Challenges and Opportunities

An Analysis of the Current Florida System of Services for Persons with Disabilities and Future Directions for System Change

A Report to the Florida Developmental Disabilities Council, Inc.

by Liberty Resources, Inc.

Human Services for Better Living

and

The Center on Human Policy at Syracuse University

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FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL, INC.

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CHALLENGES AND OPPORTUNITIES

AN ANALYSIS OF THE CURRENT FLORIDA SYSTEM OF SERVICES FOR PERSONS WITH DISABILITIES
AND
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November 2005

Introduction

The FDDC issued a competitive Request for Proposals designed to provide Council members with current information on the trends and strengths in the Florida system, as well as the challenges that prevent individuals with developmental disabilities from achieving a quality of life comparable to other nondisabled citizens in Florida. Liberty Resources, Inc., in partnership with the Center on Human Policy at Syracuse University conducted this project. The components included: six forums in Florida to obtain input from individuals with disabilities, families, providers, direct support staff, administrators, and others; interviews with Florida stakeholders; review of state and national reports and materials; and consultation with national experts.

This report is organized into three sections: Section I, "Florida: A National Perspective," provides data about the Florida service system within the context of national data and trends; Section II, "Areas of Emphasis," contains information on topical areas, based upon the Administration on Developmental Disabilities' areas of emphasis. These are: education, health, formal and informal supports, transportation, housing, employment, and quality assurance. Section III, "Opportunities for Systems Change," points to key opportunities within Florida related to promoting quality lives in the community.

Florida: A National Perspective

A review of national data yields the following conclusions about Florida's developmental disability service system in comparison with other states:

- Spending for developmental disability services in Florida has increased significantly in recent years. Continued increases in spending would be necessary for Florida to match the national average or the spending in most other large states.

- Florida institutionalizes fewer people in state facilities per its general population than the national average and all but one of the other large states. Yet, Florida lags behind most other states, including other large states, in deinstitutionalization over the past 10 years. Although Florida has closed state institutions, there was little reduction in the total number of people

served in institutional settings through 2004. Florida stands out from most other states in the percentage of children and people with mild intellectual disabilities in its state institutions.

- Florida serves significantly fewer people with developmental disabilities in its residential system in settings of all size categories (1-6, 7-15, 16+) per the general population than the national average and in most other large states.

- Florida has significantly increased the number of participants receiving and spending for individual (supported living, personal assistance) and family support services in recent years. Florida also compares favorably with others in the percentage of people who receive residential services in their own homes. These are strengths in the current service system. The decline in the number of people participating in and the funding for supported employment in recent years is a weakness. APD has committed to a five-year plan to expand supported employment throughout the state.

Areas of Emphasis

The areas of emphasis include: education, health care, formal and informal supports, transportation, housing, employment, and quality assurance. Within each of the areas of emphasis, Florida has distinct trends, initiatives, and organizations. From the perspective of stakeholders, there are numerous challenges that need to be addressed. In order to address these, within Florida there are many strengths and resources that can be used as a foundation. Also, nationally, there are many promising practices and resources to draw upon.

Opportunities for Systems Change

Within the areas of emphasis, there are distinct opportunities for systems change in Florida. Opportunities have been identified based on a confluence of events which are already occurring that are likely to support system change initiatives, and identifiable themes that represent an emerging consensus around challenges and a vision for the future. As the FDDC considers establishing strategies and planning goals which promote a more inclusive quality of life for individuals with developmental disabilities, the identified opportunities may provide some directions which hold the most promise for change.

Early Childhood Education and Health: There is an opportunity for stakeholders in Florida to come together to engage in strategic planning to examine and align the early childhood health, early intervention, and education (Part B) systems, build infrastructure, and enhance and maximize the resources that exist for children and families.

Education: Florida has a unique opportunity to address a significant systems performance issue: both instruction and the alternate assessment system in Florida's schools can be designed to include the general curriculum content as well as relevant

functional and skill-building education that will contribute to improved postsecondary outcomes for students with developmental disabilities.

Family Preservation and Permanency Planning: Florida has the opportunity to embed family preservation and permanency planning into the value base of its service system, by considering new ways of supporting families, and by instituting mechanisms that ensure that children remain with their primary caregivers or in other long-term family relationships.

Employment: The system is ready to respond to the opportunity for increasing competitive employment outcomes for persons with developmental disabilities.

Adult Health Care: There is a prime opportunity to develop and recommend a model for Medicaid reform to meet the needs of persons with developmental disabilities.

Housing: The opportunity exists to develop a new initiative to increase availability of safe, affordable, accessible housing for people with developmental disabilities.

Inclusive Community Living for Adults: There is an opportunity for stakeholders to unite around the goal of expanding funding and increasing the numbers of people who are supported to live in homes they have chosen in the community, with people with whom they want to live or by themselves, and with both formal and informal supports.

Workforce Issues: Stakeholders in Florida could come together to determine the extent of workforce retention and recruitment problems in the state, and develop strategies to address them.

In order to take advantage of these opportunities, Florida already has many strengths and resources. There are many individuals and organizations that are committed to systems change that promotes further control, choice, and quality of life. Further, there are many resources and much knowledge within Florida that can be built upon in order to ensure that all Florida citizens with developmental disabilities will experience an inclusive and self-determined life.

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CHALLENGES AND OPPORTUNITIES: AN ANALYSIS OF THE CURRENT FLORIDA SYSTEM OF SERVICES FOR PERSONS WITH DISABILITIES AND FUTURE DIRECTIONS FOR SYSTEM CHANGE

INTRODUCTION

The Florida Developmental Disabilities Council, Inc. (FDDC) will prepare a "Five Year Plan" covering the period of 2007 through 2012. This plan will guide the Council's public policy agenda and administration of funds authorized under the federal Developmental Disabilities Assistance and Bill of Rights Act to improve community services to support the needs of persons with developmental disabilities in achieving an inclusive and self-determined quality of life. In recognition of the challenges facing both persons with developmental disabilities and their families, the FDDC issued a competitive Request for Proposals designed to provide Council members with viable, useful, and current information on the trends, strengths, and challenges that prevent individuals with developmental disabilities from achieving a quality of life comparable to other nondisabled citizens within the State of Florida. The information obtained through this project will be used to guide the Council in its planning process.

Liberty Resources, Inc. in partnership with the Syracuse University Center on Human Policy was selected by the Council to conduct this project. Work on this project took place during the period of June 2005 through November 2005. The data and information which follows therefore reflect this time period. The components of the project included:

1). Forums. Six forums were conducted throughout the state in July and August 2005. During this time period, there was also an option of internet forum participation. Forums were publicized through an extensive internet and hard copy mailing list, as well as newspaper announcements. Special attention was focused on outreach to families and people with disabilities. Overall, 166 people participated in the forums. This included individuals with disabilities, parents and other family members, providers, public officials, and advocates.

2). Interviews with Florida Stakeholders. The FDDC supplied a list of Florida stakeholders. Attempts were made, in some cases multiple times, to contact the individuals on that list. A total of 35 interviews were conducted. (A complete list of those who were interviewed is in the Appendix A).

3). Review of State of Florida Documents and Reports. We reviewed numerous documents and reports on Florida that people sent to us, referred us to, or that we found through library and web searches. (A list of the documents we reviewed is in Appendix B).

4). Review of National Reports and Publications. We reviewed numerous reports and publications that were referred to us by Florida stakeholders and national

consultants and that we have identified through national searches for promising practices. (A list of the documents we reviewed is in Appendix C).

5). Consultation with National Experts. We consulted with national experts through phone interviews and e-mail to get input on Florida best practices, national trends and best practices, and to review a draft of the document. A total of 14 national experts were consulted for this project. (A list of these national expert consultants is included in Appendix D).

Through the combination of these resources critical information was obtained for use by the Council members in the development of the goals and objectives for the next five years. The information comes from all of the sources (e.g., forums, stakeholder interviews, national expert interviews, reports and other documents). Some of the information is factual (e.g., various statistics, information about system design); other information represents the perspectives of various individuals and organizations (e.g., much of the information from the forums and the interviews). Data from the forums and interviews was reviewed by a team of researchers from Liberty Resources and the Center on Human Policy. Based on this review, as well as the review of state and national literature, we generated themes based on perspectives that arose multiple times across sources.

The organization and content of this report is intended to identify both challenges and opportunities within Florida. Section I, "Florida: A National Perspective," provides data about the Florida service system within the context of national data and trends. Section II contains information on the topical areas, based upon the Administration on Developmental Disabilities' areas of emphasis. These are: education, health, formal and informal supports, transportation, housing, employment, and quality assurance. Section III points to key opportunities within Florida related to promoting quality lives in the community.

Project staff wish to express their sincere appreciation to everyone who helped with the information gathering activities associated with this project, particularly to the persons with developmental disabilities, the parents and other family members who graciously assisted with this project.

SECTION I: FLORIDA: A NATIONAL PERSPECTIVE

Florida is a unique state. It does not fit neatly into the regional categories in which most other states are normally placed. With a population of over 17 million, Florida is now the nation's fourth largest state, after California, Texas, and New York. It is home to an estimated 240,000 people with developmental disabilities and their families (Florida Blue Ribbon Task Force, 2004).

This section of the report examines data on Florida's developmental disability service system in comparison with other states. Unless otherwise indicated, the analysis is based on ongoing national studies conducted by research centers at the University of Minnesota (Prouty, Smith, & Lakin, 2005) and the University of Colorado (Coleman Institute for Cognitive Disabilities, 2005). The terms used in this section are taken from those sources and have been used for comparative purposes across the country. Each state, including Florida, reports their data annually to these national research centers. Before we compare Florida with other states, we provide an overview of Florida's system.

Florida's Developmental Disability System

This section summarizes Florida's developmental disability service system and analyzes recent trends in the system.

Profile. Florida's residential service system served a total of 16,198 people with developmental disabilities in 2004. Of these, 19.8% or 3,210 people were served in public or private institutional settings: state institutions (1,399), private residential facilities (1,465), and nursing homes (278). Sixty-three percent, or 10,432 people, were served in settings for six or fewer people. In 2004, a total of 14,348 people with developmental disabilities were served in non-vocational day programs or work programs.

A number of people with developmental disabilities and their families benefit from individualized services designed to enable people to live in their own homes or to work in regular employment settings. As of 2004, 2,958 persons benefited from supported employment programs. A total of 3,833 persons were in supported living situations and 654 persons received personal assistance services. During 2004, 17,108 Florida families received family support services.

According to the Coleman Institute, spending for developmental disability services in Florida totaled $1,269,300,000 in 2004. A significant portion of services is funded through the federal-state Medicaid program. Ninety-six percent of funds spent for services are matched by federal dollars. Federal Medicaid revenues were $628.9 million in 2004: $406.6 million for the Home and Community-Based Services (DD and FSL) Waivers; $210.1 million for public and private Intermediate Care Facilities for the Mentally Retarded (ICFs/MR); $12.2 million for consumer directed care; and $22,000 for the supported living waiver.

Recent Trends. An analysis of recent Florida data reveals both positive and negative trends. *Positive* trends include the following:

- Spending for developmental disability services (adjusted for inflation) increased significantly between 2002 and 2004, approximately 17.9%.

- DD and FSL Waiver spending per recipient increased significantly between 2002 and 2004, from $20,500 to $27,713 or an increase of over 35%.

- The number of persons with developmental disabilities served in community settings for six or fewer people continues to steadily increase, from 9,554 people in 2003 to 10,342 people in 2004 or approximately 8.2%. Since 1999, the number has almost doubled, from 5,627.

- The number of persons served in supported living increased significantly from 3,464 in 2003 to 3,833 in 2004, an increase of almost 10.7%. Funding for supported living similarly increased from $22.6 million to $27.5 million, or approximately 21.5%.

- The number of persons receiving personal assistance services, while still small, increased from 525 in 2003 to 654 in 2004, or roughly 24.6%. Funding increased from $4.4 million to $5.6 million, an increase of 26.9%.

- The number of families receiving family support services increased from 16,248 in 2003 to 17,108 in 2004, or approximately 5.3%. Spending for family support services increased from $191 million to $222.1 million, or approximately 16.2%.

Negative trends include the following:

- The number of people living in public and private institutions has remained relatively constant over the past five years. From 1999 to 2004, the populations of public and private institutions only declined from 3,295 to 3,210 the populations of state institutions only declined from 1,512 to 1,377. From 2003 to 2004, there was a negligible change in institutional populations; 46 fewer people lived in state institutions and 53 fewer people lived in both public and private institutions. Florida has continued to close state institutions with the Landmark facility closing in June 2005.

- According to the Coleman Institute (Braddock et al., 2005), the number of people with developmental disabilities in supported employment has declined precipitously in recent years. This number reached a peak of 4,298 people in 2001. By 2004, this number had declined to 2,958, down from 3,040 in 2003.

- Spending on supported employment parallels trends in the number of people in supported employment. In 2001, approximately $11.1 million was spent on supported employment in Florida. By 2004, this number had dropped to slightly under $7 million, down $729,625 from 2003.

- Although DD and FSL waiver spending per recipient increased from 2002 to 2004, the number of waiver recipients declined from 24,443 to 24,079 during this time, a decrease of 364 persons.

- Per diem (per person per day) spending for state institutions increased from $252 in 2002 to $308 in 2004. This translates into an annual per person cost of $112,728 in 2004.

- The proportion of youth (0-21 years of age) among the state institution population jumped from 1% in 2002 to 7.7% in 2004.

Florida in Comparison with Other States

Any state's developmental disability service system can best be evaluated in comparison with other states. This section compares Florida with the 50 other states and the District of Columbia and with other states having a total population of at least 10 million persons in 2004. In that year, eight states had a population this large: California, Texas, New York, Florida, Illinois, Pennsylvania, Ohio, and Michigan. The latter comparison is a better indicator of Florida's efforts, since large states are likely to have similar advantages and disadvantages vis-à-vis small states.

State Institutions: Populations and Trends. For comparison purposes, the total number of people in institutions in states can be misleading. Large states are more likely to have large institutional populations or persons in residential services than small states. One useful measure for comparing states has been developed by the University of Minnesota's Research and Training Center on Community Living. This measure analyzes states according to the number of persons with developmental disabilities in various residential settings per 100,000 of the general population. In 2004, Florida had 7.9 persons with developmental disabilities in large state facilities, or institutions, per 100,000 of its almost 17.4 million population. This compares with a national average of 14.3 per 100,000 population. Of the eight states with populations over 10 million, only Michigan had a lower number of persons in institutions (1.3) in the context of its general population.

Deinstitutionalization can best be evaluated in terms of percentage decline in a state's institutional population. Our analysis focuses on percentage decline in two periods: 1995-2004 and 2000-04. As of 2004, eight states (Alaska, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia) and the District of Columbia no longer operated state institutions. So these are excluded from our analysis. In the 1995-04 and 2000-04 periods, the populations of Florida's institutions declined by 8.2% and 8.6%, respectively. (These percentages indicate that there was a negligible decline in the years 1995-2000.) This compares with a national average decline of

33.9% in 1995-2004 and 12% in 2000-04 in the remaining 42 states. In the 1995-04 period, each of the other seven large states had higher percentage declines in institutional populations than Florida (the range was 8.7 % in Texas to 66.1% in Michigan). In the 2000-04 period, two states (Ohio at 8.2% and Texas 8.2%) had lower rates of decline than Florida, while New York had the same rate of 8.6% (however, New York had a rate of decline of 50.5% in the 1995-2004 period). Michigan's institutional population declined 50.9% during 2000-04. Florida admitted 139 persons with developmental disabilities to its institutions in 2004; 158 persons were discharged and 21 residents died.

Florida's institutional population included a significantly higher percentage of children and youth (0-21) and persons with mild intellectual disabilities than the national average. In 2004, 7.7% of the residents of Florida institutions were 15-21 years of age (no children younger than 15 were reported). This compares with a national average of 4.3%. Among large states, only Michigan (7.8%) and New York (12.8%) had higher percentages of children and youth. Persons with mild intellectual disabilities accounted for 36.8% of the population of Florida's institutions, compared with the national average of 10.2%. Of the other seven large states, Michigan (45.8%) and New York (45.5%) had higher percentages of people with mild intellectual disabilities.

Residential Services. Regardless of setting size, Florida had a significantly lower rate of persons with developmental disabilities receiving residential services per 100,000 of the overall state population than the national average in 2004. In settings of all sizes, Florida provided residential services to 75.4 persons per 100,000 in 2004. This compares with a national average of 143.1 persons per 100,000 of the general population. Each of the other large states served a higher number of persons. Texas had the closest rate, at 93.1. The other states had rates ranging from 127.9 (Ohio) to 235.1 (New York) per 100,000 of the general population. In settings housing 1-6 persons, Florida provided residential services to 48.5 persons per 100,000 of the general population, compared with a national average of 100.5. Of the other seven large states, only Ohio (22.7) served a lower number of persons. The other states ranged from 59.6 (Texas) to California (358.94).

