

Delmarva Foundation
Florida Statewide Quality Assurance Program

Personal Outcome Measure Study
Reasons Outcomes are Not Met

Florida DD HCBS Waiver

Personal Outcome Measure Study Reasons Outcomes are Not Met

Approximately four million Americans have developmental disabilities. A developmental disability is a severe, chronic disability that begins any time from birth through age 21 and is expected to last for a lifetime. Developmental disabilities may be cognitive, physical, or a combination of both. They 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.

Funding for the Developmental Disabilities program administered through the Florida Department of Children and Families has rapidly expanded over the past five years.¹ The number of consumers being fully served in FY 98-99 was 9,219. By December 31, 2001, the Department of Children & Families was fully serving 30,891, or more than three times as many Floridians with developmental disabilities as three years previously. Funding for over 24,000 of these individuals is provided through the Developmental Disabilities Home and Community Based Services (DD HCBS) Medicaid Waiver. Administered by the Florida Agency for Healthcare Administration (AHCA), the DD 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 for persons served through the DD HCBS waiver. This program, the Florida Statewide Quality Assurance Program (FSQAP), has conducted two types of review activities: 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.²

The current study is exploratory in nature and examines the Personal Outcome Measures used to determine quality of life for individuals in the Waiver program. In particular we examine the reasons that were identified either by the individual or the reviewer for the failure to meet the specific outcome being measured. By exploring the reasons and tracking them over time, we are able to identify areas needing targeted interventions.

¹ Effective July 1, 2004, the Florida Legislature created the Agency for Persons with Disabilities and the Developmental Disabilities program has moved to that agency.

² In year four of the contract, the review processes will be modified to help ensure continued improvement.

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 on Quality and Leadership (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.³ The 25 Personal Outcomes The Council now uses were identified, by the people who were interviewed, as most important in their lives.⁴ 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.⁵

Quality Assurance Reviewers with FSQAP conduct 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 POM's by The Council prior to conducting PCR's. In addition, The Council provides on going monitoring and annual reliability for all reviewers.

Sample and Methodology

The current study examines POM results from 6,680 reviews among the developmentally disabled Medicaid Waiver population in Florida complete from September 2001 through April 2004. Delmarva Foundation has collected POM data from a sample of the DD HCBS population every year for the first three years of the contract, and will continue with a fourth sample through year four. Samples were collected using random probability sampling techniques, without replacement.⁶ An over sample was used to replace individuals if they were unable to be interviewed for various reasons: if they

³ 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.

⁴ Developmental Disabilities Program Office E-Bulletin. Volume 1 No. 8. July 19, 2002.

⁵ The Council on Quality and Leadership in Supports for People with Disabilities, Research Report #2, Construct Validity and Inter-rater Reliability, April 1997.

⁶ 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.

declined to be interviewed, if they were no longer eligible, if the reviewer was unable to locate them or they were deceased.⁷ The original samples were as follows:

- Year 1: July 2001 – June 2002 n = 2,000
- Year 2: July 2002 – June 2003 n = 3,364
- Year 3: July 2003 – June 2004 n = 2,616

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 (95 percent and 76 percent response rate in Years One and Two respectively). In addition, Year Three data contain reviews that were completed, scored and stored in the database as of June 14, 2004. Approximately 85 percent of the Year three sample is included. Therefore, results included in this study are preliminary only and include the following completed reviews:

	# Completed	% of sample
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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 each POM as Present or Not Present. When an outcome is Not Present, the reviewer then indicates the reason the outcome was Not Present. For this study, we have used the term **Met** to indicate Present and **Not Met** to indicate Not Present.

The Personal Outcome Measures interview has been used by the Department of Children and Families to measure outcomes for persons with developmental disabilities since 1998. To provide a method for aggregating and analyzing reasons for outcomes not being met, staff from the Developmental Services program identified a series of pre-populated reasons for interviewers to use when the Personal Outcomes were Not Met for the individual. 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 and analyzed the percent of times they have been utilized over the years. The reasons logically sorted into several broad categorical definitions:⁸

- A lack of *education* of or awareness of rights, options, services, procedures or other relevant issues;
- An inadequate or lack of (*no*) *support* offered by provider(s);

⁷ See the Florida Statewide Quality Assurance Program Annual Reports, 2001-2002 and 2002-2003 for details on the sample.

⁸ See Appendix A for a detailed list.

- An indication that the individual's *choice* is unknown by the provider, is limited or denied, or is determined by someone else;
- An indication that *access* and/or availability of services is limited or denied (legally, organizationally or otherwise);
- If the person or reviewer believes the individual's *rights* are being violated or limited;
- If a person appears *alienated* by expressing feelings of loneliness, isolation, a lack of friendships or a lack of respect;
- or, an indication that the individual is *dissatisfied* with services, supports, or life's situation in general.

When comparing these categories it is important to understand that comparisons can be meaningful when looking *within* POM areas. However, because the reasons vary somewhat *between* POM areas, comparisons across the areas should be minimized. For example, comparing the percent of times a lack of *education* was cited as a reason when any Personal Outcome within the area of Identity was Not Met over the three years is meaningful. However, it is not appropriate to compare this to the percent of times a lack of *education* was used as a reason when any Personal Outcome within the area of Autonomy was Not Met.

In this study, we first identify the proportion of times, within each area, none and all of the Personal Outcomes used to measure that area are scored as Met. We then explore the reasons that were given either by the individual or the reviewer for the failure to meet the criteria for the outcome. By exploring the reasons and tracking them over time, we are able to identify areas needing targeted interventions.

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 Outcomes 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.

