The State of Tennessee

Department of Finance and Administration

Division of Mental Retardation Services

Annual Report FY 2005

October 2005

TABLE OF CONTENTS

INTRODUCTION **1**

FY 2004-2005: A Year of Implementing New Systems **1**

Status of Federal Lawsuits **3**
United States v. State of Tennessee (Arlington) 3
People First v. Clover Bottom 3
Brown et al v. Tennessee Department of Finance and Administration 3

THE PEOPLE DMRS SERVES **4**

People in the Community **4**
Table 1: DMRS Census by Program per Month 4
Chart 1: DMRS Census by Month 5

Waiting List for Services **5**
Chart 2: Statewide Waiting List Growth 6
Chart 3: Number of People Added to the Waiting List Compared to the Number of People who were Provided Services (and Thereby Removed from the Waiting List) 6

People at the Developmental Centers **7**
Chart 4: Statewide DMRS Developmental Center Census 7

Populations by Age Groups **7**
Chart 5: Community Population by Age 8
Chart 6: Developmental Center Population by Age 8

Where People Live **8**
Chart 7: Where People Live 9

PROVIDERS **10**

Service Needs Analysis and Provider Recruitment **10**
Table 2: Service Providers 10
Chart 8: Net Percentage Increase in Service Providers 11
Chart 9: Net Percentage of Increase in Clinical and Therapy Service Providers 11

SERVICE SYSTEM PERFORMANCE AND ANALYSIS **12**

Quality Assurance Reviews **12**
Review of Data Resulting from QA Reviews in Fiscal Year 2004-2005 12
Chart 10: Overall Statewide QA Performance Levels 13
Chart 11: QA Performance Levels by Region 13

Regional Quality Management Committees and Agency Teams **14**

CONSUMER SURVEYS **15**

Results 15
Chart 12: Percentage of Satisfaction per Domain 16
Future Goals 16

PROTECTION FROM HARM 17

The Complaint Resolution System 17
Chart 13: Statewide Rate of Complaints per 100 People 18
Chart 14: Fiscal Year Comparison - Complaint Issues by Categories 18

The Incident Management System 19
Chart 15: Average Monthly Rate of Incidents per 100 People 20
Chart 16: Average Monthly Serious Injury Rate per 100 People 20

The Investigation System 21
Chart 17: Rate of Substantiated Abuse, Neglect and Exploitation per 100 People Fiscal Year Comparison 22
Chart 18: DMRS Abuse Registry Placement Chart 23

Behavior Services: Restraints 24
Chart 19: Rate of Behavior Incidents Utilizing Restraints per 100 People 24

Mortality Reviews 25
Chart 20: Mortality Rate per 100 People in the Community 25
Chart 21: Mortality Rate per 100 People in the Developmental Center 25

DEVELOPMENTAL CENTERS RISK ANALYSIS 27

Chart 22: Total Incidents per 100 Citizens in the Developmental Centers 27
Chart 23: Substantiated Neglect per 100 Citizens in the Developmental Centers 28
Chart 24: Substantiated Abuse per 100 Citizens in the Developmental Centers 28

CONCLUSION 30

Introduction

The Division of Mental Retardation Services (DMRS) is the state agency responsible for services for Tennesseans with mental retardation. The Division is led by Deputy Commissioner Stephen H. Norris under the direction of the Department of Finance and Administration. Programs designed by DMRS are provided with funding from state revenues as well various grants and federal Medicaid Waiver monies. The state Medicaid Agency, the Bureau of TennCare, which is also under the direction of the Department of Finance and Administration, provides oversight, through its Division of Developmental Disability Services, for the federal Home and Community-Based Medicaid Waiver and Self-Determination Waiver programs DMRS provides. The Medicaid Waiver programs are sanctioned and monitored by the federal Centers for Medicare and Medicaid Services (CMS).

The Division operates across the state with Regional Offices in the three grand divisions of West, Middle and East Tennessee. The DMRS Central Office, based in Nashville, provides direction for programs as well as administrative support to the Regional Offices. DMRS provides services to Tennesseans of all ages with mental retardation. The programs DMRS oversees are Early Intervention services for children 0-3, Family Support grants, and an array of community based services funded with state and federal resources. In addition to community based services, the Division operates three Intermediate Care Facilities for the Mentally Retarded (ICF/MR). These centers are located one per region: Arlington Developmental Center in Arlington (West), Clover Bottom Developmental Center in Nashville (Middle), and Greene Valley Developmental Center in Greeneville (East).

FY 2004-2005: A Year of Implementing New Systems

During Fiscal Year 2003-2004 DMRS developed a plan that consolidated and focused the state's efforts to resolve issues with the Centers for Medicare and Medicaid Services and the three federal lawsuits (Waiting List, Clover Bottom, and Arlington). This plan, "A Blueprint for Improving the Service Delivery System for Individuals with Mental Retardation in Tennessee", directed specific short and long term actions, many of them aimed at improving the infrastructure for the Division of Mental Retardation Services and the Bureau of TennCare, Division of Developmental Disability Services.

Fiscal Year 2004-2005 was characterized by the implementation of the new systems outlined in the Blueprint. Collectively the new systems and products identified in the Blueprint are called the Tennessee Quality Management System, derived, in part, from the CMS Quality Framework for Home and Community-Based Waiver Services (HCBS) and the Interim Procedural Guidance. CMS has urged states to develop Quality Management Systems in order to provide CMS with evidence of effective state oversight of HCBS services. DMRS designed these systems in Fiscal Year 2003-2004 and began implementing them in Fiscal Year 2004-2005. The following are some of the actions and accomplishments achieved during the past year:

- Implemented a new, comprehensive Quality Management System for DMRS Community Services. The new system sets measurements of quality that reflect the Division's mission and important outcomes for individuals, identifies the information or data to be collected, integrates and analyzes the data, and uses the data to measure the outcomes identified. Measuring outcomes identifies where things are going well and where improvements in services and supports to individuals are needed. The Quality Management System includes a Protection from Harm segment that integrates incident management, investigations and complaint resolution. A revised Quality Assurance assessment instrument was implemented. This instrument is a mechanism for scoring provider performance and for ensuring resolution of issues that are identified. This continuous cycle of examining performance

and making adjustments based on data is critical to service quality for the individuals receiving services.

- Implemented a provider oversight structure that includes compliance monitoring and technical assistance. On a Regional level, providers are assigned to Regional Office Agency Teams which are responsible for monitoring and providing technical assistance that is agency specific. The Agency Teams are supplied with provider specific data that is updated monthly and includes information about demographics, protection from harm, quality assurance, compliance monitoring results, sanctions, and technical assistance. This information is compiled in the Provider Compliance Report by the Regional Compliance Unit and channeled to the Regional Quality Management Committee (RQMC), which is the decision making body. The State Quality Management Committee monitors the actions of the Regional QMCs and provides guidance, as needed, to ensure consistent quality oversight. Each month, the State QMC creates a Quality Management Report that shows regional and statewide data, and reviews it to identify trends and systemic issues.

- Completed a standardized assessment process using the Inventory for Client and Agency Planning (ICAP) to determine individual level of service needs for each individual in the service delivery system, including people in the community, in Developmental Centers and on the Waiting List. Information from these assessments is used to improve individual planning and to ensure that necessary services are provided. ICAP assessments will now be completed on a two-year cycle.

- Implemented a revision of the Individual Support Planning (ISP) process which now includes a formal risk assessment component and a streamlined ISP format to make it a user-friendly document. Staff positions were added to the Regional Offices for the purpose of reviewing ISPs for timeliness and quality. All of these changes are important because the ISP is the foundation of ensuring that individuals receive the services they need.

- Submitted to CMS two renewal applications for the Medicaid Waiver programs operated by the Division and one new application for a Self-Determination Waiver. The renewals included revised service definitions designed to increase flexibility for services. The Self-Determination Waiver is intended primarily for people on the Waiting List who do not require residential services. CMS approved all three Waivers effective January 1, 2005, but required certain Terms and Conditions to be completed before enrollment could begin. DMRS successfully met the Terms and Conditions and CMS granted enrollment into all three Waivers effective April 14, 2005.

- Implemented a new rate structure system, effective January 1, 2005, designed to significantly reduce the number of rates and to formulate rates based on levels of need rather than on staffing ratios. Impact studies were conducted prior to implementation. A rate system that is fair, equitable and that covers the costs to provide services is another essential element in people receiving quality services.

- Completed and implemented a new Provider Manual, effective March 15, 2005, designed to capture all provider requirements in one document. The requirements contained in the Provider Manual set the quality expectations for services of community providers.

- Implemented a “Real Systems Change Grant” awarded by the Centers for Medicare and Medicaid Services through which a new Consumer and Family Satisfaction Survey system was initiated in the fall of 2004. Consumer involvement in the survey process is a key element and an important change to the way in which Tennessee gathers information about how well the state is meeting people’s expectations. In addition to the Consumer and Family Satisfaction Surveys, DMRS also completed Satisfaction Surveys for Direct Support Professionals and Independent Support Coordinators.

- Created an Advisory Council for DMRS consisting of stakeholders such as parents, people who receive services, providers, advocates, the Medicaid Oversight Agency, and certain DMRS staff. The purpose of the Council is to review and comment on DMRS systems implementation, policies and procedures, data management, and to provide new ideas. The Council meets on a monthly schedule.

Status of Federal Lawsuits

United States v. State of Tennessee (Arlington)

Following a June 2004 on-site review of Arlington Developmental Center and the homes of several class members who live in the community, the parties agreed to postpone a July 15, 2004 Show Cause Hearing scheduled to address the issues of a contempt motion filed by People First of Tennessee. The State agreed that progress reports presented during quarterly parties meetings and ensuing discussions would be conducive to the State's compliance efforts. A new superintendent, Mr. Leon Owens, was hired at Arlington Developmental Center in March 2004. Compliance data tracking since the employment of Mr. Owens is showing the center is moving toward improvement.

People First v. Clover Bottom

Compliance measuring tools, based on the model used at Arlington, have been developed for Clover Bottom and Greene Valley Developmental Centers. The instrument is comprised of about 900 questions related to the hundreds of requirements contained in the Settlement Agreement. This compliance-measuring tool is completed each month, at each facility, on a sample of people who reside at the facilities. The results are displayed per requirement in terms of the percentage of questions answered "yes", reflecting compliance. It is the Division's intent to have each of the requirements scoring at 90% or higher.

Brown et al v. Tennessee Department of Finance and Administration

This case was filed on behalf of the individuals on the waiting list for DMRS services. Originally filed in 2000, U.S. District Court Judge Robert Echols signed the settlement agreement in June 2004. Two main features of the Settlement Agreement are a Self-Determination Waiver and a state-operated case management system. DMRS has been working diligently to implement the Agreement, and has been meeting monthly with the attorneys who filed the lawsuit. DMRS is committed to working toward addressing the issues raised in the lawsuit, and in implementing the Settlement Agreement.

The People DMRS Serves

People in the Community

The Division of Mental Retardation Services provides a wide range of services to more than 13,000 Tennessee citizens. Most of the people receiving services live in their home community and receive services from local community agencies. The funding to serve people comes from federal, state and local resources. Through the federal Medicaid program, the state of Tennessee has three Medicaid Waiver programs that permit the state to use Medicaid funds to provide a variety of community services. DMRS, in partnership with the Bureau of TennCare, the Division of Developmental Disability Services, operates these Waivers. The federal government provides about 65% of this funding and the state government provides the remaining 35%.

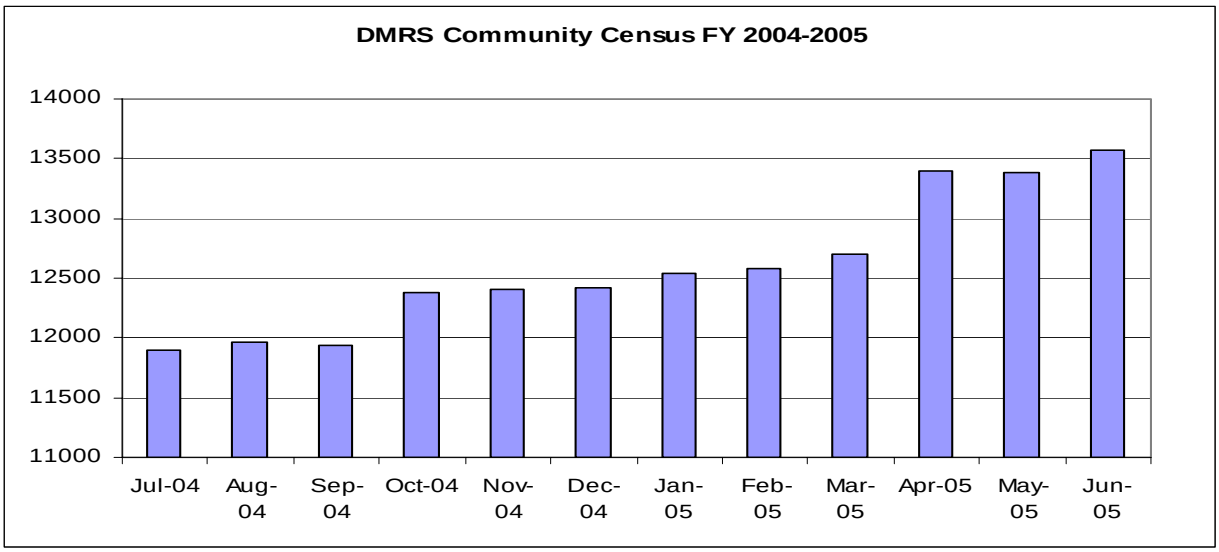
The state government also provides funding for services for people who are not eligible for the Medicaid Waiver, for the Family Support program and for a portion of the Early Intervention program. Local organizations, such as the United Way, and individual contributors provide additional support to local service providers. The Medicaid Waiver program, however, is by far the largest source for funding services.