Florida served 1,805 persons in 49 large (16 or more persons) non-state Intermediate Care Facilities for the Mentally Retarded in 2004. This was the fourth largest number of persons in large non-state ICFs/MR in the country, after Illinois (3,429), Ohio (3,076), and Texas (1,864).

In 2004, 30% of people receiving residential services lived in their own homes (i.e., homes owned or leased by the individual). This was higher than the national average of 26% and higher than all but two (California at 32% and Illinois at 31%) of the other large states.

Florida had a waiting list for residential services of 15,278 in 2004. This was the largest waiting list in the nation and almost double the size of any other state (Maryland at 7,666). Of 36 states reporting information on waiting lists, only three other states had more persons on waiting lists than the total number of current recipients of

residential services. For the waiting list in Florida to be eliminated, the current residential service system would need to grow 116.4%. This was the second highest percentage in the nation. Although data for Florida as presented by the University of Minnesota is reported as a residential services waiting list, it should be noted that Florida's waiting list as maintained by the state's Agency for Persons with Disabilities, is not specific to type of service need.

Spending. As in other states, most Florida services for people with developmental disabilities are funded under the federal-state Medicaid ICF/MR and Home and Community Based Services (DD and FSL) waiver programs. One way to gauge a state's fiscal efforts on behalf of people with developmental disabilities is spending per state resident (general population). In 2004, Florida spent $17.77 per state resident through the ICF/MR program. This compares with the national average of $40.52 per state resident. Of the seven other large states, this was lower in all except Michigan ($1.89 per state resident).

Since many states are moving away from funding ICFs/MR, spending under the HCBS waivers is a better indicator of a state's fiscal efforts. Florida spent $36.51 per state resident under the HCBS waiver program in 2004, compared with a national average of $52.80 per state resident. This figure was higher than California ($29.81), Illinois ($25.56), and Texas ($16.79) and lower than the other large states (range: $36.66-$130.92).

Florida spent an average of $26,256[1] per resident under the HCBS program in 2004. This compares with a national average of $37,486. Of the seven other large states, California ($19,229) spent less per recipient than Florida, while the other states spent between $33,303 (Illinois) and $50,168 (New York).

Summary: Florida in National Context

A review of national data yields the following conclusions about Florida's developmental disability service system in comparison with other states:

- Spending for developmental disability services in Florida has increased significantly in recent years. Continued increases in spending would be necessary for Florida to match the national average or the spending in most other large states.

- Florida institutionalizes fewer people in state facilities per its general population than the national average and all but one of the other large states. Yet, Florida lags behind most other states, including other large states, in deinstitutionalization over the past ten years. There has been little movement

[1]This figure is reported by the University of Minnesota's Research and Training Center on Community Living (Prouty et al., 2005) and is based on average daily recipients for 2004. The previously cited figure is reported by the Coleman Institute for Cognitive Disabilities at the University of Colorado. The Minnesota center and the Colorado institute use slightly different methodologies for determining averages.

of people out of state institutions in recent years. Florida stands out from most other states in the percentage of children and people with mild intellectual disabilities in its state institutions.

- Florida serves significantly fewer people with developmental disabilities in its residential system in settings of all size categories (1-6, 7-15, 16+) per the general population than national averages and in most other large states.

- Florida has significantly increased its spending and the number of participants receiving individual (supported living, personal assistance) and family support services in recent years. Florida also compares favorably with other states in the percentage of people who receive residential services in their own homes. These are strengths of the current service system. The decline in support for supported employment in recent years is a weakness.

SECTION II: AREAS OF EMPHASIS

This section of the report is organized according to the Administration on Developmental Disabilities' Areas of Emphasis. These include: education, health care, formal and informal supports, transportation, housing, employment, and quality assurance. For each Area of Emphasis, we provide a description of the system and funding; stakeholder perspectives on system challenges; Florida strengths and resources; and national promising practices and resources.

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AREA OF EMPHASIS

EDUCATION
Early Intervention

Summary Information

Challenges

- System Capacity and Infrastructure Shortcomings
  - Natural Environment Mandate
  - Managing Medicaid Expenditures
  - Service Coordination Constraints

- Scope of Services Issues
  - Early Identification Gaps and Delays
  - Restricted Standard of Need Application
  - Insufficient Parent and Family Supports

- Difficulties in Transition from Part C

Strengths/Resources

- CMS Early Steps
- Mailman Center
- Dan Marino Center

AREA OF EMPHASIS

EDUCATION
PreK – Secondary

Summary Information

Challenges

- Children in Segregated Settings
- Standards, Assessment, Accountability, and Instructional Opportunities
- Need for Increased Parent Information and Support
- Availability of Educationally Related Medical Services
- Transition Issues
    - Curriculum and Instruction
    - Participation of DVR in Transition Planning
    - Waiting Lists Status and Front-End Employment Supports
    - Shortage of Qualified Providers
    - Lack of Funding for Assistive Technology
    - Variability in School District Transition Resources
    - Lack of Accountability for Poor Postsecondary Outcomes

Strengths/Resources

- Florida Diagnostic Learning Resources System (FDLRS)
- University of Florida Transition Center
- Family Network on Disabilities
- Transition to Independence Project (TIP)
- McKay Scholarship
- Partners in Transition
- The Children's Trust, Miami-Dade
- Children's Service Council–Hillsborough County
- Center for Autism and Related Disabilities

AREA OF EMPHASIS: EDUCATION

Infants through Toddlers (Pre-K) Years

Description of the Existing Early Intervention System

The Department of Health Children's Medical Services (CMS) is responsible for Florida's IDEA, Part C, and the Developmental Evaluation and Intervention (DEI) programs. IDEA, Part C (Early Steps) is a comprehensive multidisciplinary entitlement program which provides services to address significant delays in the areas of cognitive, communication, fine/gross motor, social/emotional, and or adaptive development to eligible children birth through 3 years of age, as well as to those with a suspected diagnosis that has a high probability of resulting in disability or developmental delay.

According to the Bureau of Early Interventions web site (http://www.cms-kids.com/PPT/Bureau_of_Early_Interventions.ppt), in FY 2003-04, 36,265 infants and toddlers were enrolled in Early Steps (another 4,289 were served, but not eligible for enrollment). Of those who were enrolled, 30,603 were in the IDEA, Part C program; 2,474 were in the Developmental Evaluation and Intervention program; and 3,188 were enrolled in the DEI program and the IDEA, Part C program. In the past decade, the number of children enrolled in the Early Steps program has steadily increased, while the funding per child has decreased. For example, in 1994-95, there were 20,973 children enrolled, at $1,265 per child; in 2004-05, there were an estimated 42,702 children enrolled, at an estimated $883 per child.

The Developmental Evaluation and Intervention (DEI) program follows infants identified in Neonatal Intensive Care units (NICU), infants with or at risk of hearing impairments, and infants referred by the Children's Medical Service Genetics Screening program. All of the children served within the DEI program have a high risk for developmental disability. The DEI program provides comprehensive assessments and service coordination. While there is no financial eligibility for the Part C (Early Steps) program, there is a financial eligibility threshold for the DEI program except for infants identified with a hearing impairment. Both programs operate within a family centered service model, and a Service Coordinator assists each family.

The Part C (Early Steps) program is the primary source for early intervention services for developmentally disabled children within the state. Services are provided by 16 local Early Steps offices that are contracted through community-based organizations across the State of Florida. Many types of services and supports are available through Early Steps for eligible children and their families, such as identification, evaluation, assessment and service coordination, as well as direct intervention within the everyday routines, activities, and places of the child and family. The family receives an individualized family support plan (IFSP) outlining services the Early Steps team determines appropriate. Services are based on the concerns, priorities, and resources identified by the child's family and desired outcomes indicated on the IFSP.

Effective July 1, 2004 all newly referred children to the Part C (Early Steps) system were mandated to be served within natural environments, that is, within the daily routines and activities of the child and family. This change was required by the federal Individuals with Disabilities Act (IDEA), and has resulted in a reorientation of the system away from a "center" based model to one which is home and community based.

Early Intervention: Stakeholder Perspectives on System Challenges

This section describes the themes represented by stakeholders about the challenges they experience in the current system.

1). System Capacity and Infrastructure Shortcomings. Parents and service providers identified several issues related to the capacity and infrastructure of the system which have an impact on access to services and reliable service delivery. These include: the relatively recent shift from a center-based service delivery system to the natural environment as required by federal law; issues related to the Medicaid system; and service coordination.

a) Natural Environment Mandate. Florida instituted the natural environment standard for service delivery effective July 1, 2004 for all new children admitted to the Part C program. Parents of children who were affected by this change report the early intervention delivery system lacks the resource infrastructure required to support home based and inclusive early childhood education. The natural environment system relies on providers who work with "extenders" at community based locations to deliver service within daily routines which are typical for infants and toddlers. The types of environments may include the family home, child care centers, play groups, and other similar settings. Some of the problems with this new service delivery model identified by providers and parents include the following: the inefficiency of the model for the providers due to the necessity for child-specific travel time; the difficulty for families in pursuing inclusion in child care and pre-school centers due to exclusive admission criteria, for example, that a child must be toilet trained; the lack of adequate skilled staffing resources within typical child care settings; and competing parental responsibilities which conflict with scheduling and home-based service provision, for example, both parents working full time outside the home. Further, the quality of the services and the clinical oversight for the center based model were noted as better by parents who had experience with both models.

b) Managing Medicaid Related Expenditure. The Part C (Early Steps) program is designed to maximize federal revenue through participation in an entitlement Medicaid structure. At the same time the state is seeking to manage the overall growth in Medicaid spending. Several problems have been associated with the state's effort to manage Medicaid expenditures which have had a negative impact on the Part C program. Some provider Medicaid rates were reported to be as low as 50% to 57% of comparable Medicare rates. The low rate of reimbursement

discourages providers from participation, which impedes access to service. This is particularly a problem in more rural areas of the state.

Providers and parents also reported that regardless of the service delivery model, state funding levels have not kept pace with the increase in the number of children being referred resulting in a system which is not able to meet all of the identified needs. Parents believe the lack of sufficient funding has resulted in service rationing based on the dollars available versus the needs of each child and family. In this regard, although the Medicaid system has a due process complaint resolution procedure to address and resolve service authorization conflicts, the experience reported by parents who pursued this avenue was characterized as intimidating due to the "aggressive" defense practices of the state. Families who are not able to afford professional representation felt that they were at a significant disadvantage within the due process arena.

c) Service Coordination Constraints. Two issues emerged in the area of Service Coordination, size of caseloads, and the role of the Service Coordinator. Average caseloads for Service Coordinators were reported to be around 136 with some exceptions for specific populations of children. The ability of Service Coordinators to know each child and family is at best difficult given these numbers. This constrains their ability to adequately understand and represent the family and child's needs. The situation is further exacerbated by the turnover rate in personnel. The role of the Service Coordinator was often characterized as more of a "gate keeper" who was managing care versus someone who was representing the best interests of the child and family.

2). Scope of Services Issues. The issues identified within the scope of services theme cover early identification, standard of need, and parent and family support.

a) Early Identification Gaps and Delays. There was a general sense that children are being missed by the early identification system and entry into early intervention is delayed for many children. Pediatricians were identified as a significant resource in helping to screen for developmental delays; however, both parent feedback and information reported in the National Survey of Children with Health Care Needs (2001) suggest that developmental issues are frequently not discussed during regular visits with health care providers. Many parents reported that their child was the first child their pediatrician had seen with a developmental disability, and signs of delay were missed due to lack of experience. The adequacy of early identification was also raised in the context of subpopulations, such as working poor people, teen parents, African Americans, and non English speaking communities where social, economic, and cultural barriers impede existing screening and identification efforts. For undocumented parents who fear authorities because of immigration issues these barriers are further compounded. Parents also reported delays in completing the evaluation process once being referred to Part C, as well as subsequent extended time before actual intervention was initiated.

b) Restricted Standard of Need Application. Part C (Early Steps) requires the diagnosis of a developmental disability, or diagnosis of a condition that will likely result in a substantial developmental delay. Some parents, in particular, suggested that a broadened eligibility criteria to include more children at risk would result in improved long term outcomes for children who otherwise would not be identified and served until developmental delays were manifested at an older age. Parents were advocating for a system that promoted healthy early childhood development through early intervention rather then waiting until delays are manifested.

c) Insufficient Parent and Family Support. Parents indicated that the early intervention system did not provide sufficient support for the primary caregivers. Among the specific areas of concern were: the lack of useful information about services; limited choice of providers; lack of child care and respite; and insufficient parent-to-parent support. Information is not available through a single source, and parents reported that Service Coordinators were frequently not forthcoming with information about what services are covered under Part C as well as what the system requires to gain access to a more complete range of services. The increased reliance on technological resources to disseminate information was viewed as both a positive and negative. Some parents do not have access to a computer, may not be able to afford an internet service, or do not have the skills needed to use a computer, all of which limit the utility of this tool for part of the target population. Parents also want more provider choice within Part C. Currently, choice is limited to the Network provider who covers the specific geographic area where the child resides. Child care is not available as a service within Part C, and respite is very restricted or not available. Although there are parent-to-parent support groups these are not uniformly available throughout the state, and the move toward service within natural environments was viewed as creating an additional challenge for parents in developing formal and informal parent-to-parent connections without a centralized place where they might meet others.

3). Difficulties in Transition from Part C. The Part C program ends when the child turns 3 years of age. For children who meet the eligibility criteria under Part B of IDEA the education system assumes service responsibility, specifically, the local school district. Eligible children transitioning to Part B are reassessed by that program, and services are provided in accordance with an education plan. The child's case is closed to the Part C system and the Service Coordinator. This change in system responsibility, Health to Education, was identified as a high stress and risk point by parents due to changes in the people who are involved in the life of the family and child, the loss of the Service Coordination, and differences in the identified needs of the child based on the perspectives of the Early Intervention versus Pre-K professionals and intervention/education criteria. Although planning for this transition was occurring early in the process, often starting when the child was 2 1/2 years of age, the experience was characterized as difficult, sometimes requiring re-visiting and justifying the need for services which had previously been provided under the Part C system.

Florida Strengths and Resources

Some of the key strengths in Florida's early childhood education system are listed here. More are described in the health section.

1). CMS Early Steps. The Florida Department of Health Children's Medical Services Early Steps has made a strong commitment to a family centered approach to services and actively seeks family input in policy and practice design. Although challenges within this system have been identified, it is evident that CMS has been trying to be responsive to the needs of parents and children with difficult circumstances. Some examples of these efforts include: The KidCare Coordinating Council which provides an interagency and stakeholder forum for guidance on statewide policy and program directions. In addition, the Department has recognized the need for local interagency cooperation and collaboration through its "Program Plan and Guide," which promotes an effective and inclusive early identification and intervention system at a community based level. The statewide Healthy Start program is an example of a health system commitment to fostering improved health and developmental outcomes among infants who are at risk.

2). Mailman Center. The Mailman Center for Excellence in Developmental Disabilities Education, Research, and Service at the University of Miami is a nationally recognized resource in child development, and has an established partnership with the Florida Developmental Disabilities Council. The Mailman Center for Child Development offers programs in interdisciplinary developmental evaluation, and infant and toddler early intervention. Of particular note is the Debbie Institute Early Intervention program which operates an inclusion model for early intervention and childcare for infants and toddlers with developmental disabilities and children who are developmentally typical. The availability of this resource within the State of Florida is a significant asset.

3). Dan Marino Center. Dan Marino Center at Miami Children's Hospital is a comprehensive evaluation and treatment center for children with developmental and neurological needs. The center provides families with information on specific diagnoses, available resources, support groups, and training.

National Promising Practices and Resources

1). National Early Childhood Technical Assistance Center. The move toward providing EI services within natural environments, which is occurring nationwide in accordance with federal requirements, is consistent with early intervention best practice, and endorsed by national organizations. Although downsides to the natural environment approach have been expressed in Florida it is clear the natural environment approach has been adopted within national policy as the model for EI services. The trend is to align EI services with Head Start, Child Care, and Maternal and Child Health programs, as is being done in Florida. The National Early Childhood Technical Assistance Center provides legislative, policy, and practice information from states throughout the nation; research findings related to early childhood education; and natural environment and inclusion practice information.