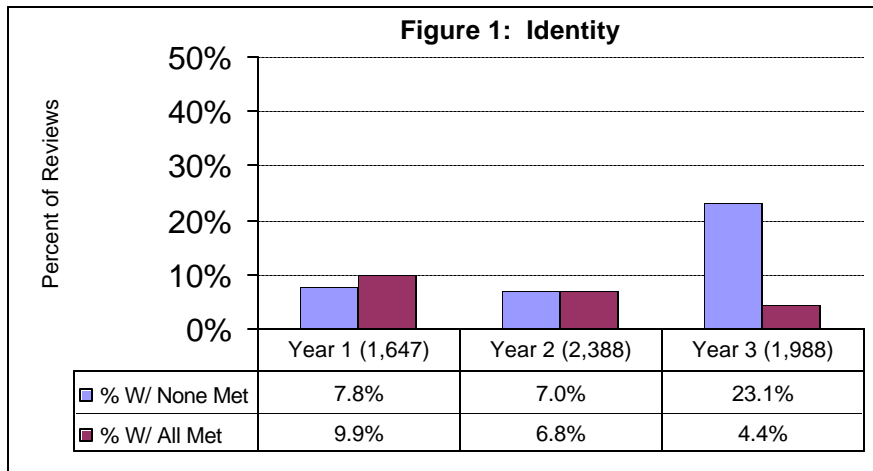


Figure 1 shows the percent of times none of the six items was met and also the percent of times all of the six items were met over the first three years of the contract for the developmentally disabled people in the Medicaid Waiver program. There is a slow and steady decline in the percent of people who have all six of the items met, only 4.4 percent of the reviews so far in Year Three, a 56 percent decrease over the time period. At the same time, the percent of people with none of the items met has jumped considerably since the first two years these items were measured, from seven percent in Year Two to over 23 percent in the most recent time period, representing almost a 200 percent increase.⁹

⁹ See Appendix B for more detailed information on each area and the number and percent of reviews within each POM.

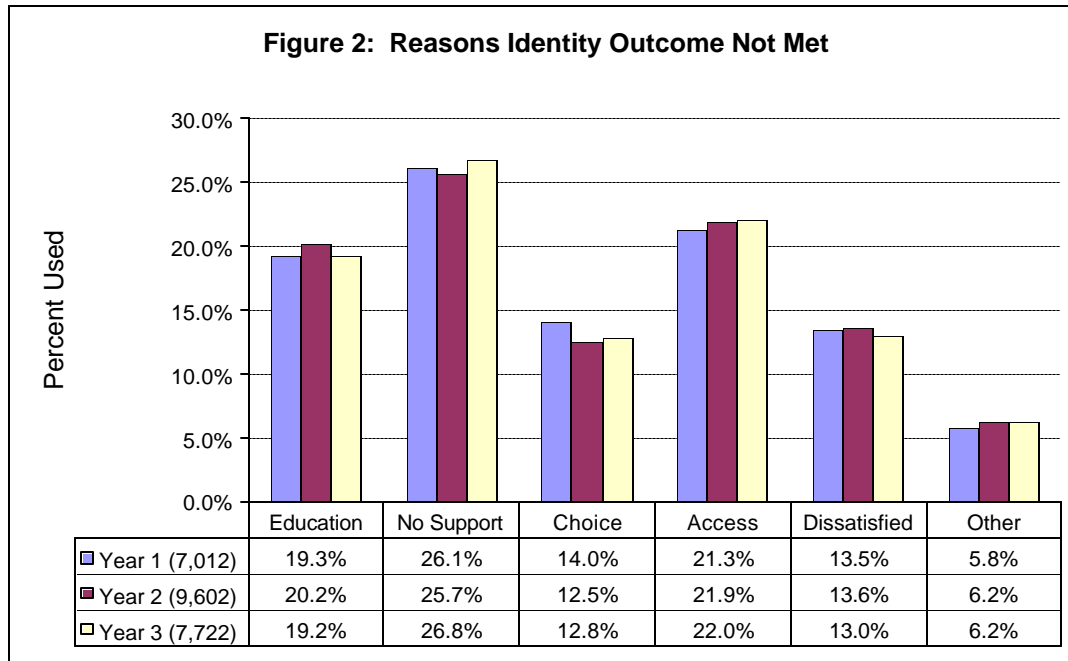


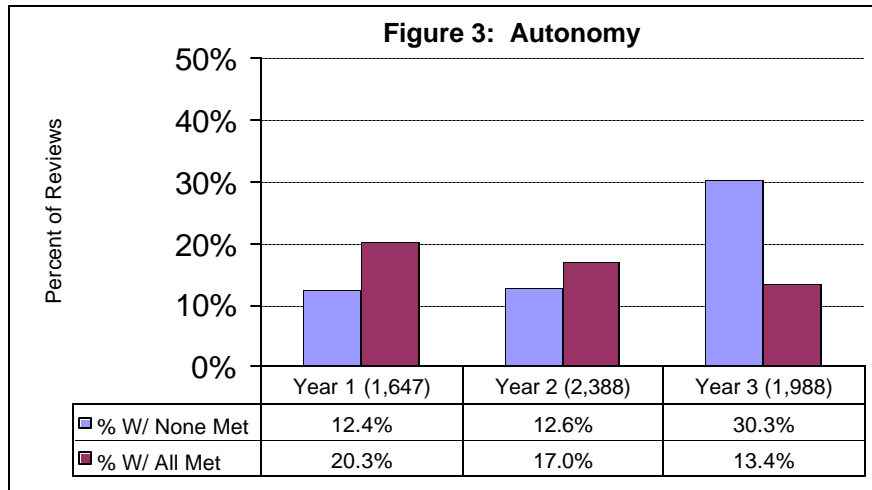
Figure 2 displays the categories of reasons that were given when Identity was not met. The proportions for each category have remained fairly consistent over the years. The data indicate that a lack of or *no support* is most frequently cited as the reason this Personal Outcome is not met. It was noted most often that the person is not given the opportunity to experience different options, that goals or needs are identified but not worked on, or that the person’s expectations are simply unknown. Limited or no options create a problem with *access* to services about 22 percent of the time when Identity was an outcome that was not met. Only a small percent of the access issues were related to legal limitations. *Education* has been consistently cited about 20 percent of the time. In general, people either need more explanation about their options, or they are unaware of the options available to them. Issues dealing with *choice* and *dissatisfaction* with services and/or life in general are cited less often. In the reviews where *choice* was defined as a problem, people indicated that others made their choices for them. When people are *dissatisfied*, they are most often displeased with services from the provider, and also displeased with the inflexibility of supports.