During Fiscal Year 2004-2005, any increase in the number of people DMRS could serve was severely restricted as a result of a moratorium on new admissions placed on the Tennessee Waivers by the Centers for Medicare and Medicaid Services (CMS). CMS granted enrollment into the Waivers effective April 14, 2005, allowing new people to begin receiving services. The following table gives specific monthly census numbers of persons enrolled in each DMRS community program during FY 2004-2005. The chart on the following page shows the growth of the census for DMRS community programs.

Table 1: DMRS Census by Program per Month

	Jul-04	Aug-04	Sep-04	Oct-04	Nov-04	Dec-04	Jan-05	Feb-05	Mar-05	Apr-05	May-05	Jun-05
Statewide Waiver	4370	4403	4410	4437	4459	4484	4502	4519	4557	4617	4712	4806
ADC Waiver	167	167	167	167	167	167	167	165	165	164	164	166
SD Waiver	0	0	0	0	0	0	0	0	0	0	8	57
SD Interim Services	0	3	18	28	41	45	51	70	97	119	140	173
State Funded	2084	2116	2070	2070	2062	2045	2015	2024	2076	2148	2016	2024
Early Intervention	2314	2314	2314	2314	2314	2314	2314	2314	2314	2314	2314	2314
Family Support	2957	2957	2957	3369	3369	3369	3495	3495	3495	4030	4030	4030
Census Total	11892	11960	11936	12385	12412	12424	12544	12587	12704	13392	13384	13570

Chart 1: DMRS Census by Month



The chart shows an increase in persons served over the year. This is attributed to several factors. One, the lifting of the moratorium on admissions allowed for new people to be enrolled. Second, the new Self-Determination Waiver program and the Interim Service program increased service rolls considerably. The Division anticipates further growth through Fiscal Year 2005-2006.

Waiting List for Services

The Waiting List for Medicaid Waiver services managed by DMRS underwent several changes during the past fiscal year. Below are some of the events and changes that occurred:

- DMRS applied for and received approval for a new Medicaid Waiver program – The Self-Determination Waiver (SD Waiver);
- DMRS received renewal of the current HCBS and ADC Waiver programs;
- In April 2005, the Centers for Medicare and Medicaid Services lifted the enrollment restrictions on all of the Medicaid waivers, thereby allowing new enrollments from persons on the Waiting List;
- A new program was initiated during Fiscal Year 2004-2005 to provide some assistance to people who remain waiting for services and who do not already receive money from the Family Support Program. This new program is called the Consumer Directed Supports (CDS) Program. A total of $2,456,975.42 was spent on the CDS Program during Fiscal Year 2004-2005;
- DMRS aggressively pursued outreach to people who may be eligible for services, thereby starting the process for obtaining services as appropriate; and
- DMRS expanded the infrastructure of each regional office to process registrations and requests for assistance, as well as provide case management to every person on the Waiting List.

DMRS has restructured the intake process by creating a comprehensive system for those waiting to be served. The Waiting List for services has been prioritized using several categories of need: crisis, urgent,

active, and deferred. Each category has specific criteria that are applied to an individual's unique situation. People in the category of crisis are given priority for services offered.

The following charts show the census of the Waiting List over Fiscal Year 2004-2005 as well as the number of people who were provided services compared to those that were added to the list. Throughout the year, the Waiting List for Waiver services increased from 3365 to 3762 for a net total gain of 397 people. While the net effect for the fiscal year was an overall gain, there were a total of 792 people placed into services. People were placed into one of several programs: the Statewide Waiver, the Self-Determination Waiver, and/or State Funded Interim Supports. The new enrollments from the Waiting List alone accounted for an approximate 25% growth for the entire service system.

Chart 2: Statewide Waiting List Growth

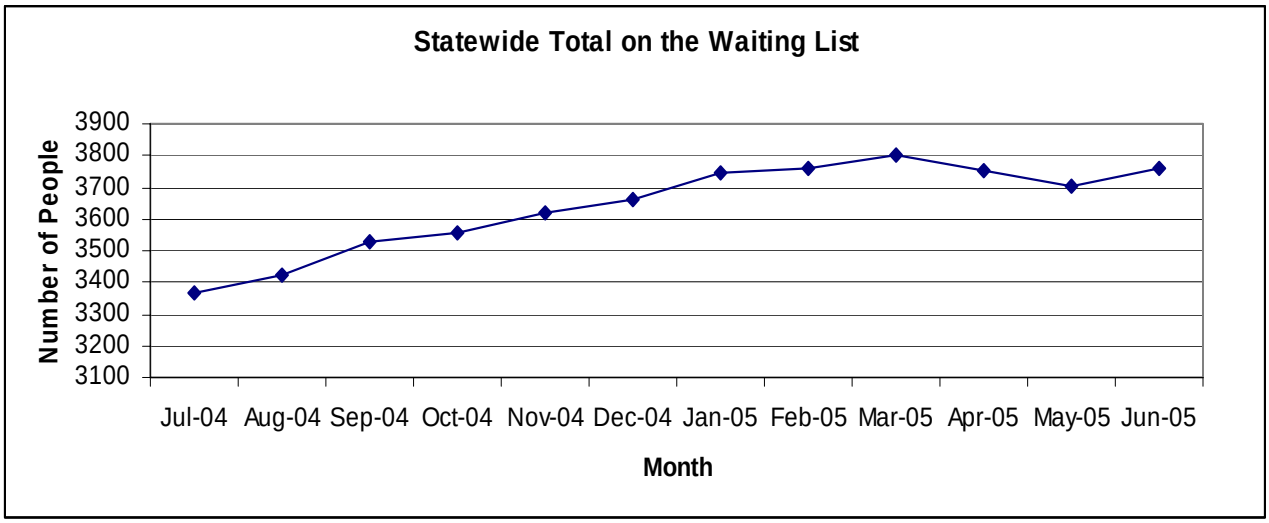
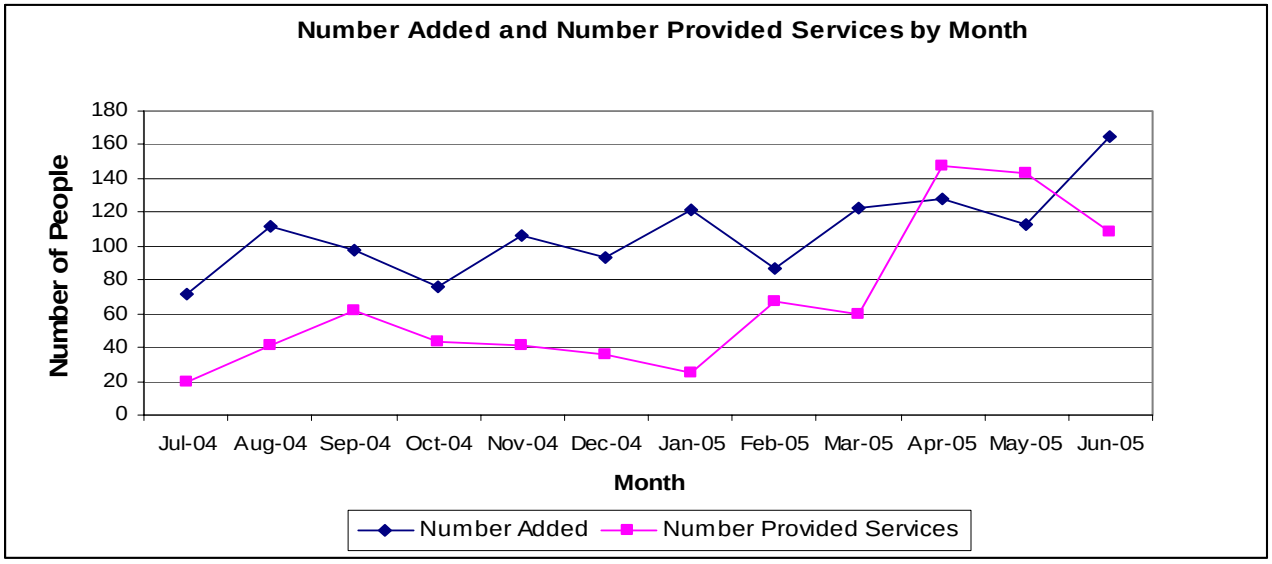


Chart 3: Number of People Added to the Waiting List Compared to the Number of People who were Provided Services (and Thereby Removed from the Waiting List)

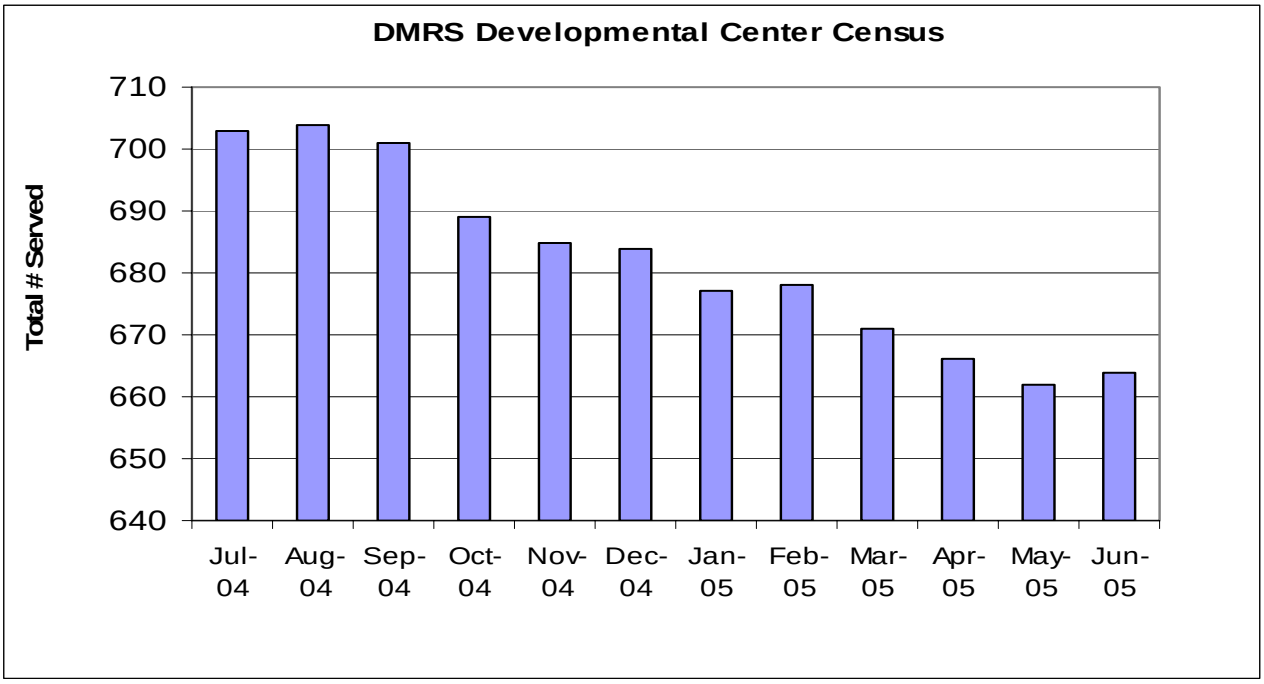


While people continued to be added at an overall higher rate than those being taken off, this past fiscal year saw the largest number of people being provided services than it has since 1999, when the DMRS began statewide management of the waiting list. The Division attributes this to increased outreach efforts throughout the year. The Division anticipates even further increases in enrollment and for those seeking services as public communication activities continue and as efforts are made to expand enrollments in the Medicaid Waiver programs.

People at the Developmental Centers

The three Developmental Centers are licensed Intermediate Care Facilities for the Mentally Retarded (ICF/MR) operated by the Division of Mental Retardation Services (DMRS). They are located in East Tennessee in Greeneville, in Middle Tennessee in Nashville, and in West Tennessee in Arlington. In addition to ICF/MR services, the Developmental Centers house state of the art Assistive Technology Clinics, provide respite care and perform comprehensive medical evaluations. These clinic services are available to both people living in the ICF/MR facilities and in the community. During Fiscal Year 2004-2005, the number of people living at the Developmental Centers declined from 703 to 664 people.