Education Pre-K through Secondary

In accordance with federal law (PL 94-142, Individuals with Disabilities Education Act, Part B), children with disabilities who reside in the State of Florida are entitled to receive an appropriate education program in the least restrictive environment. The least restrictive environment generally refers to providing education services and supports within the general education environment. The Bureau of Instructional Support and Community Services within the Florida State Education Department is responsible for supporting the 67 separate school districts to implement the Exceptional Student Education Program (ESE). Each of the separate school districts establishes its own programs in accordance with state standards to meet the needs of the ESE student population. Under the Part B program, health services (for example, speech pathology, physical therapy, occupational therapy) related to a child's educational needs are generally provided through the Medicaid School Match program for Medicaid eligible children or at school district expense for students who are not Medicaid eligible.

School districts assume responsibility for exceptional student education when the child turns three years of age. Services provided during the Pre-K years are arranged based on the child's needs and are purchased by the school districts from community providers. The State of Florida recently implemented a voluntary Pre-K program for all four year olds. This new program up to this time has largely been provided through private preschools; it is unclear whether there is a connection with the provision of services under Part B in the universal Pre-K initiative. During the elementary school years (K-6), each child's education program is individualized and instruction may be provided within the general curriculum in accordance with the child's needs. Decisions made about elementary curriculum, instruction, and student performance expectations lay the foundation for the child's secondary education program. Parents with the IEP must select a diploma track for the child during the eighth grade year or the year the child turns 14. The Florida State Education "Sunshine State Standards" establish the performance requirements for general education and exceptional education graduation. Student achievement within these standards will result in secondary school graduation or completion depending on the successful completion of an instructional program related to the academic track selected.

Most students fall within the general education track which is designed to lead to meeting all of the requirements for a regular high school diploma. For students who have significant cognitive disabilities a "Special Diploma" track is provided. There are two options under the "Special Diploma." Option 1 must be offered by all districts and is the most common choice for ESE students. Option 2 is available at the discretion of each school district and is intended to support a program of instruction related to employment and access to the community. ESE students may also receive a "Certificate of Completion" if they do not meet the requirements as specified in the "Sunshine Standards" to receive a "Special Diploma." The ESE instructional program differs from the general education program because it is based on differentiated achievement standards. Each ESE student has an Individualized Education Plan which is developed by a team of educational specialists and the child's parents. The plan identifies the

educational needs of the child and how these needs will be met. The goal is to maximize the child's educational potential within the least restrictive environment. Progress is measured using an "Alternate Assessment" system which is provided within the "Sunshine State Standards" for assessing and monitoring student achievement for ESE students who are seeking a special diploma. There are safeguards in the system to address conflicts which may arise between school officials and parents. These include both informal and formal conflict resolution procedures.

Based on Florida State Education Department information the total student enrollment Pre-K through 12 for school year 2003/04 was 2,598,231 which was a 3.8% increase over school year 2001/2002. Enrollment of students with disabilities for the same period was 398,731 (03/04), versus 376,074 (01/02) representing a 6% increase. Many of these students are receiving instruction in segregated environments. For example, information obtained from the OSEP State Reported Data (https://www.ideadata.org/arc_toc5asp#partbLRE) for the 2003 school year identified a total of 39,030 students with a mental retardation disability between the ages of 6 and 21 enrolled in the Florida education system. Although the majority, 91%, of these students attended school in regular public school facilities, more than half of these students spent in excess of 60% of their school day outside of the regular classroom. The remaining 9% of this group of students attended school in separate facilities. Overall the data suggests that the majority of the school day for students with a mental retardation disability is occurring within non-inclusive settings.

Available data on postsecondary outcomes show significant differences between disabled and non-disabled students. According to information presented in the Blue Ribbon Task Force report (BRTF), and the Education Department information system, the drop out rate for disabled students during the 2003/04 school year was 4.7% versus 2.6% for nondisabled students. The graduation rate for the same period was 64.1% for disabled students versus 72.5% for nondisabled students. The BRTF also indicated for school year 2002 that 55% of the students with a developmental disability exited school without a diploma or certificate of completion. The Florida State Education Department reports that only 33% of students with developmental disabilities exited school without a diploma or certificate of completion for this same period. It was further reported by the BRTF for school year 2002 that 12% of all students with a developmental disability were enrolled in postsecondary education, and 17% were employed following graduation, with quarterly earnings of $3,700. According to the State Education Department for school year 03/04 6% of all students with developmental disabilities were enrolled in postsecondary education and 28% were employed.

Education: Stakeholder Perspectives on System Challenges

This section describes the themes represented by stakeholders about the challenges they experience in the current system.

Stakeholders uniformly identified postsecondary outcomes for students with disabilities, and the impact these conditions are having on the lives of persons with disabilities as a significant barrier to achieving the goal of a full and inclusive quality of

community life. Although there were many obstacles within the adult service environment which also contribute to this set of conditions there were several areas identified which are specific to the education system. These include: 1) Inclusion; 2) Standards, Assessment, Accountability, and Instructional Opportunities; 3) Parent Information and Support; 4) Health Related Services; and 5) Transition.

1.) Children in Segregated Settings. Based on the 2003 school year data, more than half of the children with a mental retardation diagnosis served in public school facilities spend in excess of 60% of their school day in segregated settings.

2). Standards, Assessment, Accountability, and Instructional Opportunities. ESE standards for the "Special Diploma" and the alternate assessment system lower achievement expectations, and do not provide an adequate method to measure student capabilities and to monitor school performance throughout the child's academic experience. Under the current system decisions which parents make about the diploma track for their child will have a direct impact on educational opportunities. Lower academic expectations foster low achievement and poor outcomes. Each child's growth is limited by the instructional opportunities.

3). Need for Increased Parent Information and Support. The Department of Education provides numerous written resources to support parents with information about the Exceptional Student Education program. One example of the available material is the guide Diploma Decisions for Students with Disabilities: What Parents Need to Know. There are also existing opportunities for parent training, for example, the Florida Diagnostic and Learning Resources System (FDLRS) assists school districts to develop family friendly programs, supplies families with information, and promotes partnerships between schools and parents to support student achievement. However, knowledge of or access to these resources was not uniform throughout the state. In addition, parents reported differences in the openness and receptivity by districts to sharing information and to parent participation in general. Many parents indicated they had a distrust for local district school officials and expressed a preference for receiving information from other parents who had experience with the system. It should be pointed out, however, that these experiences were not uniformly reported. Parents and school officials from Broward and Voulsia counties reported they had established a satisfactory respectful working partnership. While not always in agreement on specific matters, there was a shared commitment to the principle of working together.

4). Availability of Educationally Related Medical Services**.** Parents reported that medically related educational services are not always available. In particular access to communication and language resources and the availability of positive behavioral supports were cited as problematic. Resource availability was reported as a factor in determining whether these and other needed services would be provided. Similar to Part C, the resource availability issue was a bigger problem in rural communities.

5). Transition Issues. Many concerns were expressed in connection with school transition. These included: a) the adequacy of the ESE curriculum and instruction in relation to equipping a student with the practical skills needed for community living and

employment; b) the participation of Division of Vocational Rehabilitation at transition planning meetings; c) the waiting list for the DD/HCBS waiver; d) the lack of an adequate supported employment provider network and other resources to fill postsecondary needs e) availability and access to assistive technology resources; f) insufficient dedicated and trained resources within districts to devote the time to transition planning, preparation and follow-up; and g) school accountability for outcomes.

a). Curriculum and Instruction. The issue of academic expectations related to instruction and diploma track was identified as a significant barrier to successful transition. There was a strong emphasis on the need for more access to the general educational program content, the need for vocational education and training, and the need to improve functional and adaptive instruction to address the real life skills which will be required following graduation.

b). Participation of DVR in Transition Planning. The participation of Division of Vocational Rehabilitation staff is needed for successful transition planning. Forum participants reported that counselors from the Division of Vocational Rehabilitation occasionally attend Transition Planning meetings, although in most instances counselors were not able to regularly participate. This was identified as a problem by both parents and school district personnel. The workload, staff vacancy, and turnover of DVR Counselor staff is well documented, for example, in OPPAGA Report No. 05-14. The issue seems to be that DVR does not have sufficient and consistent staffing resources to carry out this responsibility.

c). Waiting List Status and Front-End Employment Supports. The DD/HCBS waiver waiting list has created a substantive barrier to transition. Students who require the supports which are provided within the DD/HCBS waiver have no guarantee that needed services will be available when the student leaves the education system. Although the new FSL waiver will address some of this problem, higher need students continue to be affected. An example of how DD/HCBS waiver waiting list status can have an impact on transition pertains to those students who are eligible for DVR services, are specifically moving toward supportive employment, and require long term supports. DVR cannot provide the student with the front end intensive supportive employment service if the long term funding via the DD/HCBS waiver is not available.

d). Shortage of Qualified Providers. There is a statewide shortage of qualified providers to meet the growing expectations and demand for supportive employment services. Qualified providers are needed to meet the support requirements of persons with disabilities, and to work on a grassroots level with local employers developing work opportunities for this emerging workforce.

e). Lack of Funding for Assistive Technology. Educators and parents noted that funding for assistive technology to support both community and employment needs is insufficient or unavailable. The difficulty with access to needed assistive

technology relates to the waiting list issue described above, as well as differing eligibility criteria for available resources based on variable standards such as educationally related standards (DOE), medical necessity standards (Medicaid), and employment related standards (DVR).

f). Variability in School District Transition Resources. The information obtained through all sources indicated that all school districts do have an identifiable process and responsibility for transition. However, it was evident from the descriptions provided by parents throughout the state that there is variability in the amount of resources, training, and knowledge across districts.

g). Lack of accountability for poor postsecondary outcomes. There is no accountability or consequences for poor postsecondary outcomes. The student who leaves the education system without an adequate plan, and the supports required to carry that out, is the one who experiences the consequences. The result is that there is no incentive for the school to change the instructional program.

Florida Strengths and Resources

Many of the challenge themes which have been reported are familiar to the education system. Most notably the Governor's Blue Ribbon Task Force on Accommodations and Access for Students with Disabilities (2002) made extensive recommendations related to alternate assessment systems, graduation testing and diploma requirements, transition and school accountability. What is not clear is whether specific changes have resulted from these recommendations. The findings and recommendations of the 2002 task force support the themes expressed by parents in 2005 and provide a foundation for education system improvements. In addition to this resource, several other improvement initiatives and resources were identified within the study. This section describes some of the strengths in Florida's education system.

1). Florida Diagnostic Learning Resources System (FDLRS). FDLRS provides exceptional education diagnostic and instructional support to local school districts and to families of students. Five statewide centers support 20 associate centers. Each of the associate centers provides support services in the area of Child Find, Parent Services, Human Resource Development, and Technology. Child Find works with school districts to locate children who are potentially eligible for services under IDEA. Parent Services provides training and support to districts and parents to promote effective parent participation in the education of children with disabilities. Human Resource Development provides training, information, and technical assistance resources related to effective instructional strategies. The technology component supports the use of technologies within the education environment for students with disabilities.

2). University of Florida Transition Center. The Transition Center is a statewide transition resource which provides training and technical assistance support to education professionals, agency personnel, families, and students. The Center currently sponsors four projects: Self-Determination, Supported Employment, Project Connect,

and the Hiring Practices Initiative. The Self-Determination initiative assists school districts with implementing self-determination activities. The Supported Employment initiative provides training for staff who are directly involved in providing supported employment services. Project Connect identifies and disseminates best practice information related to transition and community partnerships. The Hiring Practices Initiative focuses on improving hiring practices of persons with disabilities in school districts. The Transition Center also supports a Transition Task Force comprised of family members, state and district educational professionals, community agency personnel, and students. The Task Force seeks to identify barriers to effective transition and work in partnership to identify solutions.

3). Family Network on Disabilities. The Family Network on Disabilities is Florida's Parent Training and Information Center and is the Region 3 Alliance Parent Technical Assistance Center, serving 10 states and territories in the southeastern United States. It is funded by the United States Department of Education, Office of Special Education. The Family Network is a resource center which provides training and information to parents on IDEA to support and promote the family role and relationship with their local school district in obtaining appropriate education services for their children. The Family Network serves the entire State of Florida through 11 area offices which cover targeted counties within their designated service areas.

4). Transition to Independence Project (TIP). The TIP is a system to assist youth with emotional or behavioral difficulties in making a successful transition from school to adulthood. The Florida TIP is supported by the University of South Florida and the Florida Department of Education, and it provides technical assistance and training to school districts and partner agencies related to the TIP system.

5). McKay Scholarship. The McKay Scholarship is an extension of the school choice program which gives parents the ability to enroll their child in the public or private school program they believe can best meet their child's needs.

6). Partners in Transition. Partners in Transition is a project spearheaded by the Developmental Disabilities Council to bring together all stakeholders in secondary school transition for the purpose of developing a strategic plan to guide policymakers and practitioners in systematically addressing the major issues and challenges facing transition services in the State of Florida. This initiative has resulted in the development of a strategic plan which is aligned with the National Guideposts for Success: Quality Youth Transition Services. Further, this work has been recognized and incorporated into the recommendations of the Governor's Blue Ribbon Task Force on Community Living, Transition, and Employment of Persons with Developmental Disabilities.

7). The Children's Trust, Miami-Dade County. The Miami-Dade County Children's Trust provides financial support to improve and expand services for children in areas where needs are not being met through other publicly or privately supported resources. Funds used by the trust are raised through a special tax district which was established by local law to address the needs of children.

8). Children's Service Council–Hillsborough County. Children's Service Councils are established by county government. Similar to Miami-Dade County, a special tax levy was passed by the Hillsborough County voters to support children's services. Hillsborough County has a Children's Board that oversees funding for support services for children, with an emphasis on early intervention projects for children birth through 8 years of age. One example of the type of work supported was the Analysis of Community Based Services and Supports for Children with Special Needs. This project looked at the needs of children ages birth through 24 years and their families in relation to service practices, availability, and barriers on the local level. It provides a very good example of local planning and stakeholder participation.

9). Center for Autism and Related Disabilities (CARD), Located at Six University Sites Throughout Florida. The CARD provides information and consultation to individuals diagnosed with autism spectrum disorders or related disabilities and their families (see Health section for fuller description).

National Promising Practices and Resources

Education outcomes in the State of Florida are consistent with national data. The Blue Ribbon Task Force on Inclusive Living, Transition and Employment of Persons with Developmental Disabilities report cited the following information from the National Organization on Disability's Harris Survey on Americans with Disabilities (June 24, 2004):

- Students with disabilities drop out of high school at twice the rate of their non-disabled peers.

- Only 25% of persons with mental retardation are employed after exiting school.

- Unemployment and poverty among persons with disabilities exceeds 80%.

1). NCCSAD. The Florida alternate assessment system complies with federal IDEA requirements. Nationally there is no uniform approach and states have flexibility to design their own system. Poor postsecondary outcomes are a national issue. In recognition of this situation and the increased emphasis on school accountability (No Child Left Behind), attention and research is being devoted toward the design of more effective instruction and accountability systems. Increased attention is being given to inclusive student assessment systems which incorporate students with moderate and severe disabilities into the general education performance systems. Most notably the University of Kentucky was recently awarded $5 million from the U.S. Department of Education to create a National Collaborative Center on Standards and Assessment Development (NCCSAD). The NCCSAD will focus its efforts on examining the technical quality of alternate types of assessments; the alignment of alternate assessment types to academic content; effective practices for developing alternate assessments; and the impact of these assessments on student learning and access to the general curriculum. The project includes a model demonstration component that will be conducted in

collaboration with the states of Colorado, Iowa, Kansas, Massachusetts, Maine, Michigan, North Carolina, New Hampshire, New Mexico, and South Dakota.

2). NCEO. The National Center for Educational Outcomes (NCEO) is another resource available to the State of Florida. The NCEO provides leadership in the design of educational assessments and accountability systems for all students including those with disabilities. The NCEO conducts and disseminates research and provides technical assistance. The NCEO is a significant resource to assist States in building assessment and accountability systems.

3). Universal Design in Education. Another important trend within education which also addresses the issue of assessments and related instruction is "Universal Design." Universal Design refers to developing educational materials, including both assessments and instruction, for use by the widest number of people including students with disabilities. Universal design is referenced in the No Child Left Behind Act of 2001 setting an inclusion standard for both instruction and assessment within federal law. Information about Universal Design resources is available through the National Center for Educational Outcomes (NCEO). Another resource for information related to universal design and inclusion is the Beach Center on Disability at The University of Kansas.

4). National Center for Secondary Education and Transition. Transition planning is mandated in the federal IDEA requirements. Although the nuances of the challenges and barriers to successful transition practices may differ from state to state the general picture is very similar as measured by the consistency of the national postsecondary outcome data for students with disabilities. Technical assistance resources are available to help address the challenges related to transition. The National Center for Secondary Education and Transition has identified research based "Guideposts for Success" which have already been adopted within Florida's Partners in Transition Strategic Plan.