Autonomy

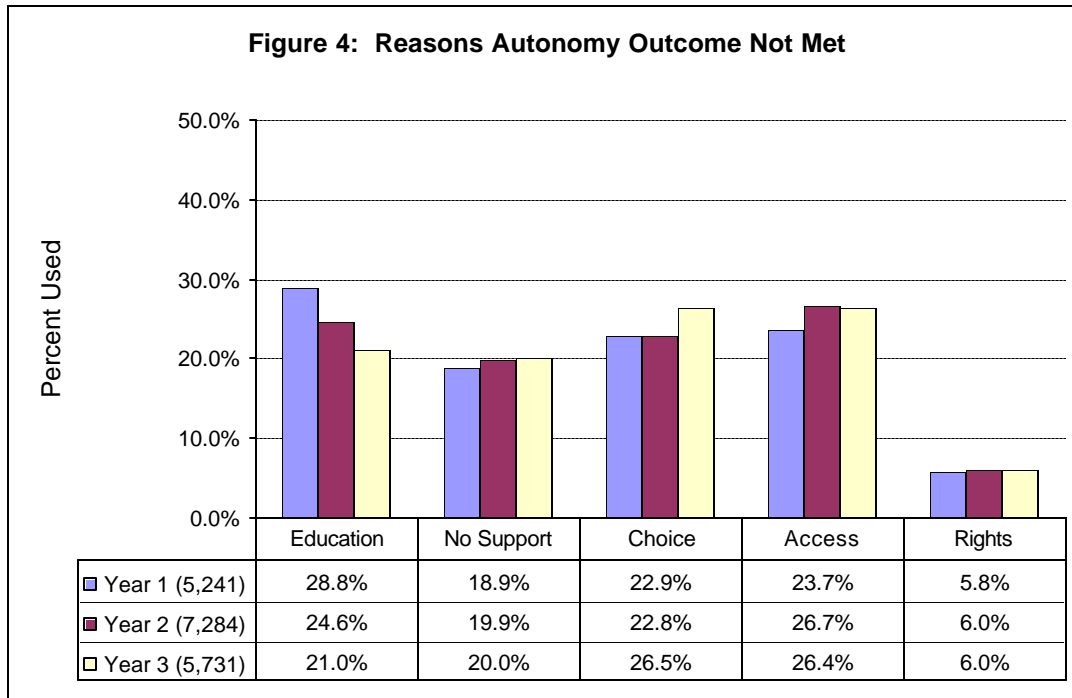
To live autonomously is to have authority and control over our lives. To have autonomy is to have the power and the authority to determine and enforce the rules and policies that govern us and to feel we have some control over our physical environment, daily schedule, our needs for privacy, and control 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 environment.



Data in Figure 3 demonstrate a similar pattern as in Figure 1. The percent of reviews with none of the four Personal Outcomes met has increased, a sizeable increase from 12.4 percent to 30.3 percent over the time period, a 145 percent increase. Again, results indicate a steady decline in the percent of individuals with all four of the outcomes met, a 34 percent decrease. A word of caution must be noted. Comparisons across the different POM areas are not always appropriate as the results may be based on a different number of Personal Outcomes. The percent with “all outcomes” met might be easier to attain when there are only two outcomes to measure (Safeguards) as opposed to six (Identity). Similarly, when six outcomes are used to measure a particular POM area, it is more difficult to have “all of them met” than if only two or three are used. For the data presented here, comparisons within each POM area across time are more appropriate.



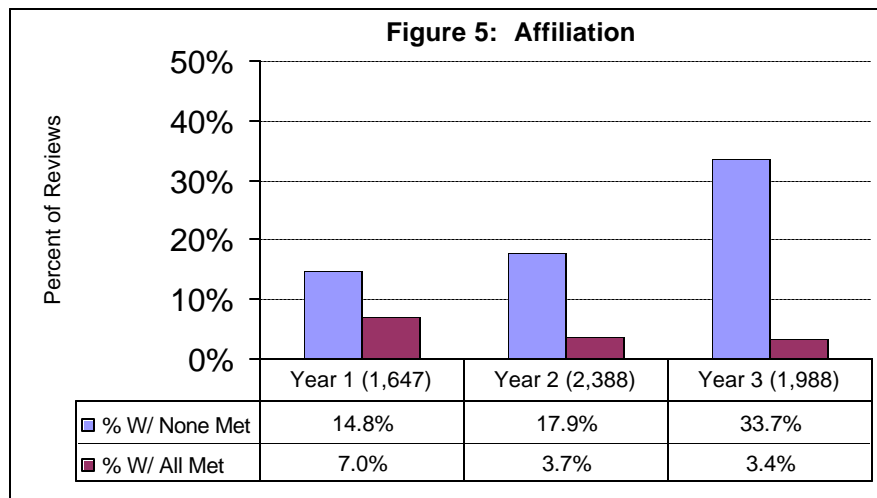
A lack of *education* of or awareness of rights, options, services, procedures or other relevant issues was cited most often among people with Autonomy not met, but has decreased consistently across the three years from close to 29 percent to 21 percent thus far in Year Three. Knowledge of where records are kept and how to access them is most often an issue. Given the data presented here, however, this is becoming less of an issue than in Year One. The proportion of reviews indicative of *access* and availability of services as an issue has remained constant over the past two years. The greatest proportion of reviews note that rules often limit access, but a need for more adaptive equipment is also important. A sense of having little or no *choice* in life, for people with Autonomy scored as Not Met, has increased somewhat for the people reviewed thus far in Year Three, from 22.9 percent to 26.5 percent. When choice was noted as an issue, having limited or no choice at all in the person’s daily routine was often cited. People in this program cited, as a reason Autonomy was not met, a lack of choice in many other daily activities. Most adults would take it for granted that some personal choice would be involved in these activities: pre-set meal times, bathing times, leisure time and bed time. Further analysis is needed to determine the number of children v adults citing these as an area of concern.

The proportion of reviews indicating a lack of *support* as a reason Autonomy was not met has remained at around 20 percent over the three time periods analyzed. Many reviewers note that training is needed to assist individuals in finding their interests. Another area of concern is that no effort is made to increase the person’s awareness of interests or options. Reasons centering on a person’s *rights* are not often an issue within the POM Autonomy area.