Chart 4: Statewide DMRS Developmental Center Census



Populations by Age Groups

The Division serves people of all ages. Over 2000 infants and toddlers receive Early Intervention services. When children reach school age, they receive a majority of their services through public school programs as well as state Medicaid programs. When young people complete their public school education, enrollments again increase in DMRS. The charts below show that the majority of people being served are between the ages of 23-60. This holds true for the developmental centers as well. However, there are no children living at the developmental centers, whereas more than a quarter of the population served in the community are people 18 years or younger.

Chart 5: Community Population by Age

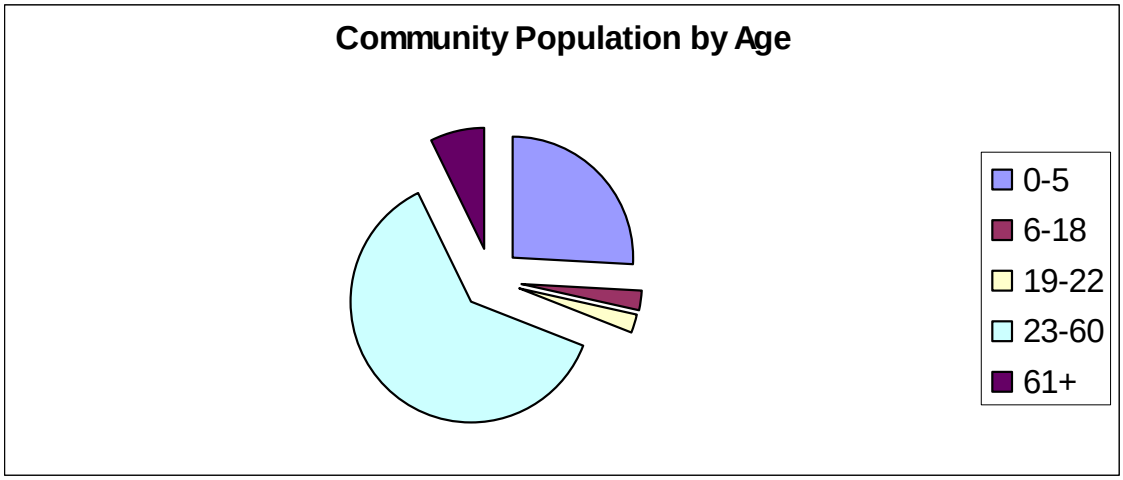
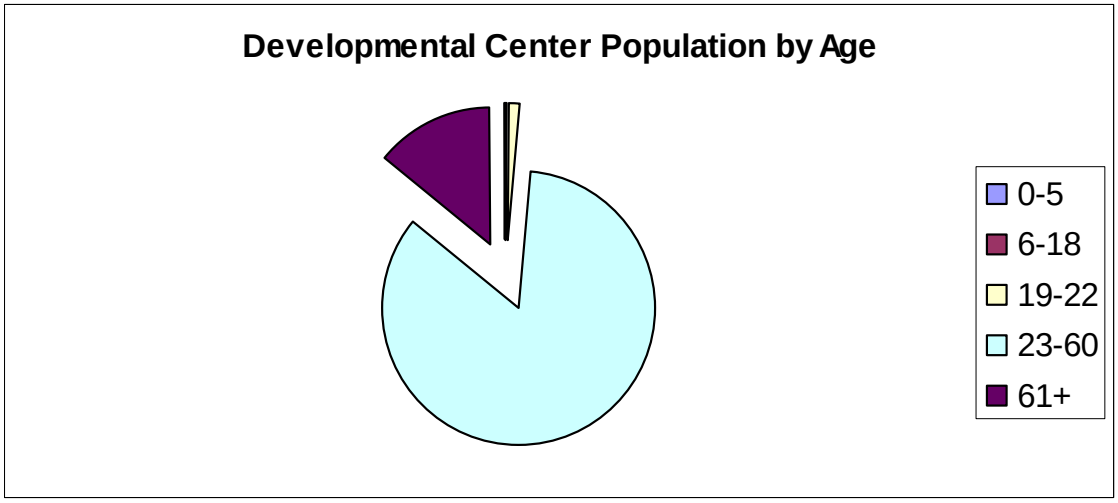


Chart 6: Developmental Center Population by Age

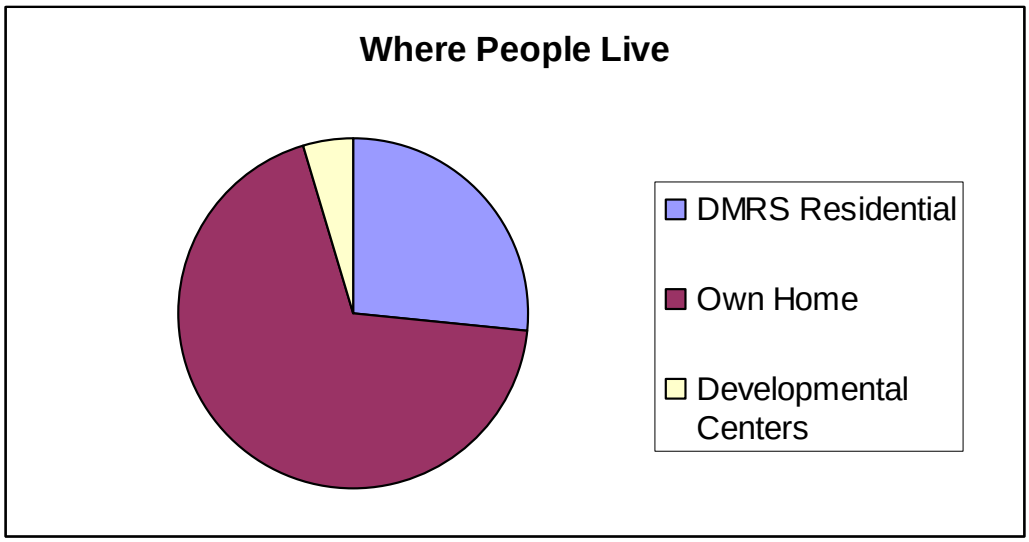


Where People Live

Most people served by DMRS, about 9800, live in their own home or their families' home and receive services in their local community. About 3800 people receive community residential services and choose from Supported Living, Family Model Residential Services, Residential Habilitation Services, or a new service called Medical Residential Services, which is designed for people who have complex medical conditions and require on-site nursing services. The total number of people who receive services in the community, either through one of the Medicaid Waivers, Early Intervention or state funding, has increased by about 12.5%.

Chart 7 compares the proportion of people living at home, in community residential homes, and in the state Developmental Centers.

Chart 7: Where People Live



Providers

Service Needs Analysis and Provider Recruitment

An adequate network of qualified service providers is essential to ensuring that people can choose the services and providers that best meet their needs. Each year, DMRS hold forums around the state to identify gaps in the provider network and to develop strategies to address the identified needs. Based on the results of the forums, provider recruitment is targeted to specific types of providers and specific areas within the state. During the past year, the following numbers of new providers were enrolled or existing provider agencies expanded. The information is provided by type of service on a statewide basis.

Table 2: Service Providers

Service	Number of Providers in FY 03/04	Number of Providers Exited in FY 04/05	Number Added to Provider Network in FY 04/05	Number of Providers in FY 04/05	Net Percentage Increase in FY 04/05
Supported Living	123	8	23	138	11%
Residential Habilitation	48	2	12	58	17%
Family Model	34	2	9	41	17%
Day Services-Facility Based	128	4	19	142	10%
Day Services-Community Based	32	5	21	48	33%
Day Services-Supported Employment and Follow Along	114	5	22	131	13%
Personal Assistance	160	3	16	173	8%
Respite	56	2	10	64	13%
Behavioral Respite	N/A	N/A	3	3	N/A-new service
Physical Therapy	80	5	4	79	-1%
Occupational Therapy	80	6	6	80	0%
Speech, Language, Hearing	56	3	11	64	11%
Durable Medical Equipment Supplier	N/A	N/A	6	53	N/A
Dietician	35	2	9	42	17%
Dentist	N/A	N/A	15	69	N/A
Orientation and Mobility Therapy	N/A	N/A	4	4	N/A-new service
Nursing Services	104	5	9	108	4%
Vision	N/A	N/A	0	1	N/A
Behavior	184	12	50	222	17%

Chart 8: Net Percentage Increase in Service Providers

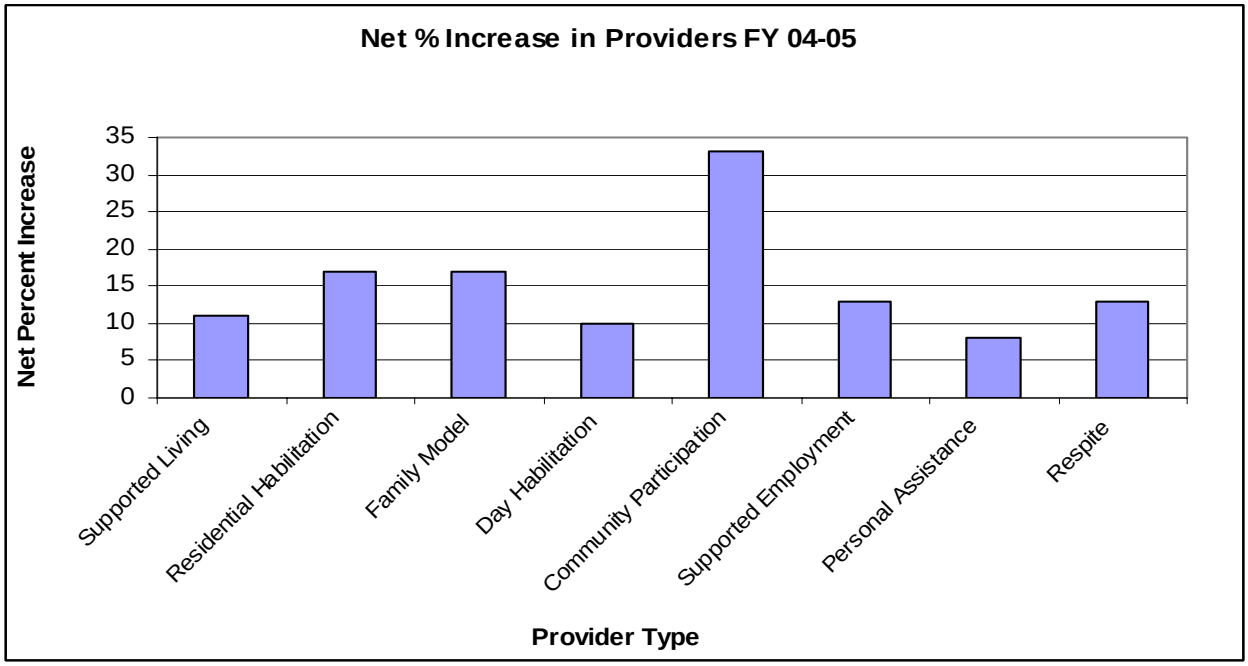
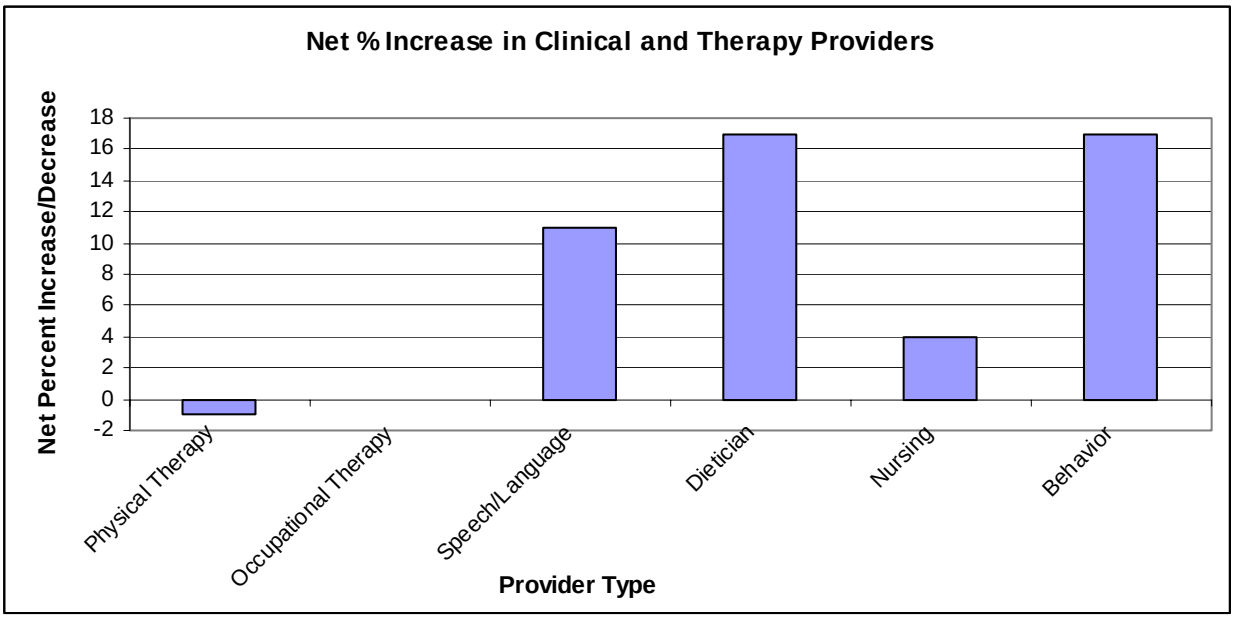


Chart 9: Net Percentage of Increase in Clinical and Therapy Service Providers



Service System Performance and Analysis

Quality Assurance Reviews

A revised Quality Assurance (QA) system for monitoring oversight of community-based providers was implemented on July 1, 2004. This monitoring utilizes a series of three checklists specific to either Day-Residential, Independent Support Coordination or Clinical provider types. These checklists represent a major component of the DMRS Quality Management System (QMS). The implementation and use of these checklists has provided for consistent monitoring of provider performance across ten possible Domains which represent quality standards in implementation of services and supports.

