

REPORT TO THE TWENTY-THIRD LEGISLATURE
STATE OF HAWAII
2006

PURSUANT TO SENATE CONCURRENT RESOLUTION NO. 151, S.D. 1,
1999 LEGISLATIVE SESSION, REQUESTING THE
DEPARTMENT OF HEALTH TO SUBMIT TO THE LEGISLATURE
A REPORT ON THE STATEWIDE COMPREHENSIVE STRATEGIC PLAN
FOR SERVICES AND SUPPORTS FOR INDIVIDUALS WITH
DEVELOPMENTAL DISABILITIES OR MENTAL RETARDATION

PREPARED BY:

STATE OF HAWAII
DEPARTMENT OF HEALTH
OCTOBER 2005

EXECUTIVE SUMMARY

In accordance with Senate Concurrent Resolution No. 151, S.D. 1, of the 1999 Legislative Session, the Department of Health (Department), through its Developmental Disabilities Division (DDD), submits this report to the 2006 Legislature regarding the implementation of the current five-year statewide, comprehensive strategic plan (comprehensive strategic plan) for services and supports for individuals with developmental disabilities or mental retardation. This year is the final year of the current five-year comprehensive strategic plan that was previously devised by the Department and DDD.

This comprehensive strategic plan included:

- (1) An assessment of the current developmental disabilities service system;
- (2) A vision for and a philosophy of the future of developmental disabilities services in Hawaii, and
- (3) Outcome-based measures that include outcome statements, target areas, performance targets, milestones, and strategies to address the:
 - a) Provision of long-term support services;
 - b) Elimination of waitlists for services;
 - c) Self-determination of individuals with developmental disabilities and/or mental retardation, and
 - d) The maximization of finances, state and federal moneys, and other resources.

This comprehensive strategic plan was modified in accordance with: (1) the Department's and DDD's obligations under the settlement agreements reached in 2000 in the case of Makin v. State of Hawaii, Civil No. 98-00997 (U.S. District Court) and in 2005 in the case of Hawaii Disability Rights Center v. State of Hawaii, Civil No. 03-00524 (U.S. District Court); and (2) the Department's and DDD's obligations following the United States Supreme Court's decision in Olmstead v. L.C., 527 U.S. 581 (1999).

This comprehensive strategic plan was structured so that the Department and DDD would fully implement chapter 333F, HRS, by supporting the efforts of individuals with developmental disabilities and/or mental retardation (DD/MR) live "their desired lives" in the community and by respecting its client's right to self-determination. To this end, the Department and DDD have utilized, and continue utilizing, Title XIX Home and Community Based Services Medicaid waiver, which is consistent with its statutory mandate that the Department and DDD maximize its funds for community services.

The Department and DDD are developing a new five-year comprehensive strategic plan. This plan will further refine DDD's service delivery system in support of individuals with DD/MR to address challenges in housing, employment, empowerment, and quality assurance. In addition, this new comprehensive strategic plan will include a statewide crisis response network for individuals with DD/MR and co-occurring mental illness and/or severe challenging behaviors. The Department and DDD anticipate that this network will be implemented in January 2006 and administered during the new five-year comprehensive strategic plan. This network is intended to address critically needed safety net functions to support continued community living.

REPORT TO THE LEGISLATURE

IN COMPLIANCE WITH SENATE CONCURRENT RESOLUTION NO. 151, S.D. 1

Senate Concurrent Resolution 151, S.D. 1, 1999, requested that the Department of Health (Department) develop and implement a five-year statewide, comprehensive strategic plan for services and supports for individuals with developmental disabilities or mental retardation prior to the regular session of 2001. Senate Concurrent Resolution 151, S.D. 1, 1999, also requested that the Director of Health submit to the Legislature a report on the plan and its implementation, including recommendations for statutory amendments, if any.