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AREA OF EMPHASIS

HEALTH CARE

Summary Information

Challenges – Children

- Delays in Early Identification
- Accessibility of Medicaid Benefit Package
- Concerns Regarding Service Coordinators
- Lack of Qualified Providers
- Low Medicaid Rates
- Family Difficulties
- Linkages Between Programs Need To Be Strengthened

Challenges – Youth in Transition and Adults

- Provider Training and Accessibility
- Medicaid Restrictions
- The Cost of Not Providing Health Care
- Lack of Coordination Across Systems
- Future Challenges

Strengths/Resources

- Mailman Center for Child Development
- FSU Center for Prevention and Early Intervention Policy
- Center for Autism and Related Disabilities
- CMS
- Miami Examples

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AREA OF EMPHASIS: HEALTH CARE

Description of Health Services for Children

In Florida, several state departments and offices provide health-related services to children with developmental disabilities. The primary departments that provide and/or fund health-related services to children are the Department of Health (DOH), Department of Education (DOE), and the Medicaid Office of the Agency for Health Care Administration (AHCA).

Within the statewide health care system for children, children with special health care needs (CSHCN) are identified as a category, but disability data may not be collected by type of disability. A standard definition for CSHCN is ***"****Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998).* This category includes children who have or are at risk of having developmental disabilities.

Florida's childhood population includes an estimated 13.1% of CSHCN, according to the National Survey of Children with Special Health Care Needs 2001.

On many indicators in this 2001 survey, Florida's families of CSHCN were struggling more than families nationally; they had more unmet needs, more difficulty getting referrals, less insurance, and more financial strains.

TABLE 1: FLORIDA[2]

Estimate of Number of Self-Reported Children with Special Health Care Needs: 488,090

NOTE: All Statistics are based on parental reports.

PREVALENCE STATISTICS

Child-Level Prevalence:	**State %**	**National %**
Percent of Children with Special Health Care Needs	**13.1**	**12.8**
Prevalence By Age:	**State %**	**National %**
Children 0-5 years of age	**8.8**	**7.8**
Children 6-11 years of age	**15.9**	**14.6**
Children 12-17 years of age	**14.1**	**15.8**

[2]Table reprinted from http://www.mchb.hrsa.gov/chscn/state_data/fl.htm.

Funding and Services for Children with Special Health Care Needs

Florida's Healthy Start initiative, operated by the Department of Health, provides for universal risk screening of all Florida's pregnant women and newborn infants to identify those at risk of poor birth, health and developmental outcomes. The program is described at http://www.doh.state.fl.us/family/mch/hs/hs.html.

If risk factors are noted, the Early and Periodic Diagnostic, Screening, and Treatment (EPSDT) program in Florida, called "Child Health Checkup," is provided to Medicaid eligible children. To be reimbursed by Medicaid, the provider must assess and document in the child's medical record all the required components of a Child Health Check-Up. The required components are as follows:

1). Comprehensive health and developmental history including assessment of past medical history, developmental history and behavioral health status;

2). Nutritional assessment;

3). Developmental assessment;

4). Comprehensive unclothed physical examination;

5). Dental screening including dental referral, when required;

6). Vision screening including objective testing, when required;

7). Hearing screening including objective testing, when required;

8). Laboratory tests including blood lead testing, when required;

9). Appropriate immunizations;

10). Health education, anticipatory guidance;

11). Diagnosis and treatment; and

12). Referral and follow-up, as appropriate.

The Florida health insurance program for uninsured children under age 19, KidCare, provides health insurance to low income children. There are four basic components of the KidCare program:

1). Medicaid. For children from birth through 18 (for eligible families). There are technical and financial eligibility criteria.

2). MediKids. For children from age 1 up to 5 whose household income is more than 133% and less than 200% of the Federal Poverty Level. The household is responsible for a monthly premium.

3). Florida Healthy Kids. This program provides medical coverage for children ages 5 up to 19 in households whose income is between 100% and 200% of the Federal Poverty Level. The household is responsible for a monthly premium.

4). Children's Medical Services (CMS) Network. For children from birth through 18 or 20 (depending on family income) who have special behavioral or physical health needs or chronic medical conditions. The household is responsible for a monthly premium for those children covered under Title XXI of the Social Security Act. CMS is a managed system of care for children with special health care needs covered through Medicaid or Title XXI funds. This network will provide comprehensive health care services and care coordination. It is the Title V Program for Children with Special Health Care Needs in Florida.

A total of 1,550,936 children were enrolled in Florida's KidCare as of June 30, 2004, and 1,479,613 as of June 2005. Of these, 7,728 (Title XXI) and 28,000 (Title XIX) were enrolled in CMS Network as of June 2005.

While an estimated 13%-14% of Florida's children have special health care needs, 28% of children served through the various KidCare programs are identified as CSHCN. At the time of the Florida KidCare Evaluation Report 2004, 83% of children served through Children's Medical Services Network had special health care needs. Twenty-two percent (22%) of Medicaid HMO enrollees, 13% of MediKids enrollees, and 21% of Healthy Kids enrollees had special health care needs. Additionally, 32%-38% of enrollees in MediPass had special health care needs.

Because children with developmental disabilities might be served by any of these publicly funded programs, Table 2 (created from information provided in the Medicaid Summary of Services, the KidCare Evaluation Report 2004, and CMS sources) provides basic information on each.

Disenrollment from various aspects of Florida KidCare is natural, but during the past year, the numbers of children enrolled went down by over 70,000. In June 2005, continuous open enrollment was established to counter that trend, due to a concern that poor families were losing access to health insurance for their children. Prior to that, families had to enroll and re-enroll during specific enrollment periods, which many of them missed. A further impediment was created with the requirement that families provide financial documentation as part of the enrollment. The requirements for documentation of financial status resulted in some families being found to not meet income requirements and others not being able to comply with the burden of completing the multiple forms associated with this process. CMSN's enrollment declined much less than in the other KidCare programs.

For uninsured children with special health care needs who are not eligible for Medicaid or the other KidCare programs, state general funds are available on a limited basis to pay for health care through Children's Medical Services. However, once those funds are exhausted, children may be turned away, or referred to resources in their own communities.

Other Services and Funding for Children

CSHCN whose families have private insurance rely on the family's insurance plan for their health services. However, a recommendation from Children's Multidisciplinary Assessment Team (CMAT) is required for Medicaid-eligible medically complex children under the age of 21 to receive the following Medicaid services:

- Medical foster care
- Model waiver (a 5-child waiver serving medically complex children at home)
- Nursing facility placement
- Prescribed pediatric extended care (PPEC) services.

CMAT is composed of family and representatives from multiple disciplines, programs, and agencies who provide assessments, recommendations, and decisions for services based on medical necessity for medically complex children. The team is headed by staff from Children's Medical Services (CMS) in the Department of Health. CMAT assessments are available to all Medicaid-eligible medically complex children under the age of 21. The program is administered by the Department of Health, Children's Medical Services.

Health care services related to a child's ESE school program are provided through the Medicaid School Match Program for Medicaid eligible students. School districts are responsible for ESE-related health services for students who are not Medicaid eligible. FDLRS, the Florida Diagnostic and Learning Resources System**,** provides diagnostic and instructional support services to district exceptional student education programs and families of students with exceptionalities statewide (from their website, http://www.paec.org/fdlrsweb/index.htm).

Finally, some children are enrolled in the Family and Supported Living Waiver, a home and community-based services program that was approved by the Centers for Medicare and Medicaid Services (CMS); it replaced the Medicaid CSLA program. Originally called the Supported Living Waiver, eligibility was restricted to age 18 and older. This waiver was expanded in July 2005 to include children under 18 and to add behavioral services. A deeming rule allows children of families not otherwise eligible for Medicaid programs to receive the Medicaid health package.

Table 2: Basic Information on Publicly Funded Programs Serving Children with Developmental Disabilities in Florida

Program	Eligibility	Premium	Major Services/Benefits	Provider Choice
Medicaid	Children 0-21	None	• Child Health Check-up (EPSDT) • Community Behavioral Health Services • Dental, including orthodontia • Dialysis services in a freestanding center • Durable medical equipment and medical supplies • Early Intervention services • Family planning services • Healthy Start services • Home and community based services • Hearing services • Home health services • Hospital services (inpatient, outpatient, and emergency services) • Laboratory services, including independent laboratory services • Mental health targeted case management services • Primary care case management (MediPass) • Prescribed drug services • Prescribed pediatric extended care services • Private duty nursing • Physician services • R.N. First Assistant services • Respiratory therapy • School-based services • Subacute inpatient psychiatric program for Children • Targeted Case Management • Therapy services (PT, OT, speech) • Vision services • X-ray services An entitlement for income-eligible children	Families must choose either an HMO or a MediPass provider. HMOs are not available in all areas of the state.

Program	Eligibility	Premium	Major Services/Benefits	Provider Choice
MediKids	Children 1-5 Income limitations apply.	$15-20/month depending on family income	• Most Medicaid benefits • Not an entitlement program – enrollment may be limited • Access to MediKids Choice Counseling to assist in registering their provider choice	Families must choose either a Medicaid participating HMO or a MediPass provider, depending on county.
Healthy Kids (SCHIP)	Children 5-19	$5-10/month, or $110/month if family income is over 200% FPL. Co-payment of $15	• Most Medicaid benefits • Dental (up to $750 per child, per year) (extra premium)	For each region, the Florida Healthy Kids Corporation selects one or more commercially licensed health plan(s) from which families may choose
CMS (Children's Medical Services) A family centered, managed system of care for children with special health care needs.	SCHCN younger than 21 (except SCHIP eligible CSHCN, whose eligibility ends at 19) Income limitations apply	None as long as family income is low through spend-down to Medicaid levels. Monthly premium $15-$20/month depending on family income	• Service Coordination Services • Prevention and Early Intervention services • Primary and specialty care • Long-term care for medically complex, fragile children. • Provides the Medicaid (non-Waiver) benefit package and additional services.	Most services are provided at or coordinated through CMS offices in local communities throughout the state. CMS procures services through private and public providers throughout the state. When necessary, children are referred to CMS affiliated medical centers. These centers provide many specialty programs with follow-up care provided at local CMS offices. Families are allowed to change their managed care plans at any time.

Mental Health Services for Children with Developmental Disabilities

In Florida, providers are increasingly being trained in behavior management, and more are proficient in working with infants, toddlers, and preschoolers (known as "infant mental health"), a relatively new field of study and treatment nationally. One informant said, "Infant mental health is 'taking off' in Florida." Others said that Florida is a national leader in the field of infant mental health (see Promising Practices section, below). According to the National Center for Infant and Early Childhood Health Policy at UCLA, "The unique focus of infant mental health interventions is most often the caregiver-infant relationship, rather than the traditional approach of focusing specifically on the child or caregiver."

Even with these promising developments, mental health services for children with developmental disabilities today can be difficult to obtain. Medicaid does pay for mental health services, including subacute psychiatric inpatient services for children, if such services are available. According to the web-based report, The Health of Florida's Children and Youth, 23% of the families enrolled in CMS Network services said that they had moderate to extreme difficulty in getting mental health treatment for their children (http://www.doh.state.fl.us/family/childhealth/childreport/hi/hi9/prev.html).

Children's Mental Health (CMH), of the Department of Children and Families, provides publicly-funded mental health services for children under the age of 18. Children who meet one of the CMH eligibility categories (serious emotional disturbance, emotional disturbance, or at risk of emotional disturbance) are eligible for children's community mental health services to address the child's mental health needs.

Children with a primary diagnosis of mental retardation are ineligible (by Florida statute) for CMH-operated residential services. However, mental health services can be provided by CMH as an overlay in a residential setting operated by the developmental disabilities system. The typical children's mental health residential treatment center in Florida is not staffed to work with children with developmental delays. However, our informants said that the extremely large waiting list for APD services results in families desperately searching for residential options, and if the problem is behavioral, coming to the CMH system. At times, children with developmental delays are accepted into CMH facilities designed for short-term treatment. At that point, they receive a mental health diagnosis, and there may then be great difficulty in getting them into APD services. Foster homes run by the Department of Children and Families become another placement option for those children with developmental disabilities whose families cannot gain access to adequate, effective mental or behavioral health treatment and ask for out-of-home placement.

Some efforts are being made to alleviate the need for more mental and behavioral health treatment for children. For children enrolled in Medicaid, community behavioral health services and mental health targeted case management services are now provided statewide. This may assuage some of the difficulties families of children with developmental disabilities now face—if the providers are trained to work with children who have developmental disabilities. Fortunately, there are nationally-recognized

programs in Florida, offered through CARD, which address the needs of these families and their children (see "Florida Strengths and Resources" section). Finally, children enrolled in the FSL & DD/HCBS waivers have access to "behavioral services."

Health Care for Children: Stakeholder Perspectives on System Challenges

This section compiles information and perspectives provided by forum participants and people we interviewed, most of who spoke as advocates for children with developmental disabilities or as professionals involved with these children and their families.

1). Delays in Early Identification. This is a big problem, according to our informants: Months or years may lapse before intervention is provided, contributing to difficulties for families and children, not to speak of added costs when intervention is ultimately provided. This was attributed to many factors: child care centers and physicians not making referrals, teen mothers' services not attending to delays the children may have, infants of mothers in juvenile justice facilities not being identified or treated, pediatricians not discussing developmental issues with parents, cultural barriers, undocumented parents fearing authorities, and the like. EPSDT screenings are provided to only 65%-70% of Florida's eligible children. Many children with developmental disabilities are missed due to this. If children are "missed" during the early years, they can be evaluated and served by FDLRS later on. This program is an option for children with special health care needs who have not been identified and served under other programs, but there are often waiting periods for evaluations under FDLRS.

2). Accessibility of Medicaid Benefit Package. The package is generous—that is, children are eligible for many different health services under this package. However, many of our informants (families and professionals alike) said it is much less accessible to families than it should be. In great part, those who qualify for KidCare are assigned to a "managed care option." The services provided by these options are provided under contract with the Medicaid office, and are negotiated with each provider. While a fairly comprehensive set of services is required, there are variations between options. Families enrolled in CMS are assisted by Service Coordinators to select a provider, but may not receive enough information to make the choice that best meets their child's needs. Additionally, provider choice is limited to the provider(s) who have been authorized to provide services within their geographic area (because there are geographical access standards that all plans must follow). Another issue raised was that the managed care philosophy shrinks the time that pediatricians have to identify and treat complex needs; therefore even if the system were able train pediatricians to identify problems and start to treat them, the pediatricians themselves would not be paid for the time it takes.

3). Concerns Regarding Service Coordinators. The size of Service Coordinators' caseloads (average 136) makes it difficult to give families the amount of time and assistance they may need, even though the CMSN values a family-centered approach that puts decision-making in families' hands. Many parents view providers, including

Service Coordinators, as holding back on information that might increase a parent's expectations for service. Many seem to see Service Coordinators as functioning more as gatekeepers to keep people out of the system. Not all Service Coordinators and service providers have the cultural competence or bilingual skills to communicate well with families. Some informants said that Service Coordinators need much more training to accomplish the mission of the CMSN properly.

4). Lack of Qualified Providers. Many providers are not qualified through training to serve CSHCN. Certain parts of the state do not have the capacity to provide the appropriate services for CSHCN, and children with medical conditions whose families live in these areas may need to live in a medical foster home in an area where services are available. For certain types of problems, especially early childhood mental health problems, there are few qualified providers available even in the cities. Infant mental health is a new area and few providers have the experience and the training to identify or treat families whose children exhibit these problems. Training in this area is very much needed. In general, mental health services are inadequate, especially for children with developmental disabilities. The mental health services that do exist are often not adequate to treat children with developmental, especially cognitive, disabilities. Even though there is a dental benefit in the Medicaid and other KidCare programs, many dentists will not take Medicaid. It is difficult for many children to get the dental care they need. Additionally, the number of speech, physical and occupational therapists is dwindling, in part due to new competency requirements that some find demeaning and discouraging, and in part because of the requirement that therapies should be provided in natural environments—if the natural environment is not conducive to the delivery of interventions the therapist prescribes, it is discouraging.

5). Low Medicaid Rates. Funding for CMS has stayed about level, even with an increased number of children being served every year. Medicaid rates are so low (in some cases, 50%-57% of Medicare rates for the same service) that many providers will not take patients who rely on Medicaid; therefore, specialists in many of the health conditions CSHCN have may not be available. While AHCA sets the rates, changes in the rate structure require legislative action.

6). Family Difficulties. Poverty, especially when parents must work or cannot get transportation, interferes with families' ability to get to appointments and provide the interventions that professionals may recommend. Also, teen parents may not have the support needed to seek and follow-up on services.