The ten possible Domains that are surveyed, depending upon agency type, are:

- ◊ Access and Eligibility
- ◊ Individual Planning and Implementation
- ◊ Safety and Security
- ◊ Rights, Respect and Dignity
- ◊ Health
- ◊ Choice and Decision-Making
- ◊ Relationships and Community Membership
- ◊ Opportunities for Work
- ◊ Provider Capabilities and Qualifications
- ◊ Administrative Authority and Financial Accountability

The QA checklists utilized during Fiscal Year 2004-2005 were comprised of expected Outcomes organized under each Domain. There were 27 Outcomes applicable to providers of Day-Residential services, 26 Outcomes that applied to providers of Independent Support Coordination and 14 Outcomes that applied to Clinical services providers. QA surveys were conducted using a representative sample of the number of people a provider served; the services provided were measured against a series of Quality Indicators within each QA Outcome. Quality Indicators were based on best practice principles regarding provider performance and person-centered services as well as systemic measures of quality.

At the end of each survey, the Quality Assurance Team conciliated final ratings for each applicable Outcome, based upon discussion of the findings. Once conciliated, a report of findings was issued to the provider detailing performance and areas needing improvement. The provider is expected to incorporate any corrective measures in its Quality Improvement Plan. Survey findings are then used by the Regional Agency Teams and Quality Management Committees to determine the extent of follow-up or technical assistance needed by the particular provider.

Review of Data Resulting from QA Reviews in Fiscal Year 2004-2005

Throughout Fiscal Year 2004-2005, regional and statewide performance on the QA Outcomes and Domains was reviewed monthly by the DMRS State Quality Management Committee. Particular Outcomes and Indicators of concern were discussed systemically and an analysis of services associated with personal funds management was completed.

The following two charts depict the distribution of QA Performance Levels. The first chart shows statewide results, while the second chart shows provider performance by region. For Fiscal Year 2004-2005, the majority of providers surveyed scored within the top two levels of performance: *Very Good*- 41%,

Satisfactory- 46%. Occurrences of providers scoring in the category of *Significant Concerns* was low (11%) and only 1% scored in the category of *Serious Deficiencies*.

Chart 10: Overall Statewide QA Performance Levels

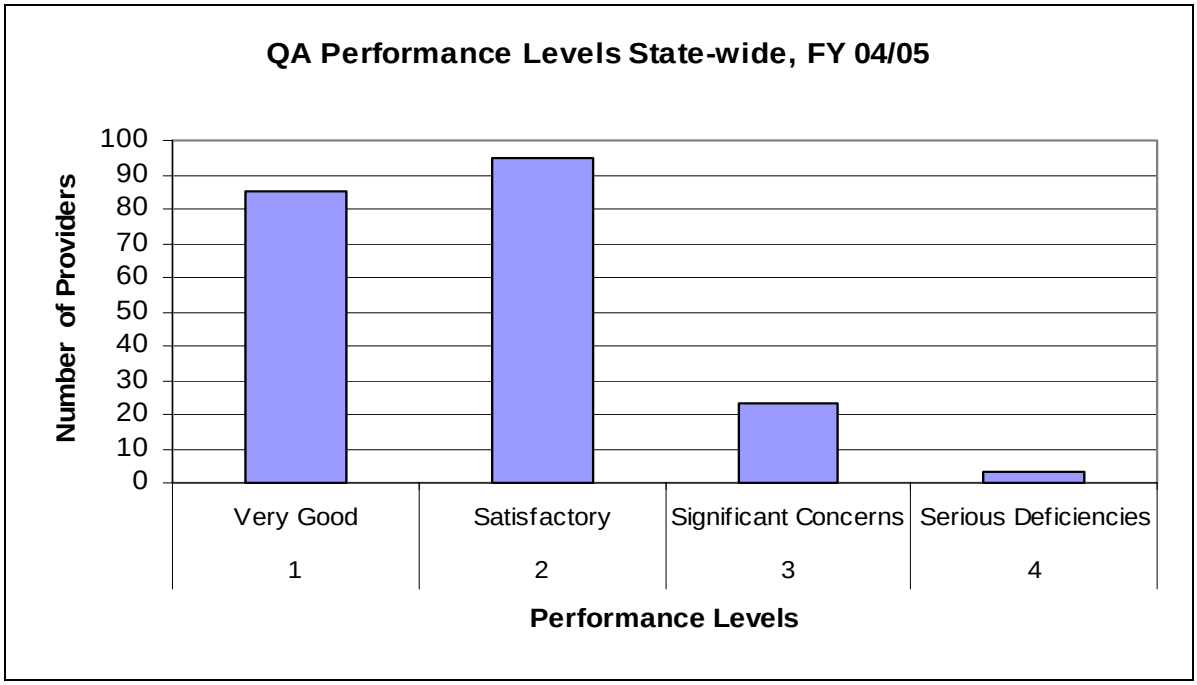
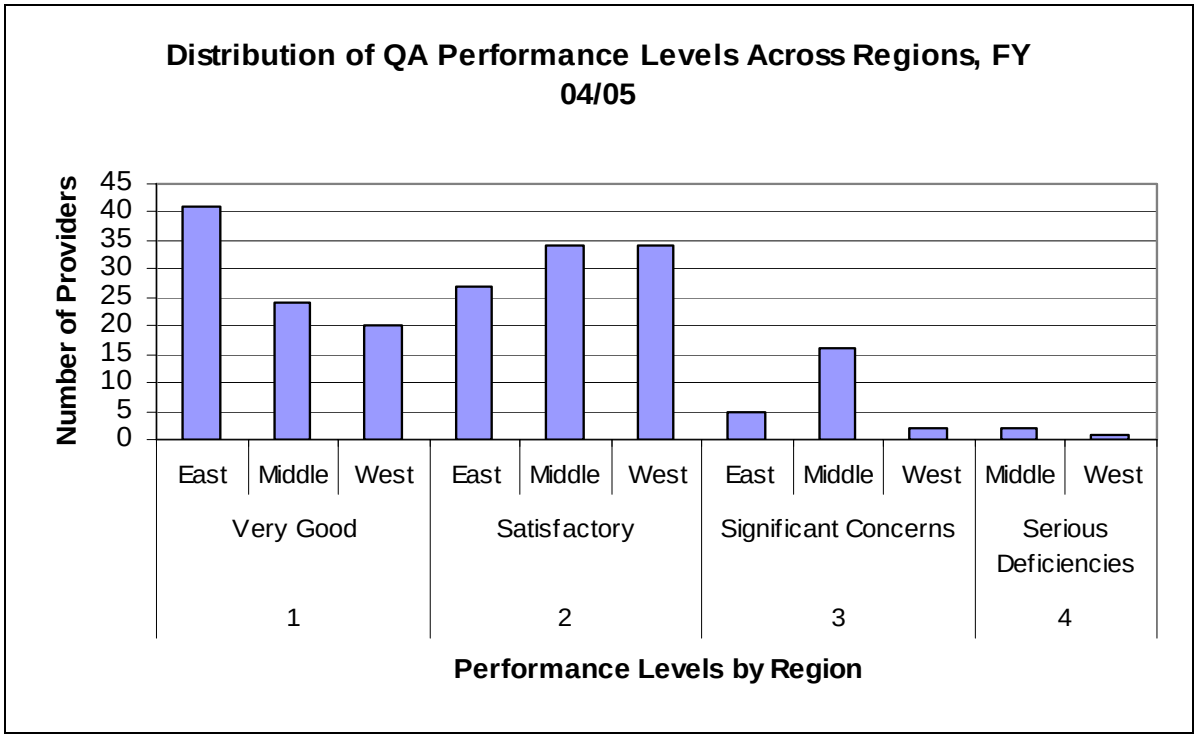


Chart 11: QA Performance Levels by Region



The completion of a full provider review cycle during Fiscal Year 2004-2005 with the new QA survey instruments, review methodology, and scoring system provides data managers with the information necessary to identify the strengths and weaknesses of the provider service delivery system. Armed with data based analysis, providers and DMRS staff can work together to develop and implement activities designed to improve areas of poor performance. The data from Fiscal Year 2004-2005 will serve as performance benchmarks against which the data from Fiscal Year 2005-2006 can be compared. Such a comparison will allow systems managers to determine performance indicators that have improved over time, those which remain constant, and those which have declined. This kind of quantifiable assessment will provide reliable information which will shape corrective activity.

Regional Quality Management Committees and Agency Teams

During the past fiscal year, the Regional Offices organized and operated Quality Management Committees and Agency Teams. These two components of the Quality Management System are designed to address the non-compliance issues of providers that are identified by Quality Assurance surveys. In very general terms, the process works in the following way: the Regional Quality Management Committees review the findings reports of QA surveys as they are completed for each provider. When non-compliance issues are identified in any level of a QA survey, the Quality Management Committees assign an Agency Team to work with the provider to develop and implement a corrective action plan which not only provides for an immediate correction but also insures that the issue is corrected systemically so that the problem doesn't happen again. Whenever possible, the corrective action plan requires the collection of quantifiable data to measure the implementation and quality of the corrective action.

During the time between QA surveys, which are completed annually for each provider, the Agency Teams review provider performance, on a quarterly basis, using a checklist composed of health and safety performance indicators taken from the larger QA survey instrument. This information, along with additional performance data such as rates of complaints, incidents, and investigations, is captured quarterly for each provider and is reviewed by the Regional Quality Management Committees. When the data indicates that a provider's performance is slipping, an Agency Team is dispatched to work with the provider so that problems can be identified and corrected.

In Fiscal Year 2005-2006, DMRS plans to emphasize the compilation and analysis of QA and Agency Team data on a Regional and Statewide basis. The intent of this activity is to identify problems which may be systemic for a Region or for the entire State. This will allow for State-wide policy adjustments in the Provider Manual and in internal operating procedures.

Consumer Surveys

The Division of Mental Retardation Services was awarded a Real Choice Systems Change Grant through the Centers for Medicare and Medicaid Services. This grant was contracted to the ARC of TN to create a Satisfaction Survey for service recipients throughout Tennessee. The ARC of TN developed a program called "People Talking to People: Building Quality and Making Change Happen" that took the consumer satisfaction survey concept and built a dynamic process that would involve face to face interviews with persons served. Survey interviews are conducted using the CMS approved Participant Experience Survey. The process includes a group of 20 service recipients and people familiar with disabilities to work as interviewers. The first phase of surveys (75) was conducted and completed in October 2004. The second set of surveys (747) will be completed by November 1, 2005. The final set of surveys (1474) is due to be completed by the end of the three year grant.

The survey itself provides indicators in four primary areas:

- **Choice and Control:** Do participants have input into the services they receive? Can they make choices about their living situations and day-to-day activities?

- **Respect/Dignity:** Are participants being treated with respect by providers?