INTRODUCTION

Under HRS § 333F-2, the Department “shall develop, lead, administer, coordinate, monitor, evaluate, and set direction for a comprehensive system of supports and services for persons with developmental disabilities or mental retardation ...” and “shall administer or may provide available supports and services based on a client-centered plan, which resulted from client choices and decision-making that allowed and respected client self-determination.” Following the closure of the State’s large ICF/MR (intermediate care facility for the mentally retarded), Waimano Training School and Hospital in 1999, all programs and services for individuals with DD/MR were directed to be provided in the community.

BACKGROUND

In 1998, the State of Hawaii became the first state in the nation to enact a law mandating self-determination for individuals with DD/MR. Under Act 133, Session Laws of Hawaii 1998, (Act 133), the Department and its Developmental Disabilities Division (DDD) were required to assist individuals with DD/MR to develop, with the help of family and friends as necessary, an individualized service plan. This individualized service plan, or ISP, was to be “a written description of what was important to the person, how any issue of health or safety shall be addressed, and what needs to happen to support the person in the person’s desired life” HRS § 333F-1. Act 133 mandated that the Department and DDD “identify the amount of dollars available to the individual to effectuate the individualized service plan” and “allow the individual to direct the expenditure of the identified funds.” HRS § 333F-7.

The Department and DDD were thus challenged to develop and implement a service and support system for individuals with DD/MR that was reflective of its statutory mandates. The five-year statewide comprehensive strategic plan addressed the outcomes and strategies necessary for the provision of long-term support services that: (1) were predicated on self-determination principles; and (2) maximized available state funds for Title XIX programs or other governmental or private finance participation programs.

In developing the comprehensive strategic plan, the Department and DDD solicited input from individuals with developmental disabilities or mental retardation, parents or family members of individuals with developmental disabilities or mental retardation, private and public agencies, the State Planning Council on Developmental Disabilities, the University of Hawaii Center on Disability Studies, and the Hawaii Disabilities Rights Center (formerly the Protection and Advocacy Agency of Hawaii), the Department of Human Services, and the collective bargaining

representatives of its employees. Input obtained from these stakeholders was incorporated in the development and implementation of the comprehensive strategic plan.

In 2000, the Department and DDD reached a settlement agreement in the matter of Makin v. State of Hawaii, Civil No. 98-00997 (U.S. District Court). This settlement agreement required the State of Hawaii provide appropriate and needed home and community services to at least 700 qualified individuals with DD/MR from the waitlist for Medicaid funded home and community based services by June 30, 2003. In addition, the Department and DDD modified its comprehensive strategic plan following the United States Supreme Court's decision in Olmstead v. L.C., 527 U.S. 581 (1999).

Following resolution of these two cases, the Department and DDD modified the comprehensive strategic plan to address the issue of applicants seeking services from DDD being "waitlisted" for services. The Department and DDD also identified desired outcomes in the comprehensive strategic plan to address moving the waitlist at a reasonable pace after June 30, 2003.

YEAR 2005 UPDATE

Since 2000, the Department and DDD have successively built upon initial efforts to create an environment where individuals with DD/MR can successfully lead self-determined lives. The outcomes set by the Department and DDD were lofty, albeit necessary to provoke necessary changes. The challenges that the Department and DDD faced (and still face) to change the system from a paternalistic one to one which respects choices and decisions made by persons with DD/MR are many. Such a system must delicately balance health and safety issues with the desires and decisions made by persons with DD/MR to live their desired lives. The "operationalizing" of self-determination is clearly a journey, a process whereupon all the stakeholders in the system must change. That change is incremental, evolutionary, and ongoing.

The Department's and DDD's outcomes for 2005 focused on the following:

- 1) Maximization of state dollars for Title XIX programs or other governmental or private finance participation programs,
 - 2) Provision of long term support services following the principles of self determination, and
 - 3) Quality of services and supports.
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- 1) MAXIMIZATION OF STATE DOLLARS FOR TITLE XIX PROGRAMS OR OTHER GOVERNMENTAL FINANCE PARTICIPATION PROGRAMS

The Department's and DDD's principal funding source for services and supports for individuals with DD/MR has been its Home and Community Based Services—DD/MR (Home and Community Based Services—DD/MR) Medicaid waiver program, a federal finance participation program.