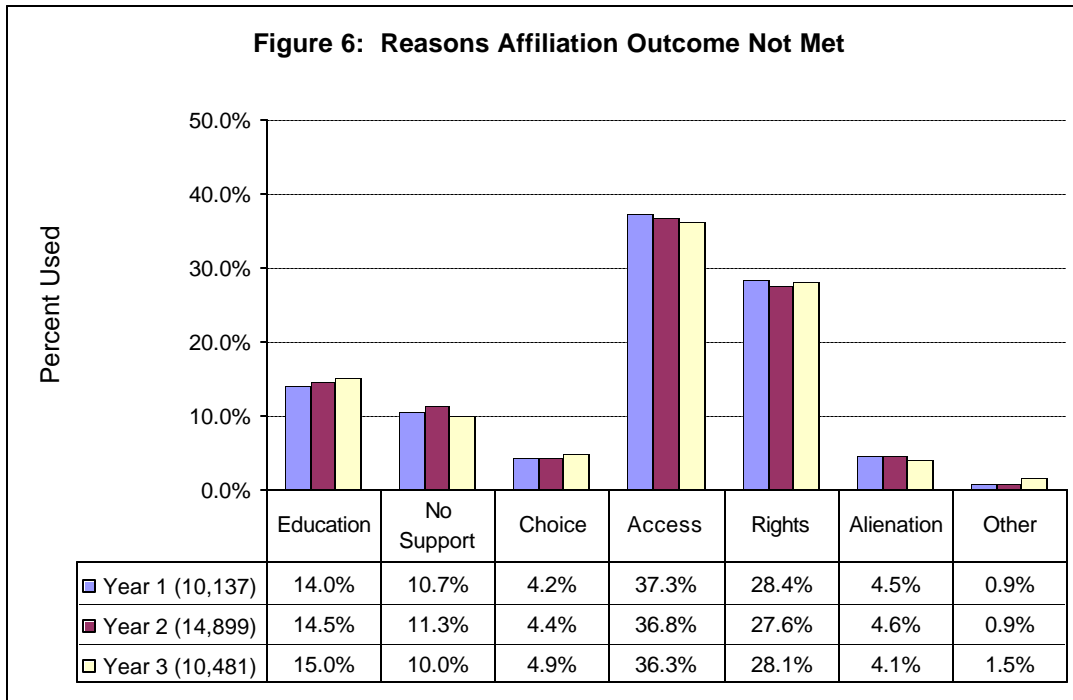
Affiliation

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.



The pattern exhibited by the data in Figure 5 for Affiliation is similar to that shown above for Identity and Autonomy: the proportion of reviews with none of the outcomes met has increased by 128 percent, while the proportion with all of the outcomes met has decreased by nearly 52 percent.



Reasons pertaining to Affiliation are cited more frequently than for any other POM area, with 14,899 noted in Year Two alone. This reflects a significant need to explore interventions that will aid in the integration of the population into the community. On average, the broad categories have maintained a fairly constant proportion, relative to each other, across the three-year period. Issues involving *access* to services and the *rights* of individuals are clearly most often cited as the reason Affiliation is Not Met. A large proportion of the *access* reasons given for a lack of Affiliation have to do with wanting more friends and also wanting more activity with current friends. Another important reason indicates the person wants to “be in” some social role, such as a club member, church member, spouse or volunteer. Incorporating a variety of social roles into our lives has been considered a major step in the development of the self by such noted sociologists as George Herbert Meade.¹⁰ It is a basic right for citizens to be integrated into the community where they can better learn about and take on a variety of social roles. Among the reasons that center around *rights*, the reviewers often stated the person wanted to be in the community more or in a different way. It was noted they often attend segregated day services, attend segregated social programs, use segregated transportation, or live, work, and/or play in a segregated setting. Learning and moving into a variety of social roles is much more difficult when constantly excluded from the mainstream population.

On average, the greatest percentage of the reasons given for a lack of *education* or knowledge about Affiliation options suggest people are unaware of the variety of social

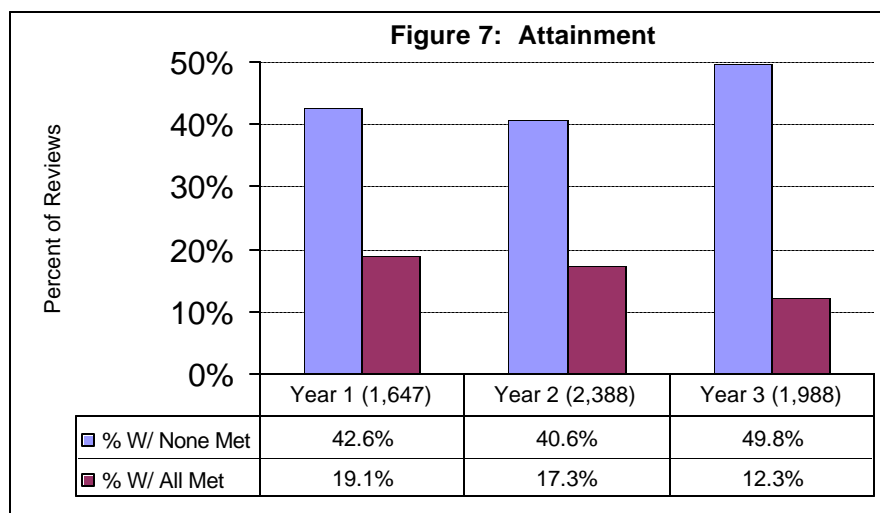
¹⁰ Giddens, Anthony, Mitchell Duneier & Richard Pl Appelbaum. Introduction to Sociology. WW Norton and Co. New York. 2003. pg. 92-93.

roles that may be available to them. This is a reasonable observation as we have seen that many are living in segregated environments. When *supports* were lacking in Affiliation, reviewers indicated the providers had low achievement expectations for the individuals they serve. Another important issue often cited is that adult consumers are not supported in an adult role. People indicate that *choices* are often made for them. Reviewers have also noted several reasons that might give people a feeling of *alienation*. Most important in this area is that the person does not feel respected and has no feelings of mutual friendships. In short, some people are indicating that they are lonely.