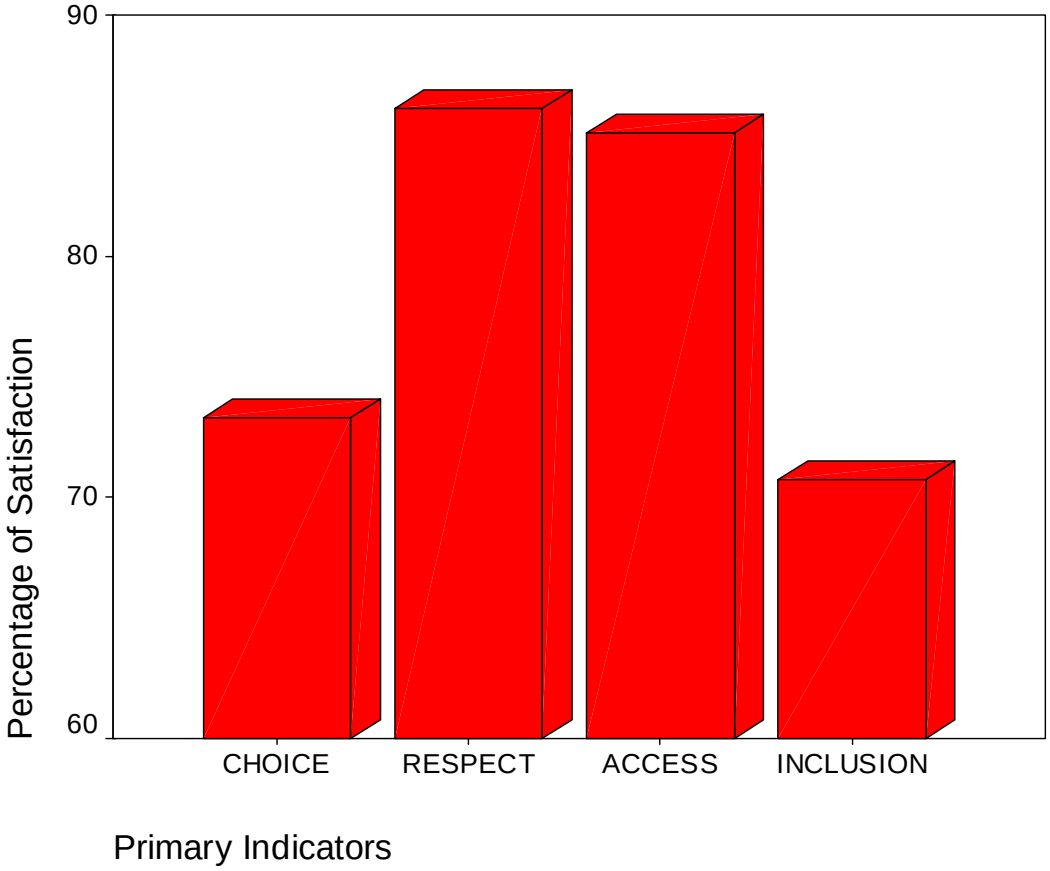
- **Access to Care:** Are needs such as personal assistance, equipment, and access to help being met?

- **Community Integration/Inclusion:** Can participants participate in activities and events outside their homes when and where they want?

Results

The results have not yet been finalized as of this report, as the second year of the program is still underway (10/01/04-9/30/05). However, trends are beginning to surface and are being studied through the quarterly analyses. The graph below provides a snapshot of what the survey instrument has been providing within the 387 interviews analyzed thus far. Every bar represents a percentage of satisfaction within the four main indicators. Each question that was quantitatively answered positive or negative was analyzed. Positive results of questions within each category were given a percentage and the average of all percentages is provided on the following page.

Chart 12: Percentage of Satisfaction per Domain



Inclusion had the least amount of satisfaction, with 70.75%. Choice follows, with 73.28%. Access rated 85.12%, and Respect/Dignity received the most satisfaction, with 86.11%.

Future Goals

The "People Talking to People: Building Quality and Making Change Happen" grant will be enhanced in the third year by adding training components to the program as well as implementing recommended reform through the Tennessee Quality Services Committee (TQSC). This committee is comprised of family members and self advocates as well as outside members of the community. The director of the program, along with TQSC, will provide recommendations for positive change to the Division of Mental Retardation Services by utilizing the statistically valid samples mentioned above by the end of the third program year.

Protection from Harm

The DMRS Protection from Harm (PFH) system is organized into three areas: Complaints, Incident Management, and Investigations. During Fiscal Year 2004-2005, current features of the system were strengthened and several new ones were added. Each Protection from Harm system is identified below with changes made and data trends derived from the data that DMRS maintains. Extensive data is reviewed by PFH staff as well as DMRS Administrative staff to improve systems.

The Complaint Resolution System

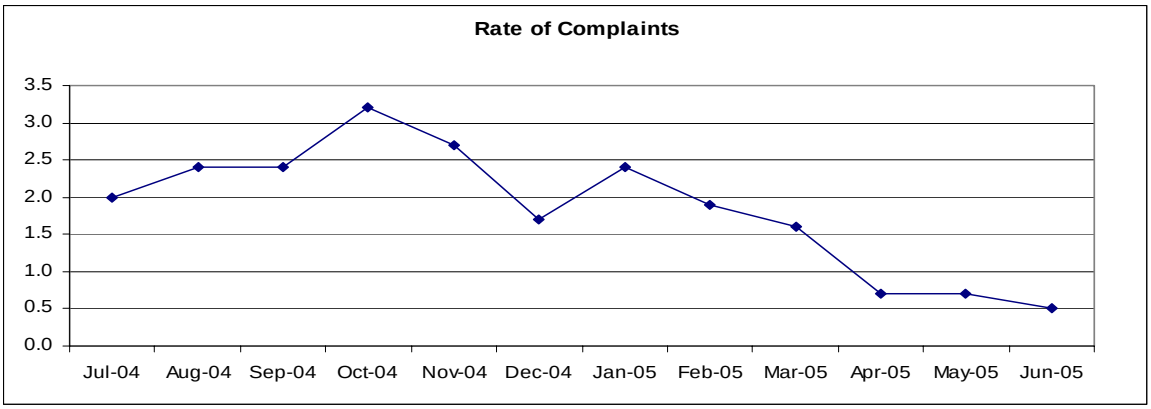
During Fiscal Year 2004-2005, a number of changes were made to the DMRS Complaint Resolution System. DMRS adheres to the philosophy of assisting service recipients, their families, legal representatives, paid advocates or other concerned citizens to resolve matters of complaints at the most direct level possible. For the first time, DMRS now requires that providers develop and implement a formal Complaint Resolution System to address service provision issues and resolutions. Many new aspects have been incorporated into the Complaint Resolution System:

- The DMRS Central Office Protection from Harm staff and Regional Complaint Resolution Coordinators meet most months to ensure consistency in reporting, tracking, categorizing types of complaint issues and sharing methods for resolution of complaints.
- Draft protocols have been written regarding the Complaint Resolution Systems for providers and DMRS.
- The Central Office tracking log of complaints was implemented January 1, 2005.
- Each Regional Complaint Resolution Coordinator and the Deputy Director of Protection from Harm received mediation training to build skills that enable DMRS staff to resolve issues for persons supported and their families. Training was conducted in March 2005.
- DMRS has obtained independent mediation contracts to assist persons served, their families, legal representatives, advocates, etc. in resolving long term, chronic issues.
- Effective April 1, 2005, providers must record complaints, take action and document resolutions achieved. Provider tracking of complaints is subject to review by the DMRS Quality Assurance Team and the Regional Complaint Resolution Coordinators.
- Data regarding the types of complaint issues, timeliness of complaint resolution, rate per 100 persons served and analysis of complaints is gathered monthly on a regional and statewide basis.
- DMRS has hired a State Director of Complaint Resolution who began September 2005.

The following charts give information on Rates of Complaints per 100 People and Percentage of Complaints by Issues Category.

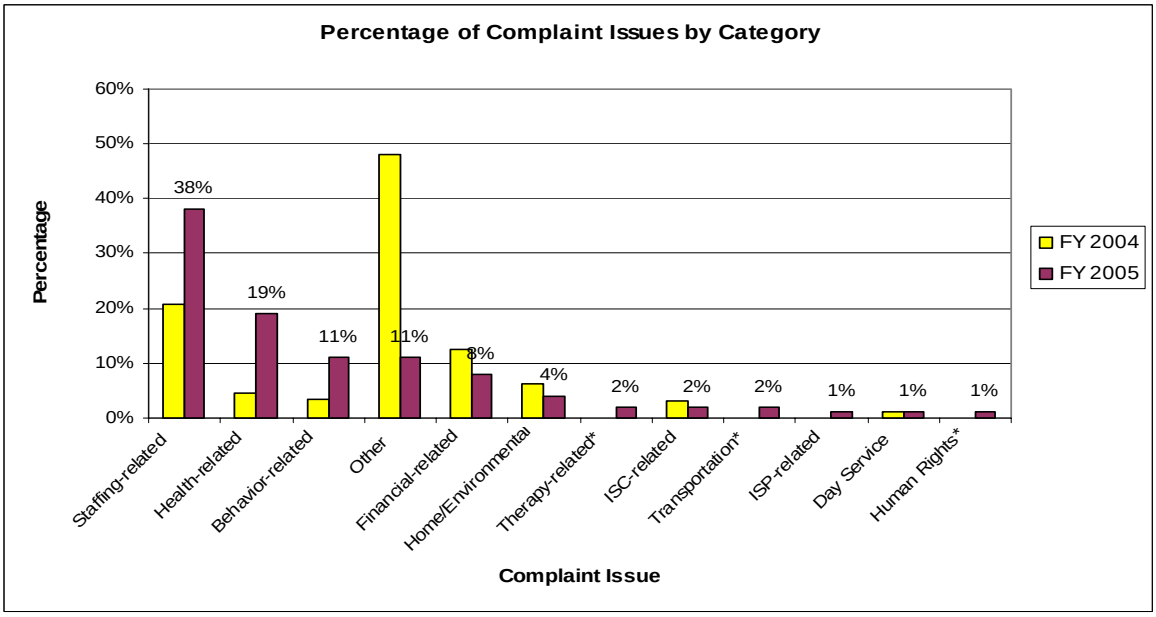
Chart 13 on the following page shows that throughout the year the monthly rate of complaints is a little less than 3 per 100 people. Complaints are counted and categorized by issue which means that 1 complaint may generate several issues. Complaints are to be resolved, to the satisfaction of the complainant, within 30 days. The statewide average of 30 day resolution success was 92.4 % for Fiscal Year 2004-2005.

Chart 13: Statewide Rate of Complaints per 100 People



During Fiscal Year 2004-2005, complaint issue categories were expanded to provide more details so that issues could be addressed more efficiently. For example, the category "Other" was more clearly defined. With this change, DMRS saw a reduction of complaint issues in this category. In Chart 14 below, the "Other" category dropped from nearly 50% last year to 11% this year. Throughout the year, new categories derived from the "Other" category including: "Transportation, Therapy and Human Rights." While these new categories are included in the chart below, the data does not reflect a year's worth of information. Also, as seen in the chart, the largest category of complaints received were "Staffing Related" (38%). Protection from Harm Central and Regional Office staff evaluated the staffing related issues to determine if the change from staffing ratios to staffing plans had an impact on people supported. Analysis of the data grids and narrative reports revealed that there was no negative impact of this significant systems change. However, staffing related issues will be subcategorized to further examine and address concerns expressed by service recipients and their families.

Chart 14: Fiscal Year Comparison - Complaint Issues by Categories



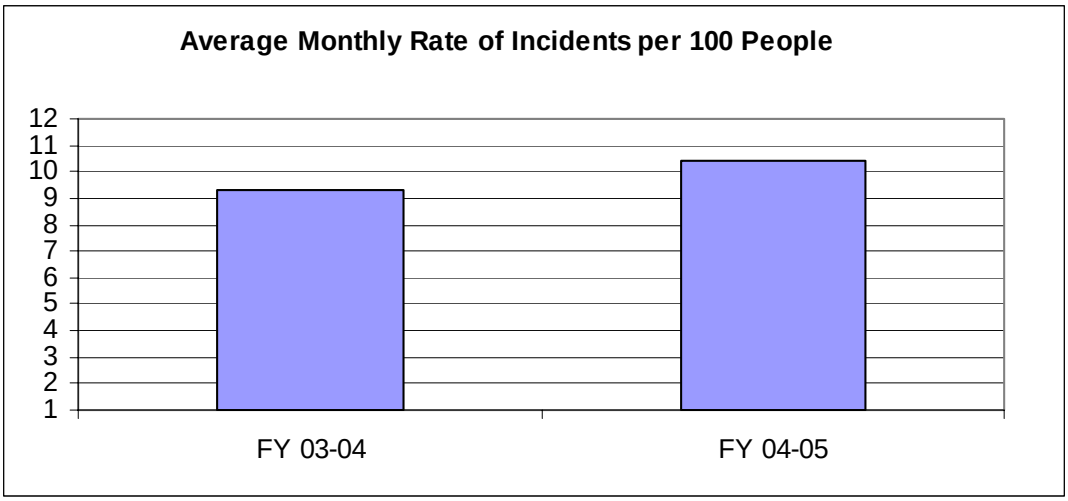
The Incident Management System

During Fiscal Year 2004-2005 DMRS placed heavy emphasis on incident prevention by working with providers to strengthen their incident management systems. In the Provider Manual that became effective in Fiscal Year 2004-2005, day and residential providers were required to continue Incident Review Committees, whose primary responsibilities include ensuring appropriate reporting of incidents, developing and monitoring the implementation of corrective actions in regards to incidents and investigations and managing data with trend analysis.