The Home and Community Based Services—DD/MR waiver includes an array of services and supports for individuals in the community, including:

- Adult day health

- Personal assistance
- Habilitation
- Habilitation-supported employment
- Respite services
- Skilled nursing
- Specialized services
- Specialized environmental accessibility adaptations, and
- Non-medical transportation.

In 2004, the State received approval from the Centers for Medicare and Medicaid Services (CMS) to provide Consumer Directed Personal Assistance (CD-PA) which allows the individual with DD/MR, or their designated representative, to hire, train, supervise, and fire their personal assistants.

Since 1983 when the Home and Community Based Services—DD/MR waiver was used to facilitate the de-institutionalization of Waimano Training School and Hospital, the Home and Community Based Services—DD/MR waiver has increasingly been the funding mechanism of choice for DDD services and supports. Table 1 shows: (1) the number of individuals served the fiscal year ending 2001 to the fiscal year ending 2005; (2) the State’s share of cost to serve these individuals; and (3) the total cost (federal and state) to serve these individuals:

Table 2: Maximization of State Funds to Serve
Individuals with DD/MR with the Home and Community Based Services—DD/MR waiver

FY	Numbers Served	State Match	Federal Match	Total Cost
2001	1333	\$12.6 million	\$ 15.5 million	\$ 28.1 million
2002	1560	\$15.2 million	\$ 22.2 million	\$ 37.4 million
2003	1772	\$18.3 million	\$ 24.8 million	\$ 43.1 million
2004	1984	\$23.4 million	\$ 44.6 million	\$ 68.0 million
2005	2142	\$29.9 million	\$ 42.0 million	\$ 71.9 million

The Department and DDD have made modest improvements in funding Home and Community Based Services for individuals with DD/MR. However, as the rankings set forth in Table 3 below demonstrate, there is much room for more improvement in the funding of Home and Community Based Services for individuals with DD/MR.

In 2000, 2002, and 2003, Hawaii ranked 50th, 51st, and 50th respectively in total spending on individuals with DD/MR. Rizzolo, Mary, *et al.*, The State of the States in Developmental Disabilities, 52 (2004). As of 2004 (the latest year for which data is available), Hawaii spending on individuals with DD/MR slightly improved—Hawaii’s ranking in such spending elevated Hawaii to 43rd out of 51 states and the District of Columbia in funding for individuals with DD/MR. Braddock, David, *et al.*, The State of the States in Developmental Disabilities, 57 (2005).

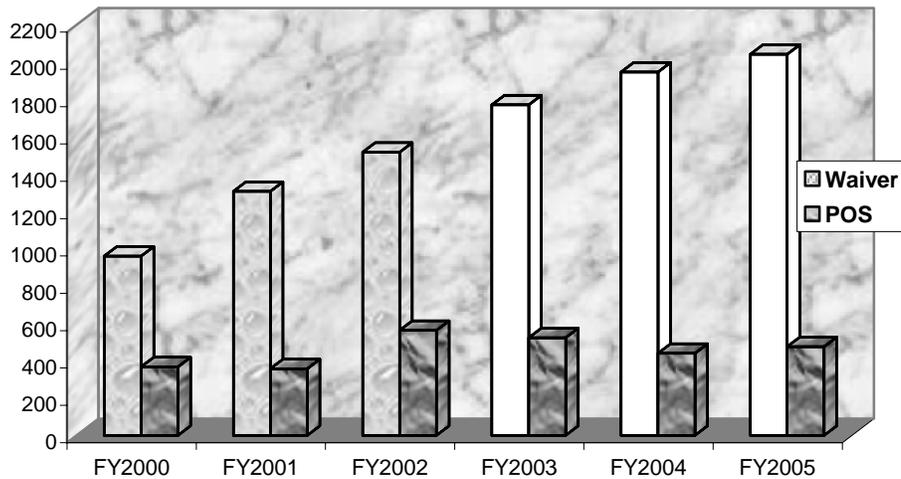
Table 3: Hawaii’s Rank Versus Other States and the District of Columbia For Funding for Home and Community Based Services for Individuals with DD/MR