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.¹¹ Attainment is measured with only two Personal Outcomes:

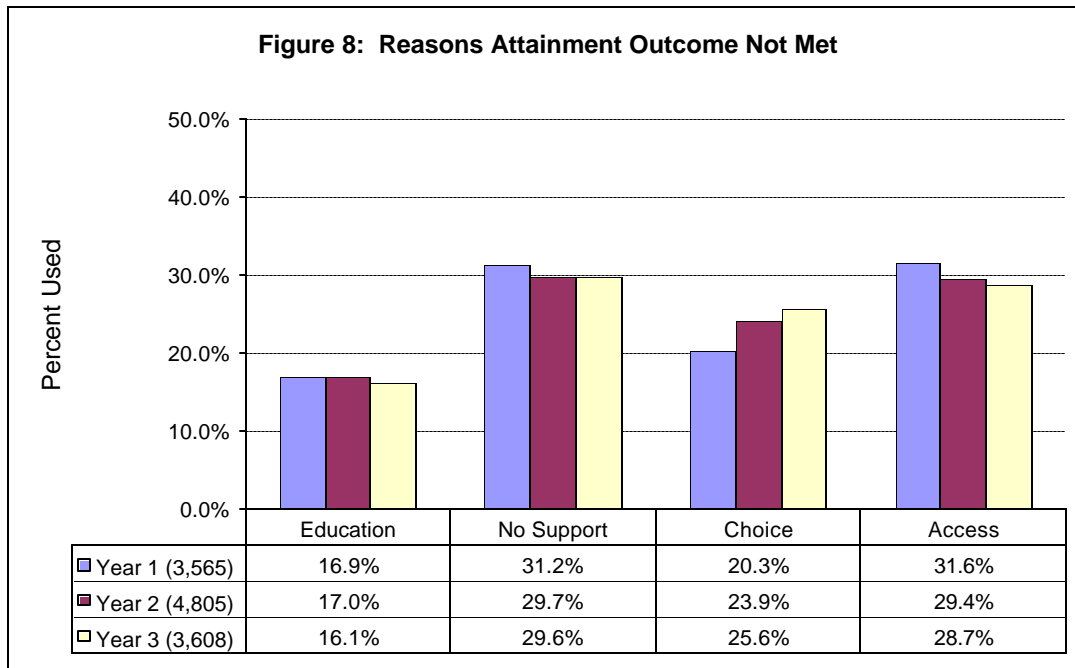
- People choose services;
- People realize personal goals.



The percent of reviews for which neither of the Personal Outcomes was met declined slightly from Year One to Year Two, but has increased thus far in Year Three. The

¹¹ Personal Outcome Measures 2000 Edition, The Council on Quality and Leadership. Go to <http://www.ncor.org/frame3.htm> for more information.

percent of reviews for which both items were met has steadily declined over the same time period, as with the other POM areas discussed.



The broad categories of *no support* and *access* have been most often cited as a reason Attainment was not met. A lack of *support* is most often expressed as the fact that the individual has recently had no significant achievement. This may be an indication that providers are not helping the individuals to set new goals for themselves and then strive to accomplish them. The use of reasons within the category of no support has dropped off somewhat since the first Year. *Access* reasons that the individual had not met the Attainment outcome have also slowly declined each year. The reason most often cited as a lack of access is that service choices are limited or not available. However, the second most often cited reason is that there are only a limited number of providers to help people choose their services or achieve goals.

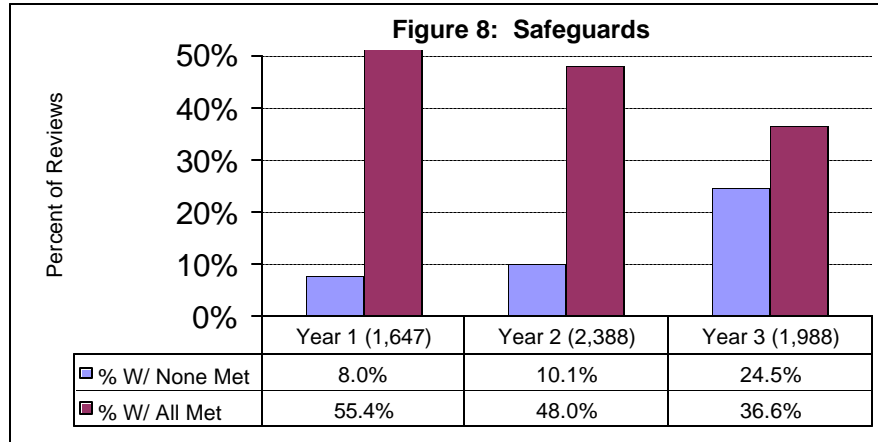
Reasons associated with *choice* have increased since Year One, from 20.3 percent to 25.6 percent. Reviewers most often note that choices are made by the family or by others without the individual’s input. A lack of *education* or knowledge is least often defined as a reason Attainment was not met. On average, close to 90 percent of the reasons indicate that awareness needs to increase.