7). Linkages Between Programs Need to be Strengthened. Juvenile justice centers, family courts dealing with abuse and neglect, Healthy Start, child care centers, CMS, and other early childhood services all need to be linked more closely.

Health Care Transition for Young Adults with Developmental Disabilities

Transition from pediatric to adult health care services is difficult for young adults with developmental disabilities, for many reasons. One is that they are faced with many other transitions as they become young adults, and are (unless guardianship

proceedings ensue) legally responsible for themselves. They must explore issues such as whether and how to seek employment or further education, where to live and how to get the support for living there, whether and how to become involved with others, romantically or in friendships, and so forth. For young people on Medicaid (either for the first time or as one who has been on Medicaid as a child), the health care services they can receive will change (see below, adult section). Young adults who have special health care needs also need to take a close look at how well they understand their conditions, how well they can make their own health decisions, and other factors, as they face changes in services and providers.

The CMS website has a number of excellent resources for young adults and their families to help them plan this important transition. Also the website has a Young Adult Advisory Board to help CMS understand the needs of youth facing health care transition.

Funding and Services for Adults with Developmental Disabilities

In Florida, a number of the optional Medicaid health care services for children are not available to adults. These include comprehensive dental care (emergency dental care and dentures are still provided), subacute inpatient psychiatric care, community behavioral health services, eyeglasses, hearing aids, visual and hearing examinations, targeted case management, and others. For example, Medicaid reimbursement for inpatient hospital care is limited to 45 days per year. Table 3 provides a list of Medicaid services provided to adults.

Health Care in the Waivers for Children and Adults with Developmental Disabilities

The *Developmental Disabilities Home and Community Based Services (DD/HCBS) Waiver* was implemented on April 1, 1982, as a combined waiver with Aged/Disabled Adult Services. In order to meet the needs of these two diverse client populations, the waiver was split into separate waiver programs in 1985.

An individual must be age 3 or older to be eligible for the DD/HCBS waiver. The waiver includes the following health care and mental health services: adult dental, behavioral, dietitian, occupational therapy, personal emergency response systems, physical therapy, private duty nursing, psychological, respiratory therapy, residential nursing, respite, skilled nursing, special medical equipment and supplies, special medical home care, speech therapy, specialized mental health services, therapeutic massage, and transportation, along with many other services described in other sections. Any service provided must be deemed medically necessary for the person.

The Consumer Directed Care Plus (CDC+) Waiver is a coordinated effort among the Department of Elder Affairs, Department of Children and Families, Department of Health, Agency for Persons with Disabilities, and Agency for Health Care Administration. An individual must be enrolled in the DD/HCBS waiver to be eligible

TABLE 3: MEDICAID SERVICES PROVIDED TO ADULTS

Florida Medicaid Mandatory Services	**Florida Optional Medicaid Services**
• Physician Services • Home Health Care • Rural Health • Family Planning • Inpatient Hospital • Transportation • Outpatient Hospital • Nursing Facility • Advanced Practical Nurse Practitioner Services • Portable X-ray Services	• Adult Health Screening • Adult Dental (emergency and dentures only) • Ambulatory Surgical Centers • Assistive Care • Birth Center Services • Chiropractic Services • Community Mental Health • County Health Department Clinic Services • Dialysis Facility Services • Durable Medical Equipment • Home and Community-Based Services • Hospice Care • Intermediate Care Facilities/Developmentally Disabled • Intermediate Nursing Home Care • Occupational Therapy • Optometric Services (if injury or illness) • Orthodontia • Personal Care Services • Registered Nurse First Assistant Services • Physical Therapy • Physician Assistant Services • Podiatry Services • Prepaid Health Plans • Prescribed Drugs • Private Duty Nursing • Respiratory Therapy • Speech Therapy • State Mental Hospital Services • Some Visual & Hearing Services

for Consumer Directed Care. The program allows for a total of 3,300 individuals receiving services from the DD/ HCBS Waiver, Aged and Disabled Adult HCBS Waiver or Traumatic Brain Injury/Spinal Cord Injury HCBS waiver the opportunity to exchange their traditional waiver services for a service option. Individuals enrolled in the CDC+ waiver receive a monthly benefit amount to purchase services directly from a provider of their choice. These providers can include members of the individual's family. In addition, consumers can save funds for approved, medically necessary purchases that might not be affordable immediately. The monthly benefit amount goes through a fiscal intermediary.

Finally, many adults are enrolled in the Family and Supported Living Waiver. The health-related waiver services for adults on this waiver include consumable medical supplies and behavioral services (not available under regular Medicaid), but none of the other health services available through the DD/HCBS waiver. As is evident, adults who are on waiting lists or enrolled in the Family and Supported Living waiver have much more limited health coverage than those on the first two waivers. Children enrolled in this waiver are eligible for the Medicaid package for children, regardless of family income, due to the waiver of the parental deeming rule.

Health Care for Youth in Transition and Adults: Stakeholder Perspectives on System Challenges

This section describes themes represented by stakeholders about the challenges they experience in the current system.

1). Provider Training and Accessibility. Relatively few physicians and dentists are trained and experienced in working with people with developmental disabilities; physicians are often not prepared to manage the complex needs of people with developmental disabilities and don't know how to deliver services so that people with developmental disabilities can participate in making decisions about their health care. Many adults with developmental disabilities experience a lack of dignity and respect in health care settings. In addition, people reported that many medical offices are not fully accessible (e.g., exam tables and chairs). This significantly limits the choice and options for individuals with mobility impairments.

2). Medicaid Restrictions. Extra time is often needed with a patient who has developmental disabilities, but it is not compensated. Medicaid has implemented cost saving strategies by making access to certain medications much more difficult, especially anti-psychotic medication. People are not able to get the medicines and other medical services they need through the Medicaid program, and some stakeholders reported that as a result they may turn to emergency rooms in hospitals and other settings that are required to provide medical services. Information received from the Department of Health indicated that in the fall of 2005 this issue was addressed and a more extensive list of options is now available on the Preferred Drug List.

3). The Cost of Not Providing Health Care. Ignoring/not providing resources for addressing health problems can be costly in the long run. For example, the differences in the health care package of services which is available to adults with developmental disabilities who are enrolled in the DD/HCBS waiver versus those who are on state plan Medicaid may mean that people require costly interventions after a health problem has progressed.

4). Lack of Coordination Across Systems. Some informants said that there is a need for health and mental health providers to take a holistic approach, working together when needed to address a person's health and mental health issues.

5). Future Challenges. People receiving both Medicare and Medicaid will be required to purchase their prescription drugs under Medicare Part D, which will likely not include all of the medications currently available through Florida's Medicaid prescription drug benefit. Additionally, the Medicaid reform waiver presents a challenge and an opportunity to people with developmental disabilities.

Medicaid Reform

According to the June 15, 2005 report issued on Medicaid reform by the National Governors Association, the Medicaid program nationwide has experienced a 40% increase in the participant caseload, and an average annual increase of 4.5% in the health care cost index. Information reported in a policy brief published by the Winter Park Foundation in July 2004 indicated that the caseload of individuals served by the Florida Medicaid program grew from 1.8 million in 2000 to 2.03 million in 2004. There was a 45% increase in the number of children below the poverty level from 2000/01 to 2003/04, and the growth in the low income elderly population was eight times the national average. The Florida State Medicaid budget has increased at an average rate of 12.5% over the past five years. This rate of growth and the impact on the state budget has focused attention on the need for reform to insure the program's long-term sustainability.

On June 3, 2005 Governor Jeb Bush signed legislation intended to reform Florida's Medicaid program for low income families, elderly, and persons with disabilities. This legislation authorized the state to submit a proposal to the federal government to implement reforms on a pilot basis. This proposal was submitted during the summer of 2005. The reform Medicaid 1115 waiver was approved by the Center for Medicaid and Medicare Services (CMS) in October 2005. The pilot will initially be implemented in Broward and Duval Counties. Expansion of the pilot into the rural counties adjacent to Duval County was also authorized in the legislation.

The legislation authorizing the state to pursue this reform waiver from the federal government requires that special delivery mechanisms for children with chronic medical conditions and persons with developmental disabilities be designed and recommended to the legislature. Based on information obtained from Beth Kidder, Bureau Chief for Medicaid Services within the Agency for Health Care Administration (AHCA), persons with developmental disabilities served through the DD/HCBS waiver, the FSL waiver, the Consumer Directed Care-Plus waiver, the Part B Medicaid School Match Program, and by the Children's Medical Services Network, including the Part C Early Intervention program, will not be affected by the pilot reform initiative in its early phases. The Agency for Health Care Administration will respond to the legislature's charge and develop a proposed delivery system for persons with developmental disabilities and children with chronic medical conditions. To this end the Florida Developmental Disabilities Council has partnered with AHCA to develop a "white paper," a model for Medicaid reform to meet the needs of persons with developmental disabilities.

The Medicaid 1115 Waiver reform initiative is intended to restrict the rate of growth in Medicaid to 8% annually. This is a fundamental change from a system where

cost increases were based on growth in enrollment and the cost of health care services. The new system is intended to stabilize Medicaid expenditures while insuring quality and accessible health care for Medicaid participants. An evaluation will be done over a five year period as part of the pilot implementation plan, and the results will be reported to the State Legislature.

A key feature of Florida's proposed reform initiative is improving consumer control over health care decisions. A primary issue for persons with developmental disabilities in Florida's Medicaid reform will be to insure that health care benefits, and the services provided under the Medicaid waivers, are sufficiently protected within the new model to meet their needs and support an inclusive and improved quality of community life.

Florida Strengths and Resources

Florida has many excellent health care resources, which can be viewed as resources for building a more accessible and comprehensive health care infrastructure statewide. Some of these include:

1). Mailman Center for Child Development. The Mailman Center is an internationally renowned University Center for Excellence in Developmental Disabilities Education, Research and Service, located in Miami. It addresses concerns of individuals with developmental disabilities and children with special health care needs through research, clinical service, training for professionals and community members, and advocacy.

The Mailman Center provides many direct services, including screening, diagnosis, and intervention for conditions associated with developmental delay and/or disability. These services also serve as the basis for clinical and research components of the University Center for Excellence. It also trains graduate students, community providers, family members, consumers, and others both inside and outside the field of developmental disabilities. The Center provides technical assistance to state agencies and policy groups and disseminates new information about the field.

The Center is also Florida's Maternal Child Health Bureau's Leadership Education in Neurodevelopmental Disabilities (LEND) training program, a major partner with Children's Medical Services (CMS) for training health care professionals. Children's Medical Services supports a large contract with the Mailman Center.

2). Florida State University Center for Prevention and Early Intervention Policy (CPEIP). The mission of the FSU Center for Prevention and Early Intervention Policy is to influence public policy by enlarging the knowledge base about families and young children. The Center's work focuses on practices and policies which prevent poor birth outcomes, build strong families, promote maternal and child health and development, and prevent disabilities. Its vision is that one day all children will be healthy, equipped to learn, and nurtured to develop their full potential.

The Center provides a wide variety of programs, including parent consultant services, technical assistance, training for caregivers of infants and toddlers, and works closely with state agencies such as Children's Medical Services, the Department of Health's Maternal and Child Health, and the Florida Developmental Disabilities Council.

CPEIP initiated the development of the Florida Association of Infant Mental Health, and offers training around the state on infant mental health awareness, including detection of problems, and resources for intervention. This center is infusing infant and child mental health awareness into many arenas, including developmental disabilities services, juvenile justice, and services for teen parents, Head Start, and others. According to the CPEIP website:

> "The latest brain research emphasizes the importance of early childhood experiences on emotional development. The area of mental health for young children has been relatively unaddressed from a systemic policy perspective. In response to the lack of infant mental health services, the Florida Developmental Disabilities Council began working with the State Medicaid Office to develop a policy for more appropriate classifications, diagnosis and treatment... The overall purpose of the project is to facilitate the availability and integration of mental health services for children birth to age five."

A major result of the project, Florida's Strategic Plan for Infant Mental Health, can be viewed or downloaded at their website, http://www.fsu.edu/~cpeip/IMHplan.pdf. Goal 2 of the plan, "Improve and expand mental health services for children under age five with risks, delays or disabilities," includes strategies for improving mental health services provided for children birth to age five with developmental disabilities, attachment disorders or other established conditions served by the Department of Health Children's Medical Services Part C service system and by the Department of Education's Part B system.

The Center is a leader in the field of infant mental health, and focuses much energy on supporting caregivers to improve mental health outcomes, through training and providing materials for workers in home visiting programs, training infant and toddler trainers, and improving the capacity for Healthy Families and Healthy Start providers to deliver high quality services by providing them with home visiting training and curricular materials.

3). The Center for Autism and Related Disabilities (CARD). The Center for Autism and Related Disabilities (CARD) seeks to provide support and assistance with the goal of optimizing the potential of people with autism, dual sensory impairments, and related disabilities. Located at six university sites throughout Florida, CARD develops programs offering support and training for individuals, families, professionals, and peers throughout Florida. Of the many services provided through CARD, training in Positive Behavior Support is extremely important and has the possibility of supporting families and professionals involved with children with developmental disabilities other than autism. Positive Behavior Support (PBS) is a broad approach for

resolving problem behaviors that are displayed by people with disabilities. Problem behaviors may include: *(1) self-injury, aggression, and other destructive acts, (2) tantrums and other disruptive responses, and (3) excessively repetitive or irritating behaviors including actions that interfere with a person's learning or social interactions.*

4). Children's Medical Services. In spite of budget shortfalls and increasing numbers of children needing to be served, Children's Medical Services does its best to adhere to its mission of providing children with special health care needs with a family centered, managed system of care that aims to ensure that every child has a medical home. CMS has many programs that apply to children of all ages. One of these, the CMS Network, provides primary and specialty health care to eligible children.

5). Miami Examples: In Miami, a number of promising ideas have made a difference: a new taxing district was created for children's health care, for example, and court personnel and probation officers have been trained to recognize delays and disabilities in children.

National Promising Practices and Resources

1). The Kansas Institute for Positive Behavior Support. The Kansas Institute for Positive Behavior Support (KIPBS) at the University of Kansas was established November, 2001 in collaboration with the Kansas Department of Social and Rehabilitation Services (SRS) to create statewide training for Positive Behavior Support (PBS) and Person-Centered Planning (PCP). This system allows professionals in the fields of developmental disabilities, mental health, and child welfare, who have successfully completed the training, to bill Medicaid for PBS and PCP services. The mission of the Kansas Institute for Positive Behavior Support is to:

- Train professionals who will facilitate individual PBS and PCP planning within their regions;
- Create a unified network of professionals who use systems change strategies to embed PBS and PCP processes into their organizations;
- Provide Kansans with access to a variety of online resources and materials free of charge;
- Facilitate state-wide and organization-wide planning processes to increase the effectiveness of individual PBS and PCP plans.

The training has been made available to professionals in the fields of developmental disabilities, child welfare, and mental health. Kansas agencies are able to obtain access to online instructional materials that can be embedded within their own ongoing in-service training efforts. The project's website, http://www.kipbs.org/main.html, contains training modules, presentations, and other good materials for anyone, anywhere (not Kansas only).

2). IMPACT: Feature Issue on Enhancing Quality and Coordination of Health Care for Persons with Chronic Illness and/or Disabilities. (Institute on Community Integration, University of Minnesota, Vol. 18, No. 1, Winter 2005). This bulletin contains articles about inclusion, cost, self-direction, coordination, family issues, and many more topics that affect the health care of individuals with disabilities and/or chronic illnesses. It provides examples of promising practices in health care nationally, discusses important issues, and provides further resources for readers.

3). The Institute for Child Health Policy. The Institute for Child Health Policy (ICHP) is located in Florida but is a national resource on child health policy. ICHP is a unique, multi-disciplinary academic unit of the University of Florida. Its National Center on Financing for CSHCN supports the Maternal and Child Health Bureau to meet the Children with Special Health Care Needs (CSHCN) National Agenda performance outcome that "all families of CSHCN will have adequate private and/or public insurance to pay for the services they need." It's Division of Policy and Program Affairs supports the formulation and implementation of health policies and programs that promote the health and well being of children and youth, especially those with special health care needs. It informs stakeholders about emerging policy and program initiatives, and disseminates research, policy and program information. Their material is accessible to policy-makers and the public through the website, http://www.ichp.edu/about_ichp.asp, and constitutes a wealth of information about Florida's programs and about national child health policy issues.