Year	Hawaii’s Rank in Spending Versus other States and the District of Columbia
2001	N/A ¹
2002	51 ²
2003	50
2004	43

The Department and DDD also provide services and supports using 100% state funds through its purchase of service (POS) programs, Partnerships in Community Living (PICL), Person Centered Adult Supports (PCAS), and Individualized Community Residential Supports (ICRS). The total amount of POS dollars available is approximately \$2.9 million.

The numbers of individuals with DD/MR served by the Home and Community Based Services—DD/MR waiver and by purchase of services are depicted in Table 3.

Table 3. Individuals with DD/MR Served By the Waiver and Purchase of Service



The Department and DDD intend to submit the current Home and Community Based Services—DD/MR waiver for a new five year renewal effective July 1, 2006. The Department and DDD are working with various stakeholder groups as waiver recipients, family members, service providers, the DDD’s Waiver Policy Advisory Committee, and Developmental Disabilities Council, to obtain input on the design of services, provider qualifications, and operations. The

¹ No Rankings were available for 2001. Hawaii ranked last in 2000.

² For 2000 and 2002, Hawaii ranked last in spending on Home and Community Based Services for individuals with DD/MR. Rizzolo, Mary, *et al.*, The State of the States in Developmental Disabilities, 52 (2004).

State Medicaid Agency, the Department of Human Services (DHS), and the Department of Health and DDD are working collaboratively to submit the Home and Community Based Services—DD/MR waiver to the Centers for Medicare and Medicaid Services (CMS) by January 2006.

One of the principal changes that will be proposed in the State's waiver renewal will be to create a mechanism to support persons in their residences of choice using waiver supports which will be defined by their needs. One proposal looks at a per diem concept of combining residential supports (e.g., personal assistance and habilitation) which would not duplicate state supplemental payments for those individuals living in certified or licensed settings, but allow a flexible means of tailoring supports as needed by individuals with DD/MR.

The waiver renewal is also exploring ways to offer flexibility to enable individuals with DD/MR to further direct and manage their resources. The Department and DDD are currently developing a model for the identification of individual waiver budgets based upon a standardized assessment of needs. Following full implementation, individuals with DD/MR will be able to direct the type and amount of services within their identified budget.

2) PROVISION OF LONG TERM SUPPORT SERVICES FOLLOWING THE PRINCIPLES OF SELF DETERMINATION

The development of the DDD service system must demonstrate a commitment to be responsive to and respectful of the input of individuals with DD/MR. The DDD service system must also include an array of services and supports provided in the community to meet various needs.

Outcome 1: Individuals will fully participate in the design and development of the DDD's system of supports.

Target Area: Developmental Disabilities Division Administration

Performance Target: By 7/05, an individual with developmental disabilities will be hired to provide technical assistance, assist with community organization, and advise on policy issues.

Status: In November 2002, two individuals with DD/MR were hired in half-time positions at Individual Mentors. These two Individual Mentors have developed a guide and training modules for self advocates to facilitate their full participation in the development of their Individualized Service Plan (ISP). They have gone to various sites to provide training for self advocates in person centered planning, offering too to assist self advocates in ISP development. The Individual Mentors are also an integral part of the staff development team for training of case managers and other stakeholders.

The Individual Mentors are also in their second year as co-chairpersons of the Community Personal Assistance Services and Supports (CPASS) grant from CMS to the DDD and administered by the University of Hawaii's Center for Disability Studies (CDS). They provide key roles in addressing the implementation of the CPASS grant and sustainability issues with their input on policy, planning, and evaluation.