Safeguards

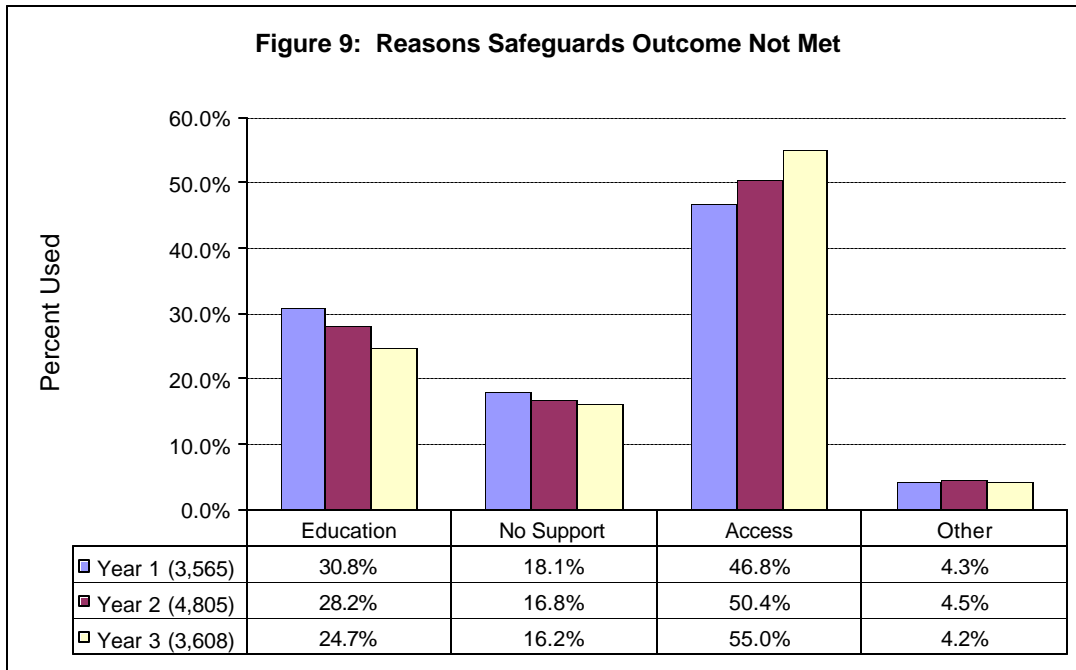
The remaining three POM areas are defined by The Council as Foundational Outcomes and include Safeguards, Rights and Health. As the term implies, Safeguards help us feel secure and safe. Being near close family members and friends, knowing they are there to

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. Safeguards is measured with two Personal Outcomes (two of the seven Foundational Outcomes):

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



As has been demonstrated for almost all of the POM areas, the percent of reviews with neither of the Personal Outcomes met has increased over the years, from eight percent in Year One to 24.5 percent thus far in Year Three, representing just over a 200 percent increase. The percent of reviews with both Personal Outcomes met has dropped by close to 40 percent during the same time period. Safeguards demonstrate the greatest gap between “none met” and “all met”, with a much larger percentage of all the outcomes met. This is a unique result, even among the other POM areas that have only two outcomes (Attainment, Safeguards, and Rights).

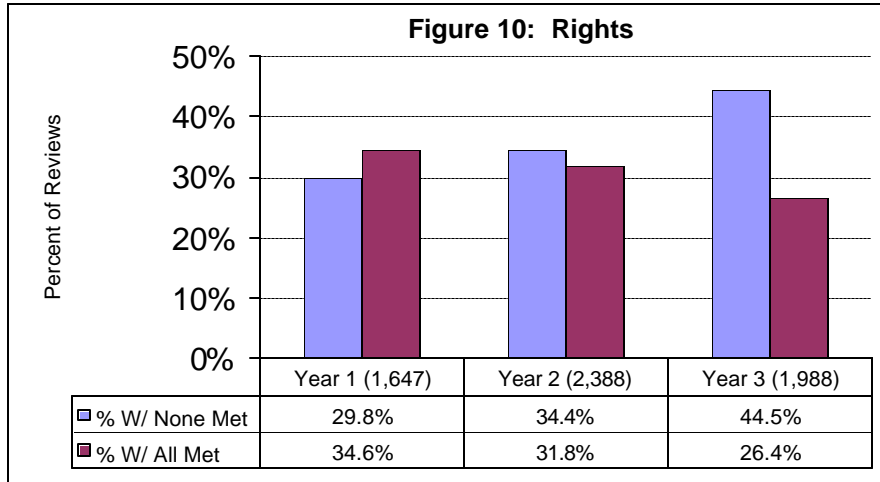


Issues revolving around *access* and availability are most often cited as reasons Safeguards are not met, and this percentage has increased from 46.8 percent in Year One to 55 percent up through June 14, 2004, in Year Three. At the same time, reasons given that are centered on a lack of *education* or a lack of *support* have declined. *Access* to families appears to be limited as reviewers have indicated that people want to see their family, siblings and parents more often. People are therefore not as likely to have feelings of being protected or of security and safety obtained when surrounded by close family members, as discussed above. In the category of *education* it is most often noted that people have little safety awareness, and are also unaware of fire safety procedures. According to the reviewers, increased *supports* are needed for specific daily needs, such as to fix smoke detectors, or to help make home, work and social settings safer places to be.