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AREA OF EMPHASIS

FORMAL AND INFORMAL SUPPORTS

Summary Information

Challenges

- Waiver Rate Reductions and Service Denials
- Permanency Planning for Children
- Need for Additional Information and Resources
- Variability in Support Coordination
- Extensive Waiver Waiting List
- Lack of Flexibility of Services
- Lack of Housing and Transportation
- Need for Support for Limited Guardianship
- Need for More Individualized Residential Support Options for Adults
- Aging Adults with Disabilities
- Aging Caregivers
- Direct Support Staff Shortages
- Foster Care Concerns
- Children and Adults with Challenging Behaviors
- CDC+ Waiver Fiscal Agent
- Need for Increased Inclusive Recreation/Leisure and Social Opportunities
- Limited General Community Accessibility

Strengths/Resources

- Family Care Council
- Initiatives Promoting Choice and Control
- Center on Aging and Disabilities
- Hillsborough County
- Wheelchairs on the Go: Accessible Fun in Florida
- Bridges Program

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AREA OF EMPHASIS: FORMAL AND INFORMAL SUPPORTS

General Description of the Florida Formal Support System

Across the country, states are struggling to provide community-based services and supports that incorporate greater individualization, choice, and control for people with disabilities. At the same time, states are under pressure to cut and/or contain costs associated with the Medicaid program which is the primary funding source for most of the service and supports provided.

Florida uses three Medicaid waiver programs to support the majority of the home and community based services for persons with developmental disabilities. These include the Developmental Disabilities Home and Community Based Services Waiver (DD/HCBS), the Family and Supported Living Waiver (FSL), and the Consumer Directed Care Plus Waiver (CDC+). The DD/HCBS waiver provides an array of 34 services as well as State Plan eligibility. It should be noted that the array of services available in Florida under the DD/HCBS waiver is the largest in the nation. The FSL waiver includes 11 services as well as State Plan eligibility. This waiver has an annual spending cap of $14,282 per individual.

According to a presentation by Beth Kidder at The Arc Florida conference, as of June 2005 enrollment in these waivers was 23,998 in the DD/HCBS, 1,917 in the FSL, and 967 people with developmental disabilities in the CDC+. The cap on the number of individuals with developmental disabilities who can participate in this waiver is 2,182. According to OPPAGA, the waiting list for the DD/HCBS waiver exceeds 15,000 individuals. The Agency for Persons with Disabilities reports the waiting list to be 12,900 individuals as of October 2005 with plans to enroll 6,700 individuals into the waiver program by the end of fiscal year 05/06. This enrollment projection includes a priority system to enroll individuals in crisis starting at a rate of 30 per month.

Within Florida the agency responsible for the provision of services to persons with developmental disabilities is the Agency for Persons with Disabilities (APD). According to OPPAGA, the state legislature has appropriated $1.2 billion dollars to APD for fiscal year 2005/06 which was an 8% increase over the previous year. APD serves approximately 32,000 people.

In 2004 a redesign of the waiver programs was initiated to address the waiting list. The redesign initiative was intended to provide a more equitable distribution of public resources to meet the needs of persons with developmental disabilities. Although waiver funding resources had continued to be increased in the preceding years, there had been minimal impact on the DD/HCBS waiting list as the average cost for current waiver enrollees continued to rise. An analysis of the waiting list conducted by APD found that 70% of those on the waiting list were children and youth. Therefore, eligibility for the FSL waiver was expanded to include children, and a triage priority designation was established for new enrollment opportunities within the DD/HCBS waiver. The legislatively mandated triage priority for the DD/HCBS waiver is as follows: a) persons with continuing nursing care needs which cannot be met through the State

Plan; b) persons requiring residential placement: and c) persons in supportive living situations who have needs which cannot be met through the FSL waiver.

Florida is also seeking federal approval to expand participation in the CDC Plus waiver. If approved, this expanded authorization would allow persons served in either the DD/HCBS waiver or the FSL the option of enrolling in CDC Plus. Individuals who are enrolled in the HCBS or FSL waivers select a Support Coordinator who assists with arranging services through the waiver, other mainstream resources, and natural supports. It should be pointed out that APD and Medicaid do not view the waiver programs as having the sole responsibility for providing needed supports. Rather they are intended to work in combination with other public, community, and private resources including natural supports to achieve the goal of a full and inclusive quality of life.

Most people with developmental disabilities who live in Florida reside with their families. A notable statistic reported in 2002 by the Coleman Institute was that 61,345 persons (second highest number in the nation) with a developmental disability resided with aging caregivers.

According to a 2005 presentation by Ed Rousseau, Supported Living Coordinator, Agency for Persons with Disabilities, among the individuals with developmental disabilities who were living outside of their family home, 30% were in supported or independent living; 26% in Intermediate Care Facilities; and 44% in group homes. Florida has embarked on a path to close state institutional facilities with the closure of Landmark in 2005, and the Gulf Coast Center expected to close over the next 5-year period. Clearly, the predominant direction of services in Florida is to support individuals within their family and in community based settings.

Children and Families. Most children live with their families. We were unable to obtain data on number of children in other out-of-home placements. According to Teri Arnoldy, of the Agency for Health Care Administration, during FY 2004-05, 593 children (under age 21) received medical foster care services. And, as of August 2005, 361 children (under age 21) were in nursing homes. Most of the primary caregivers for children with developmental disabilities are parents, and other family members.

According to the Coleman Institute, spending for family support has increased significantly in Florida in the past 10 years. In 1994, total family support funding was $18.3 million, and by 2004 spending had increased to $222.6 million. This $222.6 million supported 17,108 families, and provided the following services: cash subsidy payment ($532,377, for 137 families); and "other family support" ($222,112,102, for 17,108 families). In 2002 Florida ranked 9th nationally in the amount of family support spending with an average of $7,386 spent per family.

The primary source of family support is through the Medicaid waivers, including the DD/HCBS, the FSL, and the CDC+. Also, various types of subsidies are offered, depending on the availability of funding. There is the "family care program" subsidy, for families who do not qualify for the waiver, which can pay for parent training, respite

care, modifications to the home or vehicles, or other needed support services. There are also in-home subsidies that can be used to pay for basic living necessities or one-time start up expenses such as moving costs and equipment.

The FSL waiver is intended to be a primary source of support to families. This waiver offers an array of 11 services including: Adult Day Training, Consumable Medical Supplies, Environmental accessibility Adaptations, In-home Support, Personal Emergency Response, Respite, Support Coordination, Supported Employment, Supported Living Coach, Transportation, and Behavioral Services. As mentioned previously the total annual budget per person cannot exceed $14,282. In addition, enrollment in the FSL waiver includes eligibility for State Plan Medicaid services.

In 1997, a group concerned with the need for respite care service programs formed the Florida Respite Coalition (http://www.floridarespite.org). This coalition is working to create a statewide system of Lifespan Respite Networks. According to the Florida Respite Coalition's 2004 "Service Gap Report," respite care may be provided in approximately 15 different types of environments, including the person's own home, the family home, a respite provider's home, or a variety of center-based options. The report notes that families often seek the option of respite in the provider's home, but "this is not readily available through agencies primarily because of liability issues and associated costs" (p. 24). Respite care is a challenge for those on the waiver waiting lists (e.g., Hillsborough County Report). Statewide, there are a total of 6,358 families waiting for respite care (Florida Respite Coalition, 2004). Private pay is the main source of payment for respite care. County special tax funded authorities are the second greatest source of funding for respite care (Florida Respite Coalition, 2004).

In 1993, the Florida State Legislature established the Family Care Council, which advises the APD on the needs of families and individuals with disabilities. The FCC works at the state level and district level. There are Councils in each of the 15 state APD Districts. At least three of the members must be self-advocates and the remainder are family members; they are appointed by the Governor. The primary functions of the FCC include: (1) Assist in providing information and outreach to self-advocates and families; (2) Review the effectiveness of the APD and make recommendations with respect to service implementation; (3) Advise the APD administrators on the community and family support systems in their areas; and (4) Provide support to families. Information about the Family Support Councils is available at (http://www.fccflorida.org).

There are numerous family organizations throughout the state. For example, the Family Network on Disabilities of Florida, Inc. is a statewide network of families and individuals who may be at-risk, have disabilities, or have special needs. Their mission is to "ensure through collaboration that Floridians have full access to family-driven support, education, information, resources, and advocacy." The Family Cafe focuses on providing information and educational opportunities to individuals with disabilities and families. The organization hosts a large annual conference, with a purpose of bringing together families and different agency representatives to share information and respond to questions.

Adults. In terms of residential services to adults, since the early 1980s in Florida, there has been an emphasis on development of supported living to replace larger group homes and other facility-based services. The Florida Supported Living program sets a limit of three as the maximum number of individuals who can live together, and the provision of the support services must be separated from the housing component.

The Supported Living Project, starting in 1988, with funding from the FDDC, began to lay the groundwork for the current program. In 1992 supported living was incorporated into the first waiver initiative and since that time there has been a significant growth in the program with 1,854 served in 1995 and 4,487 in 2004 (Braddock, 2005). Data collected through the program quality assurance system indicate that people participating in supported and independent living achieve 70.9% of their personal outcomes which is the highest performance level as compared with other residential settings.

Increasing choice and control. Florida has undertaken various initiatives to promote increased choice and control for families and individuals with disabilities. Beginning in 2000, Florida launched a Medicaid 1115 demonstration waiver, the Consumer-Directed Care Plus waiver using a "cash and counseling" model. In 2003, this became the Consumer-Directed Care Plus program, operating under an Independence Plus 1115 waiver amendment approved by the Centers for Medicare and Medicaid Services. In addition, the Florida Freedom Initiative enabled people with disabilities to accumulate private resources while still retaining their benefits and services. Both initiatives provide significant opportunities to increase consumer choice and control in the areas of employment, housing, transportation, and community participation, particularly if the Consumer-Directed Care Plus waiver is expanded.

Informal Supports

APD and other stakeholders recognize that the formal support system alone is not sufficient to adequately support an individual, and further that a network of natural/informal supports is essential to the quality of everyone's life. An intentional role of Support Coordinators, Supported Living Coaches, and Nonresidential Support Staff is to support people with disabilities to develop existing and new connections with informal supports.

As evidence of APD's understanding of the significance of informal supports the Florida Network on Disabilities was awarded $181,000 to support a family-to-family initiative, the Bridges program. The contract is 15 ½ months long, ending August 15, 2006. The purpose of the program is to establish new and innovative methods for providing support, information and focused training to individuals with developmental disabilities and their families. Bridges will inform people on the waiting list about natural and community supports. The program will also offer focused training to individuals about creative ways of developing support networks.

Community Participation

It is recognized in Florida that it is important for people with developmental disabilities to not just live within communities, but to be active participants in their communities. This involves a wide variety of activities and engagements related to: pursuit of individual interests, religious expression, recreation/leisure activities and social relationships. Both formal and informal supports can play a role in helping people be a part of their communities. In addition, community organizations, not just the disabilities service system, have a key role to play in supporting community participation. Several examples of organizations which actively support the participation of persons with disabilities are: The Florida Disabled Outdoors Association which advocates for more accessible recreation activities and environments; the Girl Scouts of Suncoast Council; and the VSA Arts of Florida. There are clearly numerous other organizations throughout the State which have similar commitments to inclusion.

Formal and Informal Supports: Stakeholder Perspectives on System Challenges

This section describes themes represented by stakeholders about the challenges they experience in the current system.

1). Waiver Rate Reductions and Service Denials. According to forum participants and people who were interviewed, reductions and changes to service authorization are being made arbitrarily. This leaves individuals with disabilities and families with uncertainty about the long-term commitment of the system to the supports required for community living. Most explanations given for such reductions relate to updated "medical necessity" judgments by those who control utilization. The conclusion some families and consumers are reaching is that when your life begins to improve with the help of the support, the system concludes that you no longer need the service and takes it away. People feel that these cuts are putting increased expectations and pressures on families because the system relies on identifying performance deficiencies as the basis for service authorization versus building on and supporting strengths. Similar to observations made by families involved with the Part C system, due process is perceived to be an intimidating experience and overpowering for families. There seems to be a general disregard for the recommendations of family physicians concerning support needs. The entire experience for obtaining service authorization is a stressful, uphill battle for families. Not all support coordinators are proficient in preparing supporting documentation which meets the requirements for service authorization. This results in service denials and needs not being met. At the provider level, some forum participants and people we interviewed reported that, in the face of recent rate reductions, providers are less able to support individuals with the most severe disabilities. The rate reductions referenced by providers are those paid for by APD for service in residential settings. APD views this situation as a standardization or rates across the state which did result in some increases and some reductions. Providers who have negatively impacted by this change have been actively seeking restoration.

2). Permanency Planning for Children. Based on the information we reviewed and interviews, there does not seem to be systematic implementation of permanency planning for children and their families. There are still significant numbers of children living in public and private institutions, nursing homes, and other smaller facilities throughout the state. Increased efforts are needed to close down the pathways by which children are entering into these facilities and, at the same time, increased resources must be directed to support for family living (with their birth families, or alternative families, if this is not possible) for all children.

3). Need for Additional Information and Resources. Families reported the need for more family-to-family support and education, with information that is clear and understandable, at the time of their child's diagnosis and throughout their child's life. In addition, families and individuals with disabilities expressed the need for more information that is clear and understandable about various service options, particularly about consumer-directed supports and the "nuts and bolts" of directing their own supports. The FDDC has an initiative to develop some consumer-friendly information about consumer-directed supports.

4). Variability in Support Coordination. There is reportedly wide variation in performance among Support Coordinators, with some who seem to be much more creative and skilled than others at finding disability system and community supports that best meet individual/family needs and desires. Families and individuals who are enrolled in the waiver reply on the Support Coordinator to represent their needs through supporting documentation which they prepare. As mentioned above the skills of Support Coordinators vary thus jeopardizing the reliability of service authorization. Support Coordination is only available to persons enrolled in the DD/HCBS or the FSL waivers. It was suggested that individuals on the waiting list would benefit from the assistance of well trained Support Coordinators, who have knowledge and experience with access to mainstream resources. This would provide at least some level of assistance while waiting for waiver enrollment.

5). Extensive Waiver Waiting List. One of the biggest barriers reported in support for families is the waiting list for the waiver. Some families reported they had waited 20 or 25 years for services. They feel that the situation is not nearly as bad for younger families now waiting. However, there still were reports of people waiting 5-7 years for services. In the meantime, families and individuals who are not enrolled in the waiver are unable to obtain such things as durable medical equipment, home renovations, and respite. Some people reported that they had not applied for the waiver due to the extensive waiting list. This suggests that the waiting list estimates may not be an accurate measure of the number of people who are in need of services. While the recent changes to the FSL waiver should help address the overall waiting list problem, APD has a significant education issue associated with obtaining a buy in from families who have questions about the long-term implications of accepting the FSL option. APD has already initiated efforts which may help to address this situation through the provision of information targeted to address these concerns.

6). Lack of Flexibility of Services. Some people reported a lack of flexibility of services that could jeopardize people's community living situations. For example, if someone receiving supported living services is injured or ill and temporarily requires additional in-home support, this may be difficult if not impossible to arrange. The Agency for Persons with Disabilities reports that administrators may authorize services in response to emergency situations.

7). Lack of Housing and Transportation. The lack of affordable, accessible housing and transportation is a barrier to community living, employment, and community participation.

8). Need for Support for Limited Guardianship. While there are resources directed toward full guardianship, it was reported that there is a lack of resources to support limited guardianship options. People expressed a need for increased information and support to families around issues such as guardianship, estate planning, and futures planning in general. One public guardianship resource, Lutheran Services of Florida, was identified as a valuable resource especially for indigent individuals.

9). Need for More Individualized Residential Support Options for Adults. Seventy percent of developmentally disabled people who live outside of their family home live in intermediate care facilities, group homes or other institutional settings. Notwithstanding the state's record of closing institutions, and the growing commitment to community based supports, the current public and private residential system has maintained a stable census from 1999-2004. Discharge planning was identified as problematic with the notable exception of the teams assigned by APD to the closure facilities. There is also wide variation among residential providers, with some who seem to be more flexible and creative at developing individualized supports that are inclusive of people with the most severe disabilities. Some training on person-centered services has been provided by the FDDC. A number of people said there is need for more capacity-building among residential providers to foster movement in the system to more individualized options. This observation seems even more crucial as the system moves to one more characterized by increased individualization, choice, and control. Some parents are reluctant to explore more individualized options because they are not sure that the system is safe and reliable, and worry that, in the name of inclusion, there will be isolation and a potential for harm.

10). Aging Adults with Disabilities. A concern expressed by a number of people related to aging adults with developmental disabilities. People feel there is a lack of meaningful daytime options for this population; a lack of coordination between the aging and disability service system in relation to supports for these individuals; and a lack of supported living and other individualized housing options for them. Issues of affordable, accessible and safe housing with supports were of particular concern.