Target Area: Policy Advisory Committee

Performance Target: By 7/05, 30% of Policy Advisory Committee membership will be individuals with developmental disabilities and 30% family members.

Status: DDD continually solicits the input and participation of individuals with DD/MR and their family members. At the present time, the Waiver Policy Advisory Committee is re-evaluating its membership and is again seeking to recruit (and retain) both individuals with DD/MR and their family members. The Quality Assurance Subcommittee currently has the requisite percentage of family members, and it is also seeking ways to increase membership of individuals with DD/MR.

Outcome 2: Individuals with developmental disabilities receive services and supports based on Federal and State mandates, in the most integrated, community-based setting as mandated by the Olmstead Decision.

Target Area: Number of individuals in licensed or certified settings for individuals with developmental disabilities

Performance Target: By 7/1/05, the number of individuals in Intermediate Care Facilities for the Mentally Retarded will be reduced by 50%.

Status: In the fiscal year ending 2001, there were 96 beds in Intermediate Care Facilities for the Mentally Retarded – Community (ICF/MRC); ICF/MRCs are small, five-bed community facilities licensed to provide active treatment to individuals who choose to receive their services in a facility. In the fiscal year ending 2005, there are 85 beds statewide. By federal regulations, individuals who are determined to be at the ICF/MR level of care must have the choice of receiving services in either the community or facility. Providers desiring to operate ICF/MRCs must first apply for a certificate of need and be licensed and certified to provide services and supports at the ICF/MR level. The DDD is not involved in either the certificate of need evaluation nor the certification and licensure of facilities.

In addition, a critical support, or safety net, to ensure continued community living for individuals with DD/MR with co-occurring diagnoses of mental illness and/or who exhibit challenging behaviors is the development and implementation of a statewide crisis response system. An RFP will be issued in November, 2005 for a crisis network to provide the following components: 1) training and consultation to build system capacity; 2) prevention and crisis outreach services; 3) temporary out-of-home crisis settings; and 4) long-term behavioral oriented residential settings.

Moreover, housing needs have become critical for individuals with developmental disabilities, and the Legislature should carefully consider the recommendations from the Residential Settings Task Force for individuals with developmental disabilities and their choice of residential setting; and

Outcome 3: Individuals in Long Term Care facilities will have the option to choose support services in the community.

Target Area: Individuals with developmental disabilities in Long Term Care facilities

Performance Target: By 7/05, all individuals with developmental disabilities in Long Term Care facilities will have an individualized service plan.

Status: DDD currently completes Pre Admission Screening Resident Reviews (PASRR) for all individuals with DD/MR applying to be admitted to long term care facilities. Individuals with DD/MR can be admitted to those facilities only if they are not in need of specialized services.

There are approximately 21 individuals with DD/MR actively known to DDD in long term care facilities. Most of these individuals participate in DDD's "Friendly Hospital Visitors" program where a volunteer regularly visits an individual in the long term care facility. Most of these individuals have an Individualized Service Plan (ISP) but not all individuals in these long term care facilities have a current ISP.

DDD is also updating its PASRR listing of individuals who had been admitted to a long term care facility. During this current fiscal year, each of those individuals residing in a long term care facility will be contacted regarding their desire to have an individualized service plan to address community service needs if desired.

Outcome 4: The waitlist for services will move at a reasonable pace.

Target Area: Home and Community Based Services for the DD/MR Waiver

Performance Target: By 7/05, 1000 waitlisted individuals will receive MR/DD waiver services.

Status: By June 30, 2005, 2142 individuals were enrolled in the Home and Community Based Services—DD/MR waiver. This increase of more than 1000 reflects achievement of the performance target.

Target Area: Home and Community Based Services for the DD/MR Waiver

Performance Target: By 7/05, individuals will receive services within one year of placement on the DD waitlist.

