuals are also least likely to lack supports in this area. Health and Wellness also shows a small percent of consumers with no Supports Present (11.0%). However, people having and exercising their individual Rights presents the worst results among the Foundational Outcomes. Over 35 percent of the individuals interviewed in Year Three had no supports present in the Rights area.

Recommendation: Education and training is needed to ensure individuals can identify and exercise their rights. Additional Rights training should be provided for consumers and their families, and for providers who are required to have this training, as per the Medicaid Coverage and Limitations Handbook. An effort should be made by districts to see that all providers, regardless of requirements, attend these trainings. These should be offered on a more frequent basis for both consumers and providers. Also, an education/training session focused on EEE should be initiated. This could be provided as a web-based training module or a joint training session with Delmarva and APD. Providers should learn to better utilize EEEs in their support of people in an effort to learn about and exercise the rights most important to them.

In total, 37,874 reasons were listed indicating why a support was Not Present to help persons with developmental disabilities Affiliate more with their communities and to live and/or work in integrated environments. This is considerably more than for any other POM area. We expect there to be more reasons related to supports for Affiliation, with six POM indicators, than for Attainment, Safeguards, Rights or Health and Wellness.

However, the total number of reasons cited for Affiliation is 63 percent more than for Identity, that also has six POM indicators, and 228 percent more than for Autonomy, with four indicators. Affiliation demonstrated one of the lowest percents of Support Present among all the POM areas each year. This reflects a significant need to explore interventions that will aid in the integration of the population into the community.

Recommendation: An effort should be made to explore ways to improve supports for individuals to help ensure connections to the community for them. Initial research into this could be accomplished in focus group settings at several different locations across the state. Each group should include at least one self-advocate, consumer, family member, community representatives from relevant organizations and district APD representative.

In general, many reasons cited indicating a lack of support for consumers reflect a need to increase efforts to provide supports that promote Education, Exposure and Experience. Evidence presented here suggests a need to provide varied experiences and that more experiences need to be supported. Preferences of the consumers are often unknown and/or unexplored. In addition, options are not always explored, opportunities are not acted upon, and there are often only limited attempts to support personal advocacy. Transportation issues and staffing limitations have been noted as problematic across all three years of this study period. A need for more training (i.e., education) for both organizations and consumers has increased every year since Year One (Table 5). Even if education and training are available, exposure and experience may be limited due a lack of transportation and/or available staff to offer supports in these areas. However, the importance of educating and exposing individuals to a wide variety of opportunities and also enabling people to experience them cannot be overstated. Providers must work to become familiar with the preferences that matter most to the people they serve, and strive to open doors of opportunity for them.

Recommendation: Either more opportunities for provider training and education are indicated, or more efforts should be made to require attendance at sessions that are currently available. A continued focus on a person-centered approach to providing services will help providers learn how to become more familiar with the preferences of the people they serve. Training should also include a focus on how to provide a variety of experiences to persons with developmental disabilities, to expose them to all their options, and to enable them to participate as well.

One factor not explored, but important to consider, is that policies and procedures mandated by the Federal or State government are likely to affect the supports available for the developmentally disabled. Initiation of external Prior Service Authorization in January 2003, as well as rate changes over the years, impact providers and consumers alike. While integral to the availability of supports, analysis of these factors is beyond the scope of this study.

- *Recommendation:* A study should be considered that would explore the impact of Federal and State program and policy changes on not only the supports available to consumers but also the impact on outcomes they achieve.

Collecting data on the reasons supports are Not Present is an important component of the review process. If problem areas are identified, supports provided by the state can be improved, thus positively impacting outcomes for the people served. However, not all the reasons used by the consultants are clearly defined. For example, in the Identity area, a reason cited states that “services are legally mandated”. It is not clear how this is a reason the support would not be present. For Autonomy, a reason stating “attempt to limit not aggressive enough for person” is unclear. What is the difference between “varied experiences not provided” and “more experiences need to be supported”? How does “court imposed choices” reflect a lack of support rather than a reason the Outcome was Not Met?

Recommendation: In the study presented in Year Three of the contract, Reasons Outcomes are Not Met, it was recommended that a committee be formed to review and revise as necessary the list of reasons as to why the outcome was Not Met. This committee should also review and revise the reasons supports are Not Present. The committee should consist of relevant APD and Delmarva staff, including one or two reviewers (consultants) who select these reasons on a regular basis.

New review processes for the DD HCBS Waiver population were developed and implemented in August 2004. These have been implemented, in part, as the result of declining outcome and support results over the years, as demonstrated in this study. This was seen as a reflection of the need to change organizational practices to a focus on personal outcomes rather than provider documentation/compliance. The new consultative processes implemented in Year Four are designed to help in this area. The new processes require that providers not only have documentation and systems in place to support consumers, but that practices within the organization are also positively impacting consumers. They incorporate a new focus on a consultative approach aimed at helping the providers better understand the people they serve, rather than an audit approach designed to “catch” errors in documentation.

Provision of supports is integral to successfully achieving positive outcomes for individuals. Data to help determine if the new processes are in fact impacting individual outcomes and supports will not be available until after this first implementation year is complete. However, anecdotal evidence suggests that changes have already begun in the provision of services. Because the new review processes place the responsibility of an individual’s quality of life on all providers of services for that person, providers are beginning to interact more. They appear to be starting to work more as a “team” for the individual; collaboration of all relevant supports to support cohesive planning appears to be occurring for some people. Some of the consultants (reviewers) report that providers are responding with greater interaction with other providers in order to make the services more person-centered and integrated. Consultants are also beginning to notice a change

in the providers' attitudes to a realization that they are being helped rather than critiqued—providers are becoming more open to suggestions on how to better provide supports and services to individuals. Finally, current statewide efforts to expand supported employment should also help increase the community involvement, social integration and independence among people in this population, moving them toward more positive outcomes and a better quality of life.