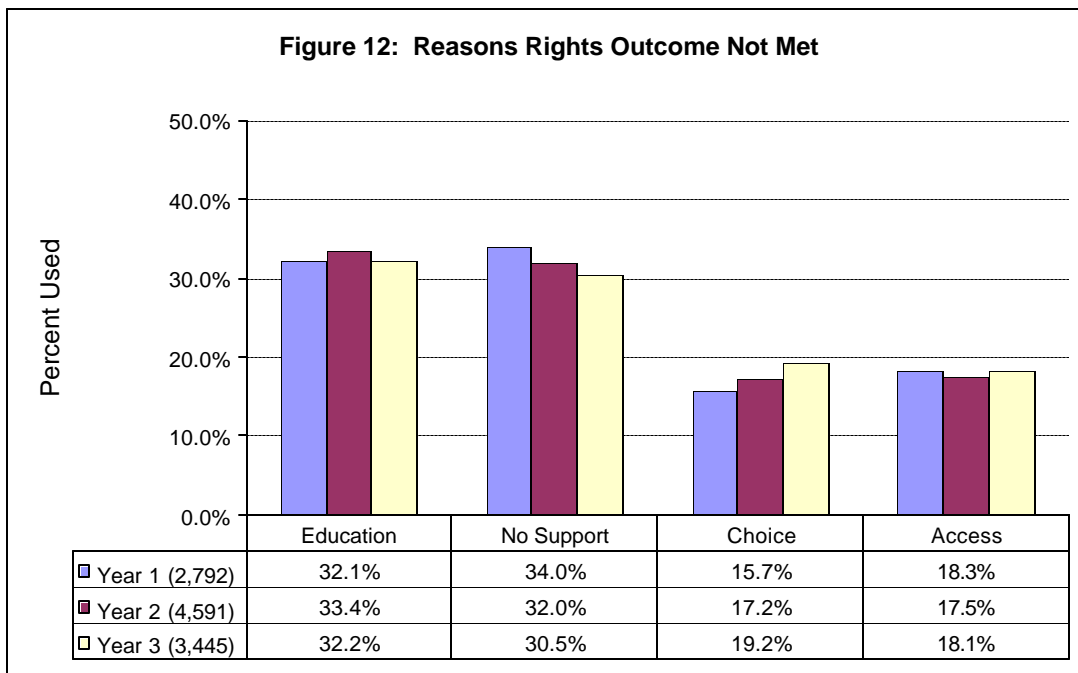
Rights

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 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 pattern of an increasing percent of reviews with no outcomes met and a decreasing number of reviews with all outcomes met is demonstrated again for individual Rights. The gap between the two is greatest for Year Three data, up through June 14, 2004. Of all the Foundational Outcome areas, Rights has the greatest proportion of reviews with no outcomes met.



Reasons defined as a lack of education and a lack of support are most often cited as indicative of Rights not being met. The majority of reviews inform us that people do not understand all of their rights. *Education* is therefore needed to enhance their quality of

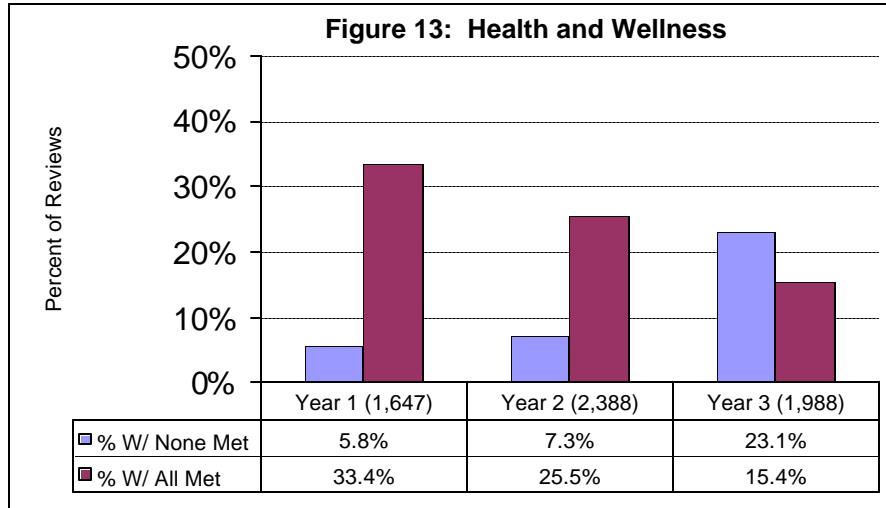
life by identifying rights, removing any barriers to those rights, and helping people exercise their identified rights. Reviewers inform us that *supports* are needed to help people exercise the rights they have identified as important to them, cited proportionately most often when Rights are not met. In addition, it is frequently noted that there is a lack of the person's consent/involvement in identifying and developing a plan to increase the person's ability to exercise rights. Finally, people are often not supported to vote, a basic American right for all adult citizens. Barriers to the right to vote are barriers to a voice developmentally disabled people can use to help effect policy change and promote greater support for their specific needs.

Items concerning *choice*, while not cited as frequently as *support* or *access*, have increased steadily over the past three years. Most dominant is that although people have not been adjudicated incompetent, others are making decisions for them. Also important is that due process is not always provided when restrictions are imposed on the individual. The top *access* reason indicating that Rights are not met is that people are not allowed to handle money. Further analysis may find this correlates with the Affiliation item indicating that adult consumers are not supported in an adult role. In some instances communication and privacy has been restricted.

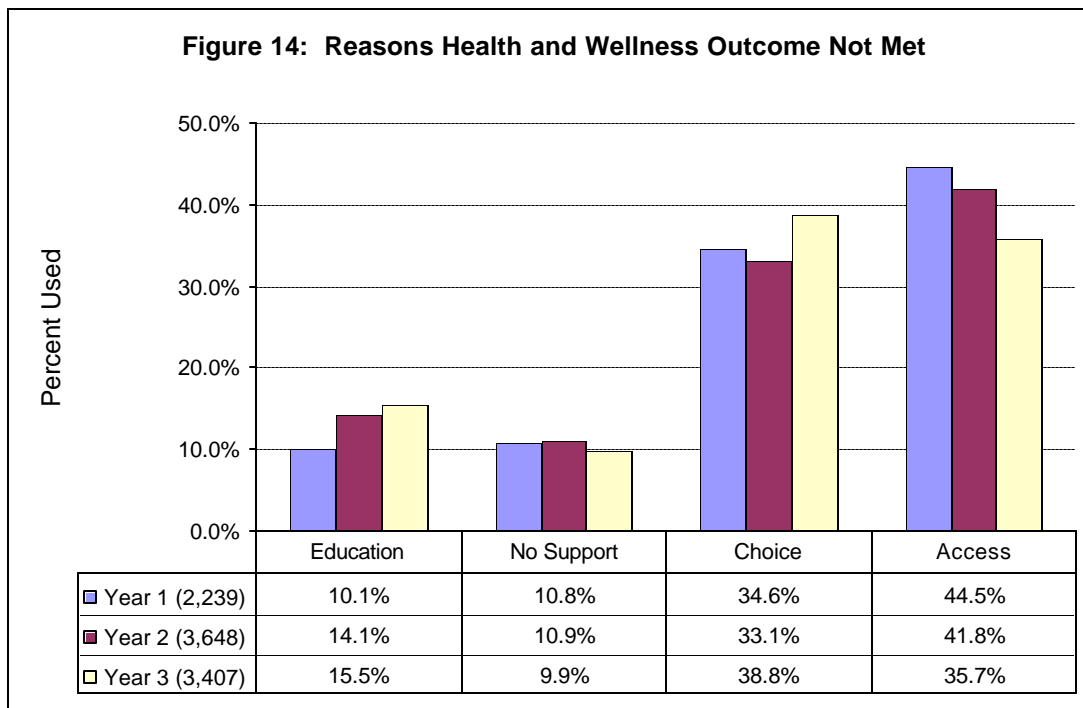
Health and Wellness

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.