Status: As of fiscal year ending 2004, there were no waitlisted individuals. Effective August 12, 2005, the waitlist for the Home and Community Based Services—DD/MR waiver services has been defined as follows: "refers to the list maintained on an on-going basis by the State of Hawaii Department of Health of persons waiting for the Home and Community-Based Services for the Developmentally Disabled and/or Mentally Retarded ("HCBS") funded by the state Medicaid program. The Waitlist shall be comprised of those persons who have submitted completed applications for HCBS, have been

determined to be eligible for HCBS under the State Medicaid waiver program, and are awaiting provision of HCBS.” Hawaii Disability Rights Center v. State of Hawaii, Civil No. 03-00524 (U.S. District Court) (Settlement Agreement). This goal has been achieved.

DDD selected various areas to measure whether the principles and practices of self-determination are being followed in the DDD service system. One of the most frequently cited measures of self-determination is whether the individual with DD/MR lives in the residence of his or her choice. Other measures include the accomplishing of outcomes identified in the individual’s individualized service plan (ISP) as developed by the individual or circle of supports, controlling budgets, working or income generating, controlling budgets, and having choice and decision making opportunities.

Outcome 5: Individuals with DD/MR live in residences of their choice with necessary supports.

Target Area: People with DD/MR will be living in their own homes.

Performance Target: 70% of people receiving supports or services through the DDD will be living in residences of their choice by 7/1/05.

Status: Of the over 3200 individuals with DD/MR served by the DDD, almost 70% live in their family home. Many others choose to live independently.

In addition, the DDD annually surveys 500 individuals with DD/MR randomly selected to participate in face-to-face interviews as part of the National Core Indicators Project (NCIP). Of those surveyed, 63% stated that they are living in the residence of their choice. This represents approximately a 20% increase since 2002. This survey may not accurately reflect the percentage of persons served by the Division that desire to live outside their family home. The survey question does not distinguish whether a person chose their family home or is satisfied living with family yet never chose the house.

Outcome 6: Individuals attain desired outcomes as detailed in their ISPs.

Target Area: Individual outcomes

Performance Target: Based on standardized outcome measures, qualities of life for individuals with DD will improve by 20% over baseline by 7/05.

Status: In a survey conducted as part of the NCIP to approximately 1000 guardians and families of individuals with DD/MR living at home, 82% indicated that they were satisfied with the ISP and the ISP planning process in 2004. This represented a 7% increase in satisfaction from 2003. No data is available for 2005.

Outcome 7: Individual, with the help of family or supports as necessary, will develop their own self-determined plan.

Target Area: Person-centered planning documentation

Performance Target: By 7/1/05, 100% of individuals surveyed will indicate they designed their plans.

Status: This goal has not been fully achieved. However, individuals are increasingly becoming fully involved in the development of their own individualized service plans (ISP). Anecdotal reports indicate that individuals are becoming more vocal in expressing their desires and in some cases, are challenging their circle members, including guardians, to evaluate their stances and decisions.

DDD has focused its energies on developing various tools to introduce and educate stakeholders on person centered planning, including roles and responsibilities of circle of support members. The Individual Mentors have also taken an increasingly active role in the education and training of stakeholders.

Target Area: Person-centered planning documentation

Performance Target: 100% of sampled individualized service plans will document that individual clients control, direct, and manage their plans by 7/1/05.

Status: This goal has not been fully attained and may not be feasible. Some clients choose their family or guardian to control their budgets. However, DDD has retained a consultant to develop a model for client control of individualized budgets.

DDD has focused its energies on developing tools, encouraging the development of self advocacy and mentorships, and educating stakeholders. The DDD's CPASS grant has implemented the concept of community support guides as a mechanism to aid individuals in the development of their plans, define and use natural supports, and achieve desired outcomes. Clients are now able to hire their own direct care staff.

Outcome 8: Individuals will have appropriate work and/or increased income.