On the regional level, DMRS compiles and reviews incident information at the individual provider level through the Regional Quality Management Committees. The State Quality Management Committee reviews incident data monthly on a regional and statewide basis. Below is a list of actions completed during Fiscal Year 2004-2005:

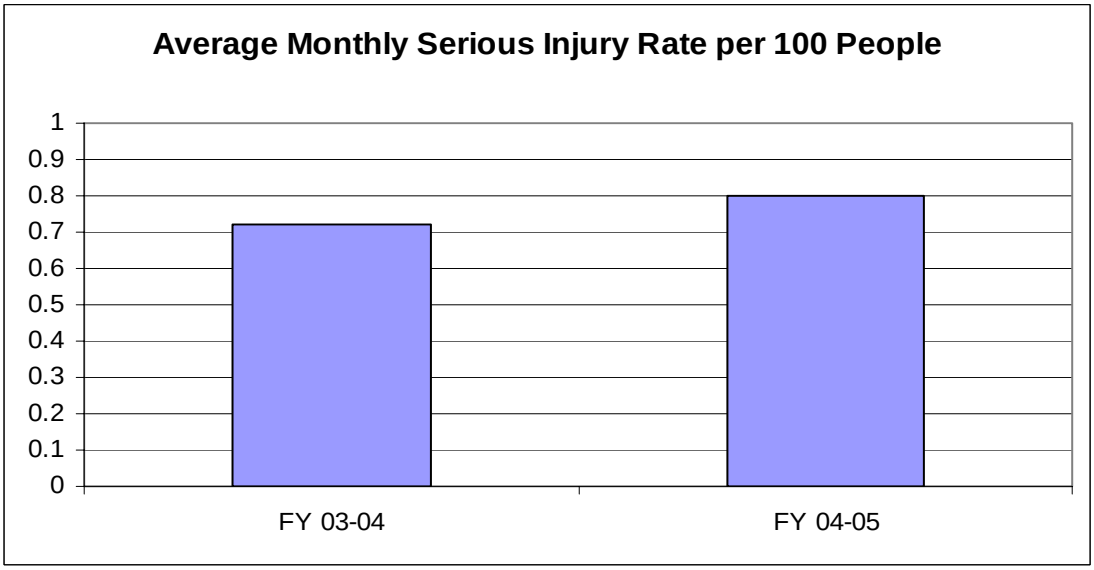
- Revised Protection from Harm protocols became effective April 1, 2005. The protocols included a change in abuse, neglect and exploitation definitions based on the requirements of Tennessee Code Annotated Title 33. All reportable incidents including allegations of abuse, neglect and exploitation are entered in the Incident and Investigations database.
- Prevention planning guidelines were developed and designed to assist providers in preventing harm to persons served through an ongoing program of self assessment targeted at the identification and correction of potentially dangerous conditions or circumstances before they result in harm. Prevention Plans must address areas such as Inside/Outside Environmental Safety, Fall Hazards, Vehicle/Transportation Safety, Wheelchair Safety, Work/Day Site Safety, Meals and Food Storage Safety, Safety on Community Outings, Durable Medical Equipment Safety, Theft Prevention, Medication Administration Accountability and Storage Safety, Emergency Management, etc.
- Initiated the maintenance of a library of Prevention Plans developed by providers who are willing to share their plans with others.
- A new training curriculum and presentation were developed and implemented for the reporting of incidents. The training was customized for direct support staff. An advanced training curriculum for program managers and support coordinators was also included.
- Fall Prevention Training was developed and implemented to address the concerns and issues surrounding individuals who are vulnerable to falls.
- A three day training session was conducted for DMRS Protection from Harm staff that addressed the following topics:
    - ◊ Protection from Harm overview
    - ◊ Quality Assurance overview
    - ◊ Protection from Harm training (Incident Management)
    - ◊ Complaint Resolution overview
    - ◊ Database procedures for Staff Misconduct Investigations
    - ◊ Investigations follow up processes
- Quarterly Provider Incident Management Committees began in October of 2004 to allow for ongoing dialogue regarding Protection from Harm issues.

Chart 15: Average Monthly Rate of Incidents per 100 People



As illustrated in the chart above, the average monthly rate of incidents per 100 people is slightly higher in Fiscal Year 2004-2005 than it was in 2003-2004. It is believed that tighter controls over incident reporting, greater emphasis on provider management systems for incident management, and increased training and dialogue with providers about incident management systems has lead to improved and more accurate reporting and thus, an increase in the incident rate. However, as providers gain more skill and experience in incident prevention planning, the expectation is that the incident rate will eventually decline. DMRS will monitor incident reporting during Fiscal Year 2005-2006 and compare it with data from Fiscal Year 2004-2005 for trending purposes.

Chart 16: Average Monthly Serious Injury Rate per 100 People



In Chart 16 above, the average rate of serious injury per 100 people has risen slightly from Fiscal Year 2003-2004. Due to the extensive changes made to the Protection from Harm System, an increase in rates was expected. The changes revolved around clarification of definitions, provider requirements, and additional

training. Although the increase is not significant, it is carefully monitored and DMRS expects an eventual decline in the serious injury rate as the system changes begin to stabilize. DMRS will monitor the serious injury rate, both for individual providers and on a regional and statewide basis to compare the data from Fiscal Year 2004-2005 with the data of 2005-2006.

The injury rate per 100 people in the population at large, as reported by the CDC in a survey in 1994**, is 23.8 per year. The definition of injury used by the CDC appears to be comparable to the DMRS definition of serious injury.

The rate of serious injuries per 100 DMRS waiver recipients for Fiscal Year 2004-2005 was 9.7.

*Scheerenberger, R.C. (1992). An exploratory study of accidents and injuries among residents in public residential facilities. *Superintendent's Digest, 11*, 47-59.

**National Center for Health Statistics. (1995). Current estimates from the National Health Interview Survey, 1994. (DHHS Publication No. [PHS] 96-1521). Hyattsville, MD: Centers for Disease Control and Prevention. Episode of injury defined as each time a person was involved in an accident causing injury that resulted in medical attention or at least a half day of restricted activity, which is comparable to the DMRS definition of serious injury.

The Investigation System

Fiscal Year 2004-2005 brought a focused effort to treat cases of abuse, neglect and exploitation as seriously as possible and is evidenced by results of Abuse Registry placement. (See Chart 18) Protection from Harm definitions were changed and are now based on Tennessee Code Annotated Title 33. DMRS investigators now conduct investigations of allegations of abuse, neglect and exploitation for any person receiving services regardless of class action lawsuit status.

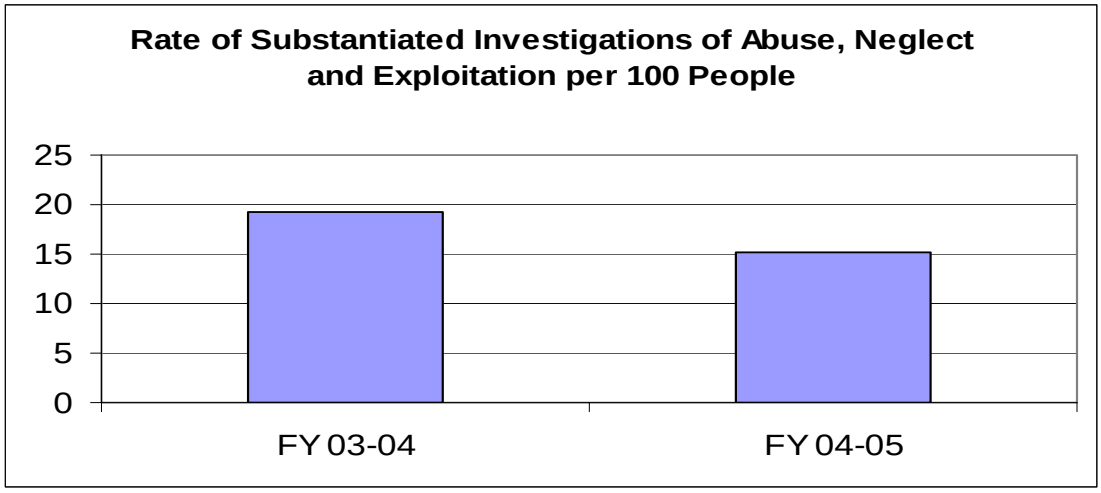
On a regional level, DMRS investigators have been assigned to review provider conducted investigations that involve Reportable Staff Misconduct. Participation in the Regional Quality Management Committee meetings by the DMRS investigators for Staff Misconduct brings immediate information regarding provider investigation rates and appropriateness of actions taken regarding the event. A Protection from Harm Provider Profile has been developed for those agencies for which the Quality Management Committee is concerned about frequency of incidents and investigations.

Identified below are new initiatives and changes that were made during the last fiscal year in the Investigation system:

- Effective April 1, 2005, DMRS investigators began conducting abuse, neglect and exploitation ($50 or above) investigations for all persons served, regardless of class action lawsuit status.
- The Reportable Staff Misconduct Investigation/Review protocol and format was developed and implemented. This format requires providers to report incidents of Staff Misconduct that cause no harm to the person supported and present minimal risk of harm. Such reportable events must include a description of the incident and what actions are taken to remedy the situation.
- Effective April 1, 2005 providers began conducting Staff Misconduct Investigations/Reviews. Providers conduct Staff Misconduct Investigations for allegations of exploitation under $50.
- An Abuse Registry Referral tool was developed and implemented January 1, 2005 that is applicable to all substantiated investigations. This tool assists each DMRS investigator in determining if the perpetrator's actions warrant referral to the committee for possible placement on the Abuse Registry.

- An Investigation Review process was developed and implemented April 1, 2005 that allows the person served, their families, legal representatives, providers and others who disagree with the conclusion of a DMRS Final Investigation Report to request further evaluation and consideration.
- A Perpetrator Search Function was developed and is currently being tested. This program will be available on the DMRS website so that providers can enter current employee and applicant data to determine if they have ever been involved in a substantiated case of abuse, neglect, mistreatment or exploitation within the DMRS service system.
- Disciplinary Guidelines were established that providers can use to determine appropriate actions as a result of substantiated abuse, neglect or exploitation.
- DMRS has hired a Director of Investigations who will begin October 2005.
- A new position has been established which will be dedicated to DMRS internal Quality Assurance for Protection from Harm.

Chart 17: Rate of Substantiated Abuse, Neglect and Exploitation per 100 People Fiscal Year Comparison



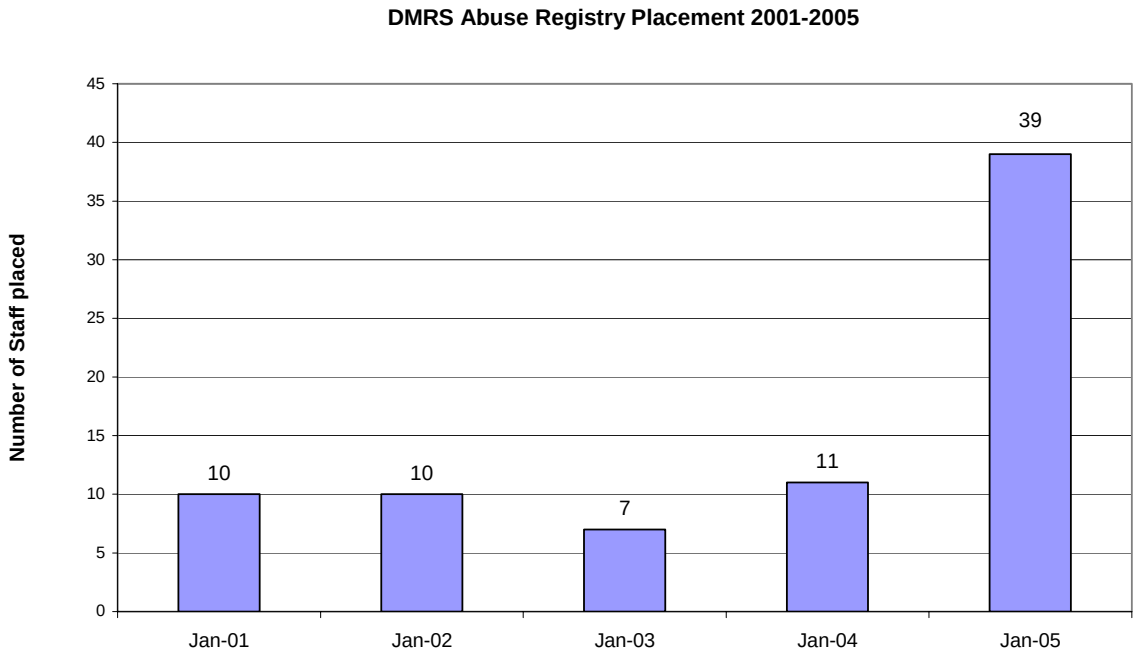
As can be seen from the above chart, the rate of substantiated abuse, neglect and exploitation fell from 19 substantiated cases per 100 people in Fiscal Year 2003-2004 to 15 substantiated cases per 100 people in Fiscal Year 2004-2005.