Health and Wellness, as with Safeguards, demonstrates a large gap between the percent of reviews with none of the outcomes met and the percent with all of the outcomes met, and in the first two years a large proportion (33.4% and 25.5%) has all of the outcomes met. Unfortunately this switches when looking at the data thus far in Year Three. The percent of reviews with none of these very important outcomes met has increased by 300 percent since Year One, from 5.8 percent to over 23 percent. A subsequent drop of almost 54 percent is evident for reviews with all of the outcomes met, over the same time period.



Choice and *access* are the biggest areas of concern among people who did not have the Health and Wellness outcome met. Reasons defined as associated with *choice* have increased in frequency and those associated with *access* have been cited less often since Year One. Reasons most frequently cited and defined as indicating barriers to care, *access* problems, are that people did not have appropriate visits to various doctors and/or specialists such as a dentist, a gynecologist or a primary care physician. Also identified as a barrier to care are inadequate economic resources and an inadequate insurance program. The percentage of reasons given that indicate access as a problem has dropped from 44.5 percent to 35.7 percent since the first contract year. Reasons associated with *choice* inform us that when Health and Wellness is Not Met, changes are not defined by the person. In addition, any requirements for continuity and security are not defined by the person.

One important reason is associated with a lack of *education*: the best possible health is not identified. Finding a plan that best suits the individual's health needs is not possible if the provider is not aware of the best health that is possible for the individual. Unfortunately, this reason has been used proportionately more often over the years of the study period. With experience, reviewers might be more aware that providers do not know what the best possible health is for the individuals they serve, consequently using this reason more often. However, this could reflect several different scenarios and is an area further study might help clarify. Finally, the most prominent reason cited that is associated with a lack of *support* is that a person is distressed over past abuse. Supports need to be in place to address this delicate issue.

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. Results are generally reported for each POM and little work has been done to explore the reasons for the failure to meet the outcome. In this report we have explored the broader concepts that the POMs define and looked more closely at the reasons they have not been met.

Within every POM area, the percent of reviews with none of the Personal Outcomes Met has increased since the first year of the contract. At the same time, the percent of reviews with all the Personal Outcomes met 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 37 percent of reviews having all (both) Personal Outcomes Met. Health and Wellness shows the smallest percent of reviews with no outcomes met (23.1%). People having and exercising their individual Rights presents the worst results with a majority of reviews indicating that people do not understand all of their rights. Nearly 45 percent of the reviews had no outcome Met in the Rights area.

Recommendation: Increased education is needed to ensure individuals can identify and exercise their rights.

The defined categories for reasons the Outcome was Not Met vary by intensity across the POM areas. However, issues surrounding *access* are especially prominent in the areas of Health and Wellness, Affiliation and Safeguards. Reviewers have noted repeatedly that people have limited or no access to friends, to family, to different social roles in the community, and to some types of medical care. Reasons most frequently cited as indicating barriers to care are a lack of appropriate visits to specialists. Within every POM area where some number of reasons are defined as associated with *choice*, the proportion for *choice* has increased since Year One, with the exception of Identity. This is an important finding due to the nature of the entire DD process with a focus on Personal Outcomes and a need to respond to the choice of the individual. Choices are limited in daily routines and are often made by family members or by others, or the provider is simply unaware of what the individual's choice might be. A lack of support is most often expressed as the reason when an individual has no significant achievements. This may be an indication that providers are not assisting individuals to set new goals for themselves.

Recommendation: Increased education is needed to help individuals identify and exercise their right to access health care and to know they have choices in their lives. Providers may also benefit from education/training to learn how to better help individuals in these areas.

A common theme across many of the POM areas appears to be a need to approach people in the program as adults, giving them adult responsibilities. Often cited as an issue when a particular outcome was Not Met are reasons such as not being supported in an adult role, not being allowed to handle money, having barriers to being able to vote, having choices made for them, and having pre-determined bed, meal and bath times.

Recommendation: Further analysis is recommended to determine the number of children v adults citing this as an area of concern.

Throughout the analysis, the meaning for the "reasons given" was not always clear. For example, does "Unaware of strangers" mean there is some danger present or that the individual cannot distinguish between friends and strangers and needs more support with this? The meaning of "Not enough for person", "Type not enough for person" or "Frequency not enough for person" is not clear. However, a majority of the reasons cited appear to be a useful method to help guide future training for providers. It is helpful to know if the Personal Outcome "People live in integrated environments" is Not Met. However, by quantifying different areas of integration (e.g., transportation, work, home) it is possible to identify problem areas more specifically. This information can then be addressed more clearly in provider training sessions. Results would indicate a significant need to explore interventions that will aid in the integration of the population into the community.

Recommendation: Reviewers now have three years of experience with the “reasons” as originally designed. We recommend a small “committee” be formed, comprised of DCF staff, reviewers and a data analyst to re-visit the “drop down” menus and possibly refine the reasons, based on experience gained over the years.

In addition to the reasons given when an Outcome was Not Met, reviewers also record a reason given when a Support was Not Present. The reasons a Support was Not Present were developed as discussed previously in regards to the reasons an Outcome was Not Met. Supports given by the provider are essential to positive outcomes for individuals. Therefore, a better understanding of why these are lacking is an important component of the overall process and can be integrated into provider training.

Recommendation: Because Supports are an integral part of the DD HCBS system of services, we recommend an analysis similar to the one presented here be performed on the reasons Supports are Not Present. The committee mentioned above should review the results of this study and revise the reasons as needed. Results from such a study can be used to impact/change current organizational practices.

The review process for the DD HCBS Waiver population is about to begin a new year with new review processes that focus on results for individuals served and quality improvement. This is a reflection of the need to change organizational practices to a focus on personal outcomes rather than provider documentation. This new process has been implemented, in part, because of the declining Outcome results over the years, as demonstrated in this study. As part of that process, we recommend that increased training opportunities for protecting rights, health issues and choice should be considered. Targeted training for providers to reduce limitations and restrictions in the areas noted in this study, and other similar areas, will help move people to more positive outcomes and a better quality of life.