Target Area: Work

Performance Target: 70% of people desiring work will have employment by 7/05.

Status: Based on the NCIP survey of 500 individuals, 21% of people who desire work are working or earning money and 52% of those who want to work remain unemployed.

The area of work remains a challenge for DDD and across the nation. Habilitation-supported employment as a service option in the HCBS – DD/MR waiver is used by less than 1% of waiver recipients. The fear of lost benefits continues to be a deterrent for many individuals and/or their guardians. Recently, the State was awarded a systems change grant from CMS to stimulate work as a viable option.

DDD has worked with various agencies create income generation opportunities for individuals with DD/MR. Currently, on the grounds of the former Waimano Training School and Hospital, Vision, Strength and Ability (VSA) affiliated with the University of Hawaii at Manoa's Center for Disability Studies encourages people with disabilities to develop their artistic and musical skills to achieve employment. One HCBS – DD/MR waiver provider agency has been able to diversify and employ individuals with DD/MR to sew smocks, aloha shirts, and other products. Many individuals are self-employed through micro-enterprise efforts. Other business incentive partnerships are needed to create job opportunities and integrated work outcomes within the private sector.

Target Area: Increased income

Performance Target: 70% of people desiring to increase their income will do so by 7/05.

Status: Based on the NCIP survey of 500 individuals, 11% working responded that they felt they were making enough money and 15% felt that they had increased their income in the past year. While this reflects more than 25% of the sample surveyed achieving this outcome, the survey tool does not accurately measure what percentage of the 500 persons desire to increase income. Regardless, it is anticipated the efforts of the Division will continue to improve work opportunity. The system of support design will change in the next fiscal year to incentive providers to seek income outcomes for the persons served.

The anticipated results of the CMS systems change grant to address work issues as well as continued encouragement of the Home and Community Based Services—DD/MR waiver providers to diversify and to support individuals to work or engage in income producing endeavors should facilitate a greater percentage of individuals becoming part of the work force. DDD staff are working with various providers to support efforts enabling individuals with DD/MR to be productive members of their communities. This area of employment is a major focus of emphasis in the next five year plan.

Outcome 9: Individuals with developmental disabilities will have a budget that they control, direct, and manage.

Target Area: Individuals utilizing public funds.

Performance Target: By 7/1/05, 100% of individuals with developmental disabilities will have an individualized budget that they direct, control, and manage.

Status: Each individual with supports funded by DDD has an identified budget to fund the desired supports and uses a circle of support to choose and control that budget. To the extent that they are able, and which is allowable under the funding source, the individual directs the expenditure of funds.

Under the current the Home and Community Based Services—DD/MR waiver, no actual cash is made available to recipients, however, individuals have the option of choosing their services, service provider(s), and in many instances, their direct support workers to provide the service. For those individuals who choose the Consumer Directed Personal Assistance (CD-PA) service, they (or their designated representative) are able to hire, train, supervise, and even fire, the direct support worker(s).

It is acknowledged that at the present time, not 100% of the individuals are able or desire to control their budget. Many individuals have guardians or designated representatives to act on their behalf.

Outcome 10: Increase opportunities for individuals with developmental disabilities to exercise personal choice and decision-making.

Target Area: Personal choice and decision-making for individuals with developmental disabilities.

Performance Target: By 6/30/05, the percentage of people who choose the place where they live will increase from 44% to 49%.

Status: This item is based on the NCIP survey of 500 individuals. However, the comparative results for 2005 are not yet available from the Human Services Research Institute (HSRI) which does the summary comparisons.

Target Area: Personal choice and decision-making for individuals with developmental disabilities

Performance Target: By 6/30/05, the percentage of people who choose how to spend their free time will increase from 90% to 92%.

Status: This item is based on the NCIP survey of 500 individuals. However, the comparative results for 2005 are not yet available from the Human Services Research Institute (HSRI) which does the summary comparisons.