11). Aging Caregivers. Another concern related to aging caregivers with grown sons and daughters who have developmental disabilities. This segment of the consumer population may warrant particular attention, given the data previously presented about

the estimated number of persons with developmental disabilities who are living with aging caregivers in Florida coupled with the waiting list issues. There is a belief that there are still a lot of these aging caregivers who have not been identified by the disability service system, and who thus are receiving no supports and no assistance with planning for the future for their sons and daughters.

12). Direct Support Staff Shortages. Concern was expressed about the adequacy of the direct support staff workforce citing low compensation (average hourly wage for community support staff is $7.63 an hour), high turnover and training needs as a threat to the system. Hiring and retaining high quality staff was viewed by stakeholders as a significant barrier to insuring the availability of long-term supports. Given the relatively low unemployment rate in Florida and competing employment opportunities, the ability to fill the direct care workforce needs poses a significant challenge to the system. National studies of workforce issues tell us that low pay, poor working conditions, the low status of the work, and inadequate training and support are some of the causes of turnover and difficulty in recruiting people who work with people who have developmental disabilities (Test et al., 2003). The Agency for Persons with Disabilities reports that "Uniform Core Competency Training" was instituted as a requirement for all direct support staff effective June 2005.

13). Foster Care Concerns. Probes to identify access to developmental disabilities services by children living in foster care settings resulted in comments about high case loads and high staff turnover in the foster care system. The general theme was that these foster care workers barely have time to know their clientele and keep up the basic work load and attention to specialized services is often overlooked. Concern was also expressed related to the coordination of services within the foster care system given the privatization of case work services and the separation of APD from the Department of Children and Families.

14). Children and Adults with Challenging Behaviors. People expressed the need for positive behavior training for families and direct support providers, within the context of family homes and other natural environments. It was reported by both parents and advocates that the lack of providers, who have skills in positive behavior approaches and who can work with families and direct care staff is creating a barrier to meeting the needs of many individuals in the community. A lack of collaboration between the developmental disabilities and mental health systems for children with behavioral issues was also identified as a deficiency within the current system. The behavior service component of the system reportedly lacks clear regulatory standards which govern the use of aversive techniques. Both standards and practices in behavior support were described as not confirming with the principles of positive behavior support.

15). CDC+ Waiver Fiscal Agent. A number of people reported that problems with the fiscal agent for the CDC+ waiver are causing financial difficulties for families.

16). Need for Increased Inclusive Recreation/Leisure and Social Opportunities. People expressed the need for more inclusive opportunities for socialization and recreation.

17). Limited General Community Accessibility. Many community places are not accessible, including doctors' offices, businesses, and other community facilities. This limits choice and opportunities for community participation for people who have mobility impairments. People identified the need to conduct communitywide surveys in order identify accessible and inaccessible community places (e.g., medical offices, businesses establishments, playgrounds, and so forth) followed by advocacy to increase community accessibility.

Florida Strengths and Resources

Selected strengths and resources are described below. However, this does not represent a comprehensive listing.

1). Family Care Council. The creation of the Family Care Council was a significant step to help give families voice and visibility. The FCC along with various other family organizations within the state are working to provide information, training, and advocacy services which are more family-centered.

2). Initiatives Promoting Choice and Control. The CDC+ Waiver and the Florida Freedom Initiative both are affording individuals and families much greater control and choice with regard to their services. Florida has requested an expansion of the CDC+ waiver, which would increase opportunities for choice and control, and potentially expand opportunities on other waivers for individuals on the waiting list. Also, it seems that the CDC+ waiver is not at capacity now (with 967 people with developmental disabilities enrolled, and a cap of 2,182 people with developmental disabilities). Therefore, effort could be directed toward locating individuals within the control group for that waiver, and, if the expansion is approved, individuals now on the other waivers, to determine interest in the CDC+. In addition, the Real Choice Partnership is working at state and local levels to create collaborative networks of individuals to work on targeted issues and barriers related to promoting control and choice.

3). Center on Aging and Disabilities. This center focuses on advocacy, education, and training related to issues of aging and disability. Through its initiatives and collaborative projects (e.g., Sherman & Bloom, 2000), this Center has a wealth of expertise in strategies and lessons about fostering collaboration between aging and developmental disabilities service systems.

4). Hillsborough County. At the local level, there is coordinated planning for community services, beyond just disability services. Within this, there is an attempt to identify and address needs. For instance, a respite program was created through county funds to assist families who are on the waiting list for services

5). Wheelchairs on the Go: Accessible Fun in Florida, by Michelle Stigleman and Deborah Van Brunt. This is a good example of a guide that assists people with disabilities in accessing community recreational and leisure resources.

6). Bridges Program. This program focuses on assisting those who are on the waiting list to develop informal support networks and gain access to generic community services.

National Promising Practices and Resources

1). Systems Change. As Florida pursues further systems change to promote more choice and control, there are a variety of different sources that give examples of strategies and lessons from other states. A few selected resources include:

a). The Website for Centers for Medicaid and Medicare Services (CMS) includes a section describing promising practices in home and community based services from various states. This can be found at: http://www.cms.hhs.gov/promisingpractices/states.asp.

b). Having it Your Way: Understanding State Individual Budgeting Strategies. This manual, by Charles Moseley, Robert Gettings, and Robin Cooper, is a report that summarizes the results of study of state individual budget development practices conducted by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in 2002. The report describes individual state budgeting activities, identifies factors that are instrumental in implementing effective methodologies, and provides information on how to transition from traditional program funding to individual budgeting.

c). Human Services Research Institute (HSRI), "Person-Centered Supports—How do States Make Them Work?" This document was prepared as part of the "Reinventing Quality" Project in collaboration with The National Association of State Directors of Developmental Disabilities Services (NASDDDS), The Human Services Research Institute (HSRA), and The Institute on Community Integration at the University of Minnesota (ICI/UM). The report provides case studies of four states where there is evidence that person-centered practices are widely used: Wyoming, Wisconsin, Kansas, and Connecticut. It discusses the methods used, lessons learned and potential implications for other public systems in fostering person-centered supports for people with developmental disabilities in these very distinct states. Because these four states span the most common ways in which states organize their developmental disability service systems, the strategies they use present implications for other states. This paper can be found at the following web site address: www.hsri.org/docs/793ESummary.Doc

d). Center for Self-Determination. The Center for Self-Determination offers information, resources, and technical assistance to individuals, organizations, and states as they attempt to change their systems based on principles of self-determination. The technical assistance covers a broad array of critical issues,

including: general systems change, support, income production, leadership, and fiscal issues. For further information, see: http://www.self-determination.com/.

e). Piedmont Innovations. This initiative in North Carolina is part of the CMS Independence Plus Initiative. It is designed to promote systems change encompassing person-centered planning and individual budgets. It targets individuals with developmental disabilities who are at risk of placement in an ICF/MR. Further description of this initiative can be found at: http://www.dhhs.state.nc.us/dma/InnovationsWaiver.pdf

2). Support Coordination. Developing new roles and competencies for support coordinators is key to systems change that promotes real choice and control. Possible resources include examples of other states that are working toward systems change and have incorporated new training and roles for support coordinators as part of this. Examples include: The Real Life Choices initiative in New Jersey (http://www.fscnj.org/rlcprovover) and Pennsylvania's system change efforts (http://www.cms.hhs.gov/promisingpractices/patspmr.pdf)

3). Developing the Capacity of Organizations to Provide Individualized, Person-Centered Supports. Across the country an increasing number of agencies are moving away from use of group homes to providing more individualized supports. In addition, new agencies are being created which offer only individualized supports, and not group homes. Various initiatives have occurred to help develop the capacity of organizations to move in these directions. For example, the Partnership for Excellence is a project of the Louisiana Developmental Disabilities Council. It is a training and technical assistance program for agencies that provide individuals with developmental disabilities support to live in their own homes. Participating agencies receive training to provide person-centered supports, organizational change, and leadership development. The training emphasizes deep, permanent organizational change based on a commitment to person-centered planning and individualized supports. Additional information regarding best practices in person-centered planning can be found on their website. Information can be found at the Louisiana Developmental Disabilities Council website: www.laddc.org/plans/activities/index.php#partnership.

4). Direct Support Workforce Initiatives. Across the country, an increasing number of states and localities are taking steps to develop and enhance their direct support workforce. Two resources related to this include:

a). The National Alliance for Direct Support Professionals (NASDP). This national coalition of organizations and individuals is committed to strengthening the quality of human service support by strengthening the direct support workforce. The Alliance has developed a national agenda to address conditions that are harmful to people who rely on human services, including high staff turnover, low social status, insufficient training, limited educational and career opportunities, and poor wages. NASDP believes that people with disabilities and their families are partners with direct support professionals in the move toward self-determined lives, and that well-planned workforce development strategies

are critical if the goals and dreams of people receiving support are to be fulfilled. Its website is http://www.nadsp.org/index.html.

b). The College of Direct Support (CDS). The College of Direct Support is a web-based instructional program, based on a careful analysis of the knowledge, skills, and attitudes required of DSPs in their daily work. The CDS helps users understand and apply these important competencies and ethical practices through timely, innovative, engaging, and interesting training. CDS was developed by a collaboration between several national organizations and the University of Minnesota's Institute on Community Integration with funding from the Administration on Developmental Disabilities and the National Institute of Disability and Rehabilitation Research, US Department of Education. Its website is http://www.collegeofdirectsupport.com/. While the CDS can be costly for any one agency, it may be more feasible to purchase it through a larger organizational entity or consortium of agencies.

5). Permanency Planning for Children with Developmental Disabilities. In the 1980s, Michigan began an effort to ensure that all children, including those with the most severe disabilities, would live with families, rather than in group homes, institutions, nursing homes, or other facilities. This involved articulating a value that "all children belong with families," and implementing a policy of "permanency planning" for children with developmental disabilities. A crucial component of this process was identification of all the children who were in any type of out-of-home placement, and examination of the pathways that had led to out-of-home placement. Next, focus was placed on "closing the front doors" to placement of children in facilities, and, at the same time, directing resources toward family care. This included provision of family support to the birth family, "whatever it takes" to keep children at home." If it was not possible for children to live with their birth families, then adoptive or foster families were found and supported, with efforts, though, to maintain birth family involvement where possible. A beginning resource is a Policy Research Brief published by the University of Minnesota that discusses issues related to permanency planning and provides additional resources. The Policy Research Brief is entitled, "Do We Really Mean Families for All Children? Permanency Planning for Children with Developmental Disabilities." It can be found at: http://ici.umn.edu/products/prb/112/default.html

6). Promoting Community Membership and Participation. Nationally, there is increased attention to promoting meaningful community connections and community participation, based on the person's interests and choices. Two notable initiatives supported by DD councils in other states (e.g., in Massachusetts, the Association Integration Project; and in Pennsylvania, "citizen participation" project) have created examples of strategies that have been disseminated widely so that other staff and agencies can learn from these. The book, Friendships and Community Connections between People with and without Developmental Disabilities, edited by Angela Novak Amado, includes a chapter that describes the Association Integration Project. The other chapters in this volume also contain many valuable strategies for promoting social relationships for individuals with developmental disabilities. The book, Crossing the River: Creating a Conceptual Revolution in Community & Disability, by David B.

Schwartz, includes a chapter describing the "citizen participation" initiative in Pennsylvania. Other chapters in this book discuss the role of DD Councils in promoting conceptual change. Finally, Involving All Neighbors: Building Inclusive Communities in Seattle is an initiative to promote community participation that was located in the Seattle Department of Neighborhoods, and involved a collaboration between this department and the Washington State Division of Developmental Disabilities. It is a Seattle-based project that celebrates the goal of helping neighborhoods to become genuine communities for all who live in them. This unique program is housed under The Department of Neighborhoods which collaborates with over 300 other programs around Seattle. The program provides tools for other communities to use to assist in the process of including individuals with disabilities. The website provides resources, strategic plans for community building, and personal stories from community members. The web site can be found at: www.seattle.gov/neighborhoods/involve/default.htm.

7). Aging and Disability. The Rehabilitation Research and Training Center on Aging with Developmental Disabilities (http://www.uic.edu/orgs/rrtcamr/) offers resources and technical assistance related to people with developmental disabilities who are aging, as well as aging caregivers of people with developmental disabilities. An example of one of their products is: Aiding Older Caregivers of Parents with Intellectual and Developmental Disabilities: A Tool Kit for State and Local Aging Agencies. This booklet provides useful information to state and area agencies on aging about the needs of aging caregivers of persons with disabilities. This document provides descriptions of how developmental disability services are structured, examples of planning processes for aging parents, a glossary of services that are provided by the various states, networking and collaboration methods, cultural information, court decisions, and resources for future planning. This useful tool can be found at the following website: www.uic.edu/orgs/rrtcamr/Aiding_older_caregivers.pdf.

8). National Center for Family Support. The Human Services Research Institute (HSRI) has established the National Center (NCFS) for Family support at HSRI. NCFS was established to provide training and technical assistance on family support to 56 project sites. The Center, as well as the sites, are funded by the U.S. Administration on Developmental Disabilities. In addition to information about the project sites, the NCFS web site includes family support resources and publications addressing best practice and policy in family support. The NCFS web site address is: http://www.familysupport-hsri.org/

9. Positive Behavior Support. The Technical Assistance Center on Positive Behavioral Interventions and Support (http://www.pbis.org) is a consortium that conducts research, disseminates information, and provides technical assistance in relation to promoting positive practices in behavioral support. In addition, the Center for Evidence-Based Practice: Young Children with Challenging Behavior is a collaborative project that provides research, technical assistance, and training in effective practices that are linked to positive outcomes for children and families (http://challengingbehavior.fmhi.usf.edu).

10. Person-Centered Planning. Connie Lyle O'Brien and John O'Brien, (2000). The origins of person-centered planning: A community of practice perspective. This is a chapter in a book but can be found at (http://thechp.syr.edu/PCP_History.pdf). Also, some good resources on person-centered planning are listed by David Pitonyak at (http://www.dimagine.com/page27.html).

AREA OF EMPHASIS

TRANSPORTATION

Summary Information

Challenges

- Impediment to Community Employment and Broad Community Participation
- Specific Transportation Service Issues
- Service Boundaries
- Medicaid Waiver Limitations

Strengths/Resources

- Transportation Disadvantaged System
- Broward County Transportation System
- Space Area Coast System
- Florida Freedom Initiative
- A Blueprint for Self-Determination in Florida

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AREA OF EMPHASIS: TRANSPORTATION

Description of the Florida Transportation Disadvantaged System

Nationally, transportation is a key issue and barrier to full community participation for many people with disabilities. For example, a national study conducted by the U.S. Bureau of Transportation Statistics in 2002 found that 6 million people with disabilities have difficulties obtaining the transportation they need (National Council on Disability, 2005). Particularly in rural areas, some individuals have been forced to move into institutions and other facility-based services (e.g., nursing homes) due to lack of transportation for needed therapies and other services (NCD, 2005).

It is notable that there has been significant effort in Florida to establish and fund a coordinated system of accessible transportation. The Transportation Disadvantaged System is a coordinated system of transportation, mandated by F.S. Chapter 427, for residents who are considered transportation disadvantaged. It was created in 1979, based upon the work of the Coordinating Council on the Transportation Disadvantaged, including their collection of testimony from consumers, families, and providers about transportation challenges within the state. People served by the Transportation Disadvantaged System include low-income individuals, children, elderly people, and individuals with disabilities. TD providers do not identify the type of disability of the people they service; thus, it is not possible to determine how many of those are people with developmental disabilities.

Each county or area of the state has a county transportation coordinator (CTC) who is responsible for arranging or providing trips in that county. The CTCs report to the statewide Transportation Disadvantaged Commission in Tallahassee. Chapter 427 also established the TD Trust Fund, which provides additional funding for the system to try to address unmet needs, particularly in rural areas.

According to the Transportation Disadvantaged summary report for 2004, in 2004, 19,779,563 rides were provided for individuals with disabilities. Of these rides, approximately 36% were for medical purposes, 19% for education/training/daycare, 14% for nutritional, 9% for employment, and 22 % for “life-sustaining/other” trips. The number of unmet trip requests was 682,037. This is a decrease from 1,065,528 in 2002, and 709,597 in 2003. In addition, in 2002, the TD system served 9.9% of individuals considered “transportation disadvantaged,” and in 2004 it was 14.10$. The total revenue for the program in 2004 was $307 million, and total expenses were $303 million.

Transportation: Stakeholder Perspectives on System Challenges

This section describes themes represented by stakeholders about the challenges they experience in the current system.

1). Impediment to Community Employment and Broad Community Participation. Among people who attended the forums, those who we interviewed, and reports that we reviewed, there was agreement that transportation constitutes a significant barrier to community employment and to all other aspects of participation in community life. For example, in a study conducted in Hillsborough County, 64% of post high school youth reported that transportation was a barrier to employment and other community involvements. There is an emphasis on rides for medical purposes versus rides for employment and education and training purposes. Noting the decrease in rides for employment after 2001, the authors of the Blueprint for Self-Determination report commented that this has helped move the fund "from a balanced medical and nonmedical system to one skewed in favor of medically related transportation."