DMRS takes seriously any substantiated case of abuse, neglect or exploitation. In order to help protect persons served from repeat offenders of abuse, neglect and exploitation, an Abuse Registry is used to list employees who have been substantiated as a perpetrator in an investigation. Providers are required to check the list when hiring new employees and are prohibited by law from hiring anyone who has been placed on the registry.

Since January 1, 2005, an Abuse Registry referral tool was developed and must be completed for each DMRS substantiated investigation that meets identified criteria. The tool has been effective in ensuring that appropriate referrals are submitted to the committee for consideration. DMRS has committed to ensure that egregious events of abuse, neglect and exploitation are submitted to the Abuse Registry Committee to prevent staff that cause harm from working with the DMRS service recipients. The chart below shows the

number of people who have been placed on the registry through DMRS protocols. It is apparent that significant improvement in using the Abuse Registry committee as a safety initiative is effective.

Chart 18: DMRS Abuse Registry Placement Chart



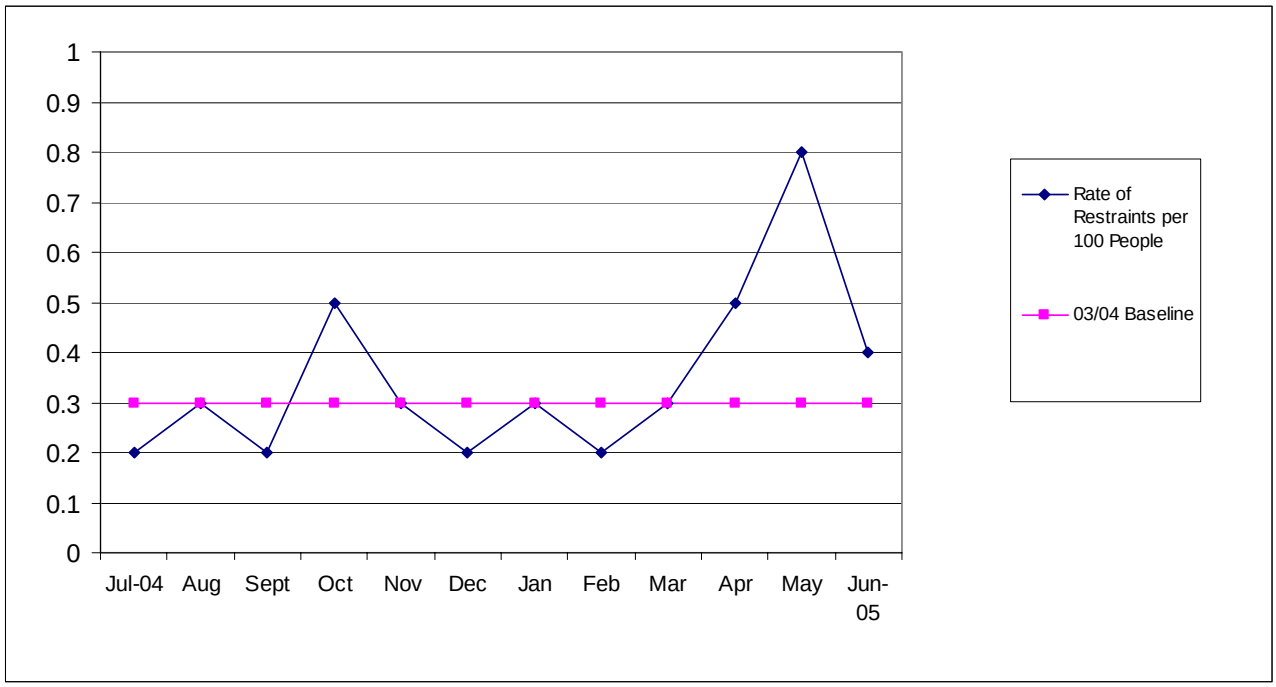
DMRS makes the commitment to ensure that all service recipients benefit from the basic protections in health and safety. The past year has been marked with significant improvements in Protection from Harm initiatives by the Division of Mental Retardation Services. Although much has been accomplished in this arena, there is much more to do. It is readily acknowledged that the evolution of the DMRS Protection from Harm system is challenging and will require an ongoing transformation. Identified areas for improvement that directly impact the basic protections of service recipients include recruiting and maintaining respectful and well trained staff, developing effective Provider Incident Management Committees, increasing skills of DMRS investigators, utilizing Incident data to make management decisions and responding appropriately to events. The Division continues initiatives and efforts to assure that service recipients live and work in safe environments and are served by providers who maintain strong Protection from Harm Systems.

Behavior Services: Restraints

DMRS Behavior Services include functional assessments to develop positive behavior supports for persons needing a managed environment. On occasion, behaviors may become so intense that special restraining measures must be taken to protect the person from harm or to protect others from harm. Such measures must be monitored to reduce any risk of injury as well as protect the rights of individuals. Below is a summary of the sanctioned use of restraint in the community service system.

Chart 19 shows the rate of restraints that occurred per 100 people. This means that the identified points on the graph show how many restraints occurred for every 100 people served.

Chart 19: Rate of Behavior Incidents Utilizing Restraints per 100 People



The rate of restraints usage remains low for Fiscal Year 2004-2005, despite a large increase in the number of persons served and an increase in the movement of individuals with behavior challenges from the developmental centers and the mental health institutes. The rate per one hundred individuals for Fiscal Year 2004-2005 has risen slightly over that of 2003-2004, and is likely to be due to the increasing numbers of individuals transitioning from these facilities.

During this year, the Regional Behavior Analyst directors initiated a system to review the behavior support plans of community behavior providers and the number of applications of restraints. Plans are reviewed each month for proper design, effectiveness, and the application of restraints.

During Fiscal Year 2004-2005, Intensive Consultation Teams in each Regional Office were initiated to provide consultation and other supports to help prevent, manage, and respond to behavior/mental health crises. The Intensive Consultation Teams have integrated their services with the services of the Regional Behavior Analysts. These integrated supports have aided in more rapid discharge from the mental health institutes and in the low levels of restraint usage.

Mortality Reviews

DMRS maintains data on deaths of service recipients in both the community setting and in the developmental centers. It is very important to the Division to review mortality data for trends and healthcare issues of the service population.

Between July 1, 2004 and July 1, 2005, there were a total of 89 deaths, or 1% of the total population that the DMRS serves. Of the total number of deaths, less than 1% was individuals who had resided in the developmental centers. Of the total number of deaths, 73 of those (or 1%) were individuals who had resided in the community.

The following charts depict the number of deaths per 100 people in the community and in the developmental centers.

Chart 20: Mortality Rate per 100 People in the Community

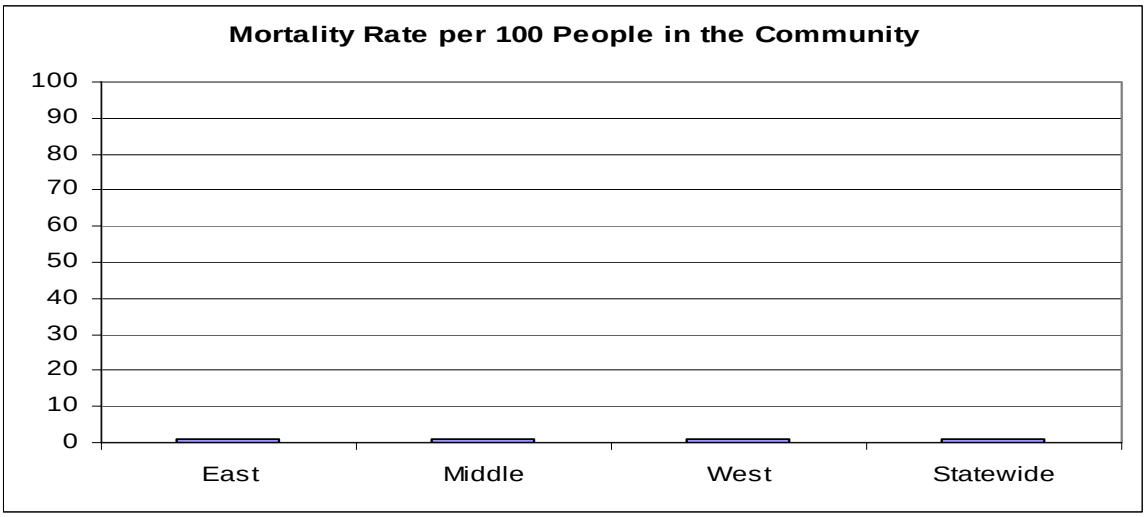
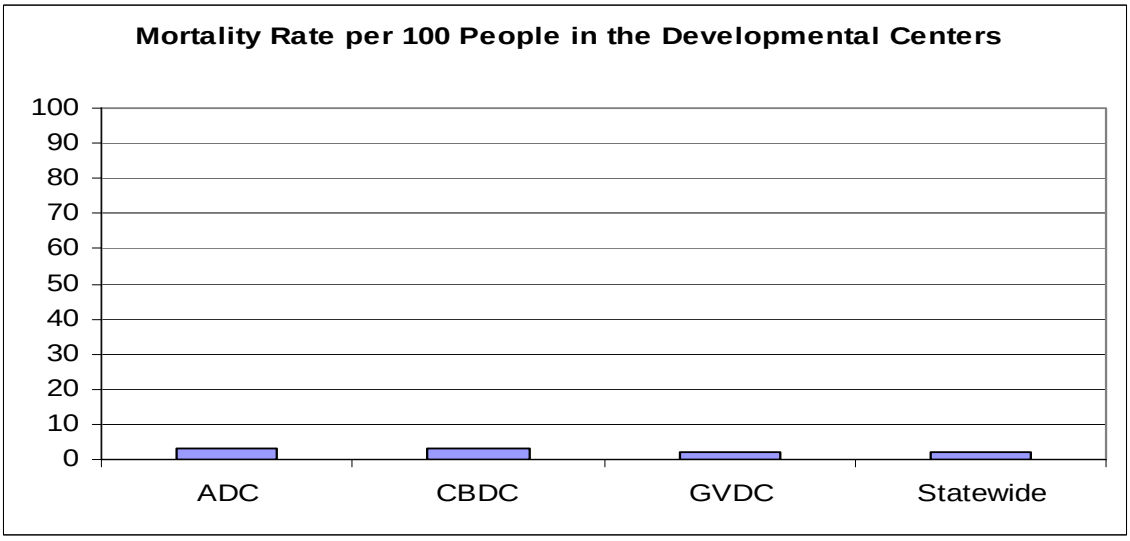


Chart 21: Mortality Rate per 100 People in the Developmental Center



The Mortality death rates in the developmental centers were higher than in the community: 2 per 100 people in the developmental centers compared to 1 per 100 in the community. However, people who died in the developmental centers had an average Physical Status Review Level (PSR) of 5.5 while to the average PSR Level for those who resided in the community was 3.9. The PSR identifies risk factors as two or more chronic health problems that destabilized at least once within the last twelve months. Or, had a combination of chronic heath conditions that are predictably unstable and require intermittent intervention by a licensed nurse, primary care provider, and/or required licensed professional intervention more than every two hours in a twenty-four hour period. Therefore, it is reasonable to expect a higher Mortality death rate in a more medically fragile population.

Of particular concern to the Division are deaths that are related to choking and aspiration. The population served is vulnerable to these conditions. In identifying these issues in mortality data, the Division is able to pinpoint areas of enhanced training and care that is needed. The Division has approved and distributed a Risk Assessment Identification Tool, which support coordinators use for all service recipients living in the community. This assessment helps to identify potential risks for service recipients, including risks for choking and aspiration, such as pica, eating too quickly or without chewing, and having a previous history of aspiration.

Developmental Centers Risk Analysis

DMRS maintains comprehensive data at each of the 3 developmental centers for measurements of a safe and humane environment. This data collection and analysis began in August 2003. The Fiscal Year 2004-2005 shows positive movements of incidents falling below expected target rates. The goal of this trend analysis is to reduce the risk of individuals in the centers of experiencing incidents. The following information and charts show the progress toward keeping people safe.