Target Area: Personal choice and decision-making for individuals with developmental disabilities

Performance Target: By 6/30/05, the percentage of people who choose their day program or job will increase from 55% to 65%.

Status: This item is based on the NCIP survey of 500 individuals. However, the comparative results for 2005 are not yet available from the Human Services Research Institute (HSRI) which does the summary comparisons.

Target Area: Personal choice and decision-making for individuals with developmental disabilities

Performance Target: By 6/30/05, the percentage of people who choose what to buy with their spending money will increase from 84% to 89%.

Status: This item is based on the NCIP survey of 500 individuals. However, the comparative results for 2005 are not yet available from the Human Services Research Institute (HSRI) which does the summary comparisons.

Anecdotal information suggests that individuals have more opportunities to exercise personal choices and decision-making from food choices to activities they wish to participate in, including volunteering. Some individuals are also considering personal relationships, including marriage. Providers of the Home and Community Based Services—DD/MR waiver services also report that they purposefully ask recipients what activities they wish to engage in and often respect their interests.

3) QUALITY OF SERVICES AND SUPPORTS

One of the principal means of evaluating quality of services and supports is through a reporting mechanism, the Adverse Events Reports (AER). The AERs are required by providers of services and supports (residential and waiver services included) for recipients of waiver services. While limited in its scope, the AERs provide the Department and DDD with indicators of health and safety concerns to be addressed.

For the fiscal year ending 2006, both the Departments of Health and Human Services are working to improve the AER form and format. The present AER form does not lend itself readily to capturing details of type and magnitude with any consistency. Input on the AER form is being solicited from staff of both departments as well as providers. A trial of the revised AER form will be conducted in late 2005 and early 2006. It is anticipated that the new AER form and training to use the form will be conducted in mid-2006.

Outcome 1: Persons will be safe and in good health.

Target Area 1: Abuse and Neglect

Performance Target: Reduce cases of abuse and neglect to 0 by 7/1/05.

Status: In FY 05, there were 34 cases reported of alleged abuse (21) and neglect (14), two were confirmed by either Adult Protective Services or Child Protective Services. Corrective actions were taken immediately to resolve the situations.

Target Area 2: Injuries

Performance Target: Reduce injuries to 50% of baseline by 7/05.

Status: According to available reports, there were 196 instances of injuries reported in fiscal year ending 2002, 204 in fiscal year ending 2003, 337 in fiscal year ending 2004, and 350 (thus far) in fiscal year ending 2005.

The number of incidents of injuries may not necessarily be reflective of a poor service system. It is of note that the number of waiver recipients increased by 258. Further, most of the injuries were neither life threatening, nor required hospitalization.

Regardless, DDD will be addressing injury prevention by offering training as well as arranging for on-site consultation and reviews.

Target Area 3: Dental care.

Performance Target: 80% of individuals requiring dental services receive such services by 7/05.

Status: Results of NCIP survey indicate that 87% of the respondents indicated that they received needed dental services in 2004. DDD administration continues to advocate for increased access to dental services statewide.

Summary:

The Department and DDD have made significant progress towards fulfilling their mandate to implement a service and support system for individuals with DD/MR predicated on self-determination. In the seven years since the passage of Act 133, DDD has several noteworthy benchmarks:

- Two Individual Mentors have been on staff since November 2002. These two individuals participate in education and training of stakeholders (case managers, individual self advocates, families, guardians, and providers' staff). They are actively involved in policy issues and program planning.
- Individuals with DD/MR appear to be more involved in exercising choice and decision making.
- Services and supports funding long term supports for individuals with DD/MR living in the community adhere to the "maximization" mandate. That is, state funds are used as matching funds for a federal finance participation program, the Home and Community Based—DD/MR waiver.
- There are currently nearly 2200 individuals living in the community receiving the Home and Community Based—DD/MR waiver services. These services are flexible and increasingly facilitate consumer choices and direction. This is an increase from 1333 individuals receiving community based services in 2001.