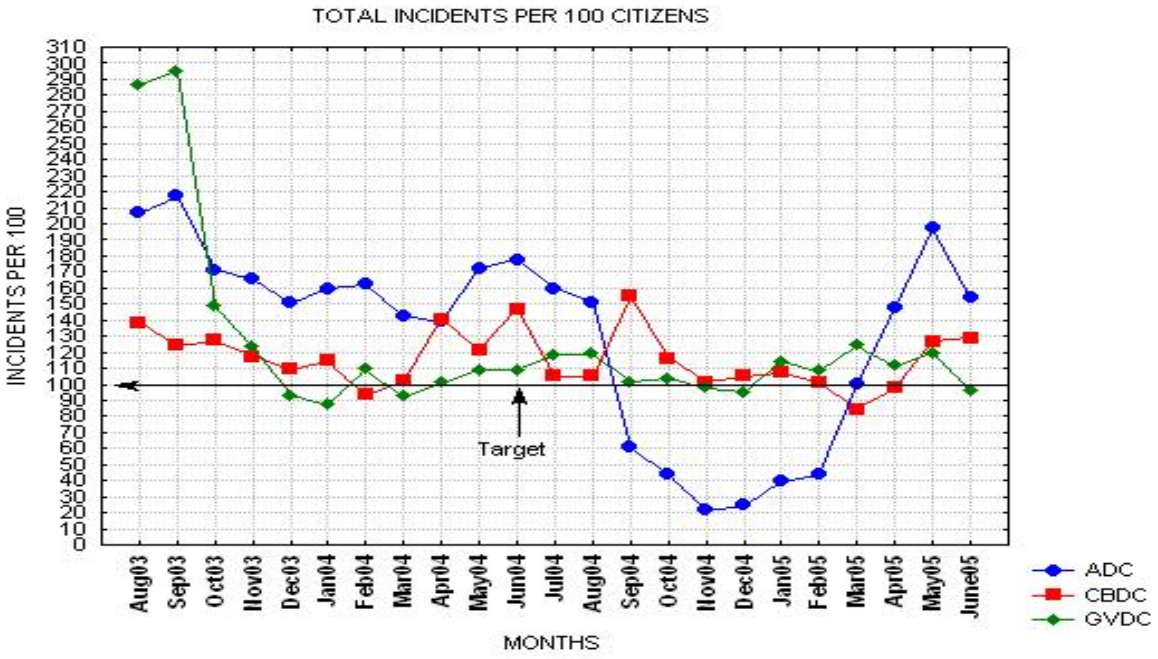
The data is comparable beginning August 2003 to the end of June 2005. While a full report is completed monthly that looks not only at the items listed in this section, but other areas as well (self-injurious behavior, witnessed and discovered injuries, serious injuries, etc.). This section of the Annual DMRS Report will only focus on Total Risk, Substantiated Abuse and Substantiated Neglect. The Division began utilizing new definitions concerning staff misconduct and mistreatment. This data collection began in April 2005 therefore it is not addressed in this report.

The Total Risk scores are comprised of the total number of all types of incidents at the developmental centers. This would include incidents of choking, PICA, witnessed and discovered injuries, physical aggression, etc.

A target rate of no more than 100 incidents per 100 citizens per year (or no more than 1 incident per person per year) has been set for the developmental centers. The rate of "per 100 citizens" is calculated by dividing the total number of incidents by the census of the facility, and multiplying by 100. This method of calculating data is a standard approach within the health care industry. By approaching the data in this manner it not only makes it easier to compare within the state, but with other state-run and private facilities across the country.

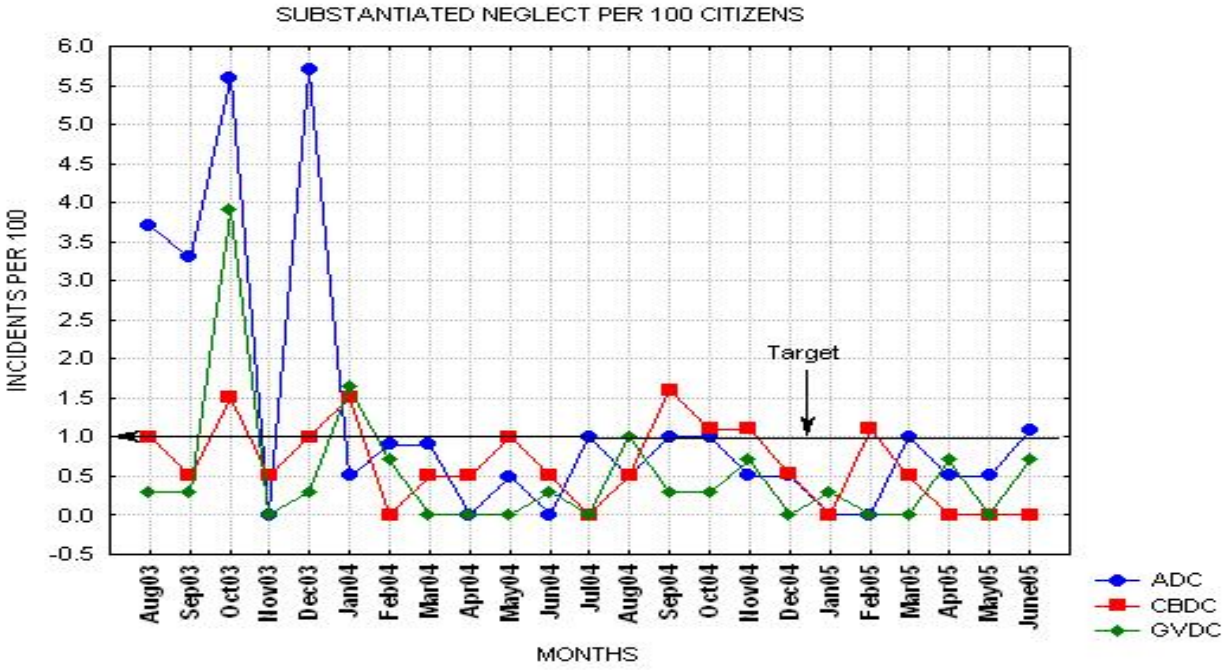
The following graph shows the **Total Risks** incidents per 100 citizens per month. The number of incidents has remained relatively stable for Clover Bottom Developmental Center (CBDC) and Greene Valley Developmental Center (GVDC) although CBDC did show a spike for May and June. There is an upward trend for Arlington Developmental Center (ADC). However, officials at the centers report that this trend is decreasing as the new fiscal year proceeds. The chart shows a relative decline overall from August 2003.

Chart 22: Total Incidents per 100 Citizens in the Developmental Centers



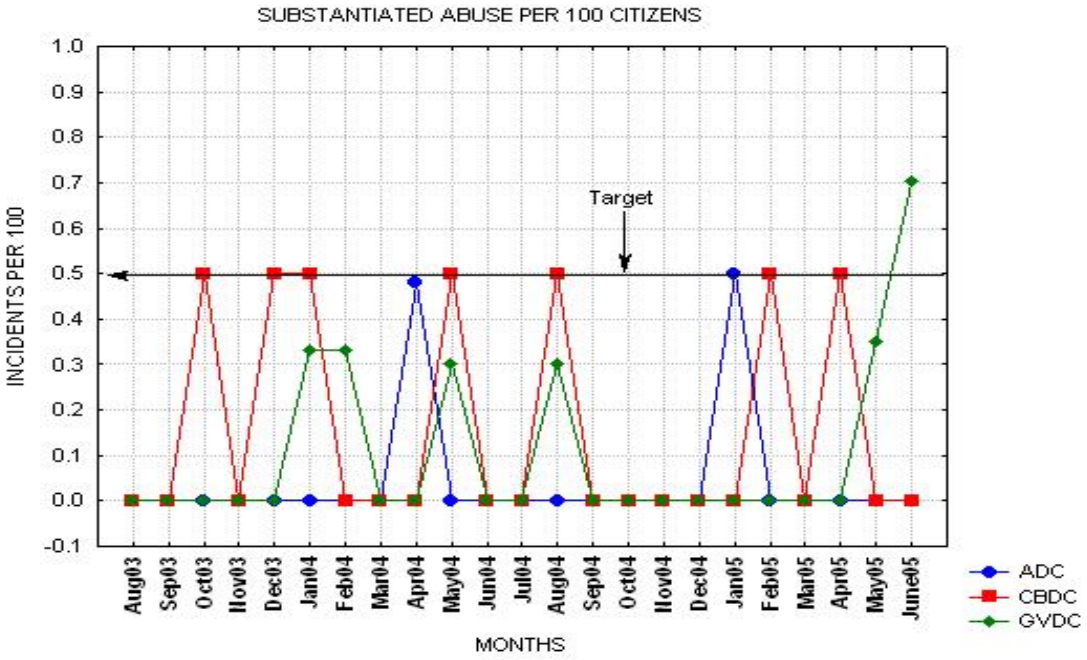
The second graph below shows the **Total Substantiated Neglect** incidents per 100 citizens per month. All facilities were at or below the target since November 2004.

Chart 23: Substantiated Neglect per 100 Citizens in the Developmental Centers



The graph below shows the **Total Substantiated Abuse** incidents per 100 citizens per month. The rate has been low. The Target is no more than .5 incidents per 100 citizens. GVDC exceeded the target for the first time.

Chart 24: Substantiated Abuse per 100 Citizens in the Developmental Centers



As stated previously, a monthly risk index report is completed tracking areas of risk at the developmental centers. The monthly report is sent to the Superintendents of the Developmental Centers so they can use the information to improve the provision of services and conditions at the centers and avoid further risk of harm to the citizens. Below are several ways officials at the centers use the information:

- Develop plans of correction to address overall issues regarding risk;
- Increase specific services as well as revise plans (such as a behavior plan) for an individual in response to citizen specific recommendations;
- Go back to the raw data and categorize it by injury type to determine the numbers for each type. Review possible causes and determine possible preventative measures that could be done;
- Review the locations where injuries occurred to see if there are any environmental or maintenance issues that need to be addressed;
- Meet with home team leaders that may have had a high number to discuss possible causes of how they occurred and ways to prevent; and
- Leadership and Incident Review Committees act upon the recommendations to decrease and/or eliminate risks targeted in the monthly report as well as the quarterly analysis report.

Conclusion

Fiscal Year 2004 - 2005 was a year of implementing the new systems designed during the previous year to address the waiting list and Brown lawsuit, the CMS moratoria on the Waivers, the Clover Bottom and Arlington lawsuits, and general improvement in delivering quality services. Many of these implementation activities are evolutionary in nature and new initiatives arise as the new systems mature. As DMRS embarks on its journey into Fiscal Year 2005 – 2006, the task at hand is to distill from the achievements of the previous year new opportunities for progress in the coming year. Planning is already underway for the following:

- Direct Support Staff. DMRS, along with Tennessee's Direct Support Staff Professionals organization (DSPAT), recognizes that no service delivery system can be successful without well trained and caring direct support staff. Components of a stable work force include adequate compensation, professional credentialing, and recognition. In conjunction with DSPAT, DMRS is developing plans to address all these issues.

- Provider Capacity. During Fiscal Year 2004 – 2005, almost a thousand new people began receiving Waiver services. This has stretched provider capacity to its limits and has opened opportunities for the expansion of current providers and the approval of new providers. A comprehensive study of the anticipated needs of service recipients and the characteristics and capabilities of the provider community is currently underway in the West Region. The goal will be the development of a capable provider network. In the future, this planning effort will be expanded to the Middle and East Regions of the State.

- Implementation of Quality ISPs. Quality Assurance monitoring data has consistently identified that there is ample room for improvement in the quality of ISPs and in their implementation. Recognizing that the ISP and its implementation is the heart and soul of the service delivery system, DMRS has undertaken to develop a Resource Manual and a concomitant training program designed to improve ISP quality and to improve provider implementation of ISPs.

- Protection from Harm. An important component of keeping people safe is to remove abusive staff from the work force. A new system is being planned which will allow repeat offenders to be identified and prevented from moving around between providers without a record of pervious work history.

- Housing. During Fiscal Year 2005 – 2006, DMRS will implement a plan worked out with the Tennessee Housing and Development Agency (THDA) in which twelve new community-based homes in each of the coming years will be constructed. DMRS will retain ownership of the homes and be responsible for their maintenance, but the people living in them will be Waiver participants who receive services through community residential providers.

- Employment. Socialization, income, and personal achievement are all benefits of having a job. The complexity of day services is predicated upon individualization. No one model fits all. DMRS recognizes the value of both supported employment and facility-based day services, but also the tension that exits between the two. This will be an important issue to explore further in 2006.

- Tennessee's Home and Community Based Waivers are mostly for people who need residential services. However, Tennessee also has a Self-Determination Waiver with a $30,000 a year cap. The potential of this new Waiver to meet the needs of people who do not require residential services has yet to be realized. DMRS will continue to introduce the Self-Determination Waiver to people on the Waiting List whose service needs could be adequately met within the financial limits of the cap.

The above are but a few of the initiatives that have spun out of the implementation the new DMRS systems during the past year. The expectation is that as Fiscal Year 2004 – 2005 was marked by the achievement of putting new systems into place, Fiscal Year 2005 – 2006 will be characterized by maturing the new systems and by further refining them by addressing the new challenges they present.

We hope you have found this report informative. If you have questions about any portion of the Report or would like more information about DMRS, please contact the Compliance Unit in the DMRS Office in Nashville at:

Division of Mental Retardation Services
Attn: Compliance Unit
Andrew Jackson Building
500 Deaderick Street, 15th Floor
Nashville, Tennessee 37243

Or by phone:

Compliance Unit Director: Mr. John Kaufman
(615) 532-6542

Tennessee Department of Finance & Administration
Division of Mental Retardation Services
Authorization No. 344030, 514 copies printed November, 2005.
This public document was promulgated at a cost of $1.69 per copy.