2). Specific Transportation Service Issues. Some of the problems people mentioned regarding transportation include long and/or inconsistent wait times, lengthy "en route" times, very limited if any service in rural areas, and very limited if any service on evenings and weekends. In addition, people report a lack of sidewalks, curb cuts, and safe waiting areas for transportation.

3). Service Boundaries. The paratransit services will not make trips across county lines.

4). Medicaid Waiver Limitations. The waiver will not pay for transportation to community job sites, only to facilities.

Florida Strengths and Resources

1). Transportation Disadvantaged System. It is positive that there has already been significant effort within Florida to coordinate and fund accessible transportation. The Transportation Disadvantaged system is described as one of the "success stories" within IMPACT: Feature Issue on Meeting Transportation Needs of Youth and Adults with Developmental Disabilities, published by the Institute on Community Integration, University of Minnesota (2005).

2). Broward County Transportation System. According to a 2005 National Council on Disability report, Broward County represents "best practice" in terms of providing quality, accessible transportation. It is also listed as a "useful practice" on the United We Ride web site (http://www.unitedweride.gov/). According to the United We Ride web site, services operated from 5:30am to 10pm Monday to Saturday, and from 7:30 am to 8:00 pm Sundays and Holidays. In addition, there is a policy of "zero trip denials." There have been multiple efforts to make the system more user-friendly, provide more options for customers, and improve efficiency. Key elements of this include: establishing centralized control, use of a software system to administer and monitor paratransit services; and allowing customers to choose from multiple providers. In addition, the quality assurance program includes monitoring by mystery riders, frequent visits to contractors' offices, and onboard passenger surveys. A full-time travel trainer was hired to train people in use of the fixed-route system.

3). Space Area Coast System. In a 2004 report of the Transportation Research Board, the Space Area Coast Transit (SCAT) was described as a best practice. It has evolved from a system serving people labeled "transportation disadvantaged" to serving the entire community. There are many different options including fixed routes, ADA paratransit, paratransit for people considered to be "transportation disadvantaged," a bus pass program, Medicaid brokerage, and a Community Assistance Program. SCAT also uses its bus fleet to serve several nonprofit agencies, and manages a volunteer driver program.

4). Florida Freedom Initiative. Under the Florida Freedom Initiative, individuals can establish interest-bearing Freedom Savings Accounts that can be used to purchase a vehicle.

5). A Blueprint for Self-Determination in Florida Report (2003). This report makes some important recommendations for increasing access to transportation in Florida and the potential role that the Transportation Disadvantaged Commission could play in relation to these. They include: needs assessments which focus more on quality aspects of transportation services; enabling direct support staff to provide transportation through changes in job descriptions and compensation packages; and assisting individuals with disabilities to purchase, lease or barter for vehicles, even if the person does not drive.

National Promising Practices and Resources

1). School-Based Training Possibilities. In some districts nationally, the schools are teaching public transportation skills and driver education to students with disabilities, and including this within IEPs and ITPs.

2). Information for Service Workers. Providing information on transportation options, resources, and creative strategies to support coordinators and direct support staff.

3). New Freedom Initiative Funds. There has been recent federal attention to the issue of transportation. As part of the President's New Freedom Initiative, Congress has set aside funds that will be available to local transit authorities to provide transportation service to people with disabilities above and beyond what is required under the ADA.

4). Self-Determination Initiatives. Through self-determination initiatives, increasing numbers of people with disabilities are having personal care attendants provide transportation. In addition, more people with disabilities are purchasing or leasing vehicles of their own.

5). Rural Solutions. Creative solutions to transportation needs are being devised, particularly in rural areas. For example, according to a 2005 National Council on Disability report, the Alaska Independent Living Center (ILC) received a grant from the Alaska Department of Transportation and the Alaska Mental Health Trust Authority to acquire a lift-equipped van. A local cab company leased the van from the ILC free of

charge. The taxi company gives ILC consumers discounts on rides. The cab company is in charge of all driving, dispatching, and vehicle maintenance, while the ILC administers the voucher program which provides coupons for individuals with disabilities.

6). Arkansas Innovation. As also reported by the National Council on Disability in 2005, in Arkansas, a demand-responsive curb-to-curb service has been created that focuses on individuals who are going to and from work, employment training, or school. Funding comes from a variety of state sources, including Rehabilitation Service, Temporary Employment Assistance, Workforce Investment Centers, and the Highway and Transportation Department.

7). Easter Seals Project ACTION (http://projectaction.easterseals.com/). Funded through a cooperative agreement with the U.S. Department of Transportation, Federal Transportation Administration, Easter Seals Project ACTION promotes cooperation between the transportation industry and the disability community. This organization offers resources, as well as training and technical assistance related to accessible transportation.

8). United We Ride (http://www.unitedweride.gov/). This is the web site of the Federal Interagency Coordinating Council on Access and Mobility. This web site offers resources related to its objectives, which include: education and outreach; development of coordinated human service transportation, with enhanced customer access at the local level; comprehensive planning for the coordination of transportation; addressing regulatory barriers; and providing information about "useful practices."

9). IMPACT: Feature Issue on Meeting Transportation Needs of Youth and Adults with Developmental Disabilities. (Institute on Community Integration, University of Minnesota, Vol. 18, No. 3, Summer 2005). This bulletin includes personal accounts about the importance of transportation on individual lives; strategies for increasing accessible transportation within various localities, including rural areas; strategies for teaching transportation skills, including driver's education, to children and young adults with disabilities; examples of state and federal initiatives; and a variety of other resource materials related to transportation.

10). The Current State of Transportation for People with Disabilities in the United States (National Council on Disability, 2005). This is a comprehensive analysis of transportation systems in the U.S. in relation to accessibility for people with disabilities. The report reviews how well people with disabilities are being serviced by existing transportation systems. It documents successful practices, as models for other communities. Finally, the report offers recommendations for service improvements.

11). Strategies to Increase Coordination of Transportation Services for the Transportation Disadvantaged (Transportation Research Board, 2004). This research reports presents information related to: current transportation trends and challenges; transportation services and options; processes used to plan, budget, and promote coordination; funding sources; and the application of technology to transportation

coordination. Examples within each of these areas are provided through the use of case studies.

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AREA OF EMPHASIS

HOUSING

Summary Information

Challenges

- Lack of Housing for Very Low-Income Families
- Public Housing Authorities Not Reaching as Many People with Disabilities as They Could
- Long Waiting Lists for Section 8 Vouchers; Concerns About Safety
- Need for Education and Training for Those in the Disability Field and in the Housing Field
- Home Modifications Process and Limitations

Strengths/Resources

- Florida Freedom Initiative Options
- Training Resource Network
- Blueprint for Self-Determination Recommendations
- BRTF Recommendations
- Mailman Center Report Recommendations

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AREA OF EMPHASIS: HOUSING

Description of Housing Resources and Trends in Florida

Access to affordable, accessible, quality housing is a national issue for people with developmental disabilities. According to the Blue Ribbon Task Force (BRTF) report, 27% of people with developmental disabilities live in a home of their own, either independently or with supports; 73% live in group homes and institutional settings. People at the forums, people we interviewed, and reports that we reviewed were in agreement that housing is a priority need and issue in Florida.

There are a number of housing resource centers in Florida which offer a range of information on affordable housing, though not necessarily targeted toward assisting individuals with developmental disabilities in obtaining housing. The Florida Housing Coalition is a statewide nonprofit organization that provides technical assistance to governments and nonprofit organizations in all areas of affordable housing. The Affordable Housing Opportunities project is funded by the FDDC and conducted by the Florida Housing Coalition. The Florida Housing Finance Corporation seeks to assist people in obtaining safe, decent housing. The State Housing Initiatives Partnership (SHIP) provides funding to local governments to develop affordable housing programs, with inclusion of some extremely low-income households. The Shimberg Center for Affordable Housing was established in 1988 at the University of Florida by the Florida legislature. Its mission includes facilitating the provision of safe, decent, and affordable housing and related community development throughout the state. Founded in 2001, the Florida Supportive Housing Coalition (FLSHC), a nonprofit organization, is a coalition of organizations, providers, and advocates of housing and services for individuals with special needs.

The Technical Assistance Collaborative (TAC) and the Consortium for Citizens with Disabilities Housing Task Force have prepared a number of key national reports on housing for individuals with disabilities (Going It Alone; Priced Out in 2002; Priced Out in 2004). In 2004, the TAC prepared a report focused on Florida for the Florida Supportive Housing Coalition (Florida Supportive Housing Resource Inventory). And, in 2003, the Florida Housing Finance Corporation produced a report, "Analysis of Florida's Affordable Rental Supply and Remaining Housing Need." Together these reports contain much valuable information about housing and people with disabilities nationally and in Florida.

Nationally, supportive housing organizations use SSI as a "best proxy" for income of people in need of supportive housing. In Florida, in 2003, the mean monthly SSI benefit for a person with a disability living independently was $552. Based on this figure, according to the report "Priced Out in 2002," an individual in Florida would need to spend over 108% of his or her monthly SSI benefit to pay for a one-bedroom apartment. According to the FHFC report, the greatest unmet need for affordable housing in Florida is for individuals with extremely low incomes (e.g., at 30% and below of area median income). At the time that report was written (2003), there were 131,210 units available to that income group, with a remaining need of 217,315.

According to the Florida Supportive Housing Resource Inventory, the state accesses a wide variety of funds in an effort to create affordable housing. From 1997-2003, Florida acquired over 650 Section 8 Mainstream vouchers. In FY 2003, Florida received a total of $84.2 million in HOME funding from HUD (e.g., for tenant-based rental assistance for households below 30% AMI). In FY 2003, Florida received a total of $190.8 million in CDBG funding (according to the report, some states have used CDBG funds as a valuable resource for supportive housing)

According to the FHFC report, Florida Public Housing Authorities (PHAs) had a total of 79,861 Section 8 vouchers in 2003. The Florida Supportive Housing Resource Inventory report notes that, since 1997, Congress has funded Section 8 voucher set-asides for people with disabilities. Since that time, approximately 2,600 have been awarded to 19 PHAs and 3 nonprofit disability organizations in Florida.

A key strategy in developing housing for those individuals with the lowest incomes is combining low-income tax credits with rental subsidies. In the Florida Supportive Housing Resource Inventory, it is recommended that a systematic, coordinated approach to use of these funding sources is needed to increase housing,

Over the years, the FDDC has made numerous efforts related to housing, working in partnership with the Florida Housing Coalition, the Florida Supportive Housing Coalition, and other entities. Their legislative priorities related to affordable and accessible housing include: providing incentives to acquire and develop affordable and accessible housing in local communities; establishing at least one nonprofit housing corporation in each county; improving the accessibility of housing as Florida rebuilds after the hurricanes; including a person with a disability on the corporate board of the Florida Housing Finance Corporation; and developing programs and training opportunities regarding the safety and well-being of people with developmental disabilities in emergency and disaster situations.

Housing: Stakeholder Perspectives on System Challenges

This section describes themes represented by stakeholders about the challenges they experience in the current system.

1). Lack of Housing for Very Low Income Families. According to FHFC, while there has been some success at finding housing for people with incomes above 50% of area median income, it has been a challenge to find housing for people with 0-50% of area median income; there is a need for initiatives which target these individuals.

2). Public Housing Authorities not Reaching as Many People with Disabilities as They Could. Despite the diverse housing resources acquired by Florida, a review of ConPlans (Consolidated Plans—federally mandated "master plans" for affordable housing in local communities and states) by the Technical Assistance Collaborative (contained within the "Florida Supportive Housing Resource Inventory" report) found that some of the money that could be used for people with disabilities is not, and that PHA (public housing authority) plans lacked data regarding the housing needs of people

with disabilities. The conclusion drawn by the authors of this report is that the PHAs are not reaching as many disabled people as they could. This is, in part, documented by the following data included in the report. Nationally, 22% of Section 8 households are nonelderly and disabled; in Florida, 16.8% of Section 8 households are nonelderly and disabled. Florida has two of the nation's largest PHAs with regard to the number of Section 8 vouchers: Jacksonville and Miami-Dade. Data indicated that neither of these PHAs assist a large number of non-elderly disabled households (14.3% and 12.3 % respectively); in fact, Miami-Dade PHA ranked 48th out of the largest 50 PHAs in the nation in assisting nonelderly disabled households in the Section 8 program. Participants at the forums felt strongly that development plans for every county should be required to consider the needs of people with disabilities. The Consolidated Plan is the basis for decisions about how federal funds will be spent. Thus, it is critical that the voices of people with disabilities, their families, and advocates be heard through public hearings regarding the Consolidated Plan and by other means.

3). Long Waiting Lists for Section 8 Vouchers; Concerns about Safety. Reports that were reviewed and input at the forums indicated that there are long waiting lists for Section 8 vouchers. Also, forum participants expressed reservations about the safety and quality of some of the Section 8 housing options.

4). Need for Education and Training for Those in the Disability Field and in the Housing Field. Information about housing is often highly complex, as is the process of navigating through all the steps required for homeownership, for Section 8 rent subsidies, or other housing initiatives. Individuals with disabilities, families, support coordinators, disability service agency administrators and others who are not very familiar with housing resources and processes, and who do not have significant time to devote to it, may have difficulty understanding the intricacies and complexities of housing. There is a need for those who do have knowledge and experience using housing resources to assist individuals with disabilities, families, and those in the disability field to learn about available housing resources and strategies. In addition, it is critical to educate those in the housing field about disability issues.

5). Home Modifications Process and Limitations. Forum participants raised three issues related to home modifications. First, they said that contractors who want to become vendors are discouraged from participation because of the complicated process required to become authorized as a DD/HCBS home modification vendor. Second, payments to contractors are very slow, creating cash flow problems for some of them, particularly the smaller contractors. Third, the DD/HCBS waiver limits home modifications to every five years (with some exceptions for special circumstances). People felt that this time limitation is not sufficiently flexible to respond to changing needs of people.

Florida Strengths and Resources

1). Florida Freedom Initiative Options. Under the Florida Freedom Initiative, individuals can establish interest-bearing Freedom Savings Accounts that can be used to purchase a home.

2). Training Resource Network. Dale DiLeo has published a number of papers which include resources and strategies for creating affordable housing; these can be found on the web at: http://www.flse.net/affordable_housing/7resources.htm

3). Blueprint for Self-Determination Recommendations. The Blueprint for Self-Determination in Florida report contains many valuable recommendations related to expanding rent subsidy programs and developing a nonprofit housing corporation infrastructure that is sensitive to the needs of individuals with significant disabilities. In addition, the report proposed amending the Medicaid 1115(c) waiver to allow funding of rent subsidies.

4). BRTF Recommendations. The Blue Ribbon Task Force report also contains important recommendations related to optimizing resources to benefit people with disabilities, working with local PHAs, and developing useful housing information and materials.

5). Mailman Center Report Recommendations. The Mailman Center report, "Promises Made...Promises Kept," includes a description of many housing resources within the state, including examples of agencies that have made in-roads into development of accessible, affordable housing for people with disabilities. The report emphasizes the need for continued advocacy for additional housing resources targeting individuals with disabilities, as well as the need for technical assistance to increase expertise around housing issues and disability.

National Promising Practices and Resources

1). Going it Alone. The publication, Going It Alone: The Struggle to Expand Housing Opportunities for People with Disabilities, a report of the Technical Assistance Collaborative, Inc. and the Consortium for Citizens with Disabilities Housing Task Force, offers examples of strategies, resources, and best practices in the development of affordable housing.

2). Other Best Practices. In A Blueprint for Self-Determination in Florida, some national best practices are highlighted. For example, the report discusses the complex process of applying for Section 8 rent subsidies, and describes an organization, Creative Housing, Inc., in Columbus, OH, that works with the local PHA to assist people with disabilities in this process.

3). Community Land Trusts. In some communities, Community Land Trusts have been formed to help increase the supply of affordable housing. For example, the Brattleboro Area Community Land Trust, in Vermont, targets its housing to the low and very low income population (see http://www.baclt.org/overview.html).

4). Affordable Housing NOW! In Portland, Oregon, the Affordable Housing NOW! Initiative targets as a priority those at 0-30% of the median family income (see http://www.cdnportland.org/ahn.html).

5). Wisconsin Housing Specialist. In Wisconsin, a supported housing specialist position was first created by the DD Council, and is now funded through the Wisconsin Department of Health and Family Services.

6). National Housing Resources. The Consortium for Citizens with Disabilities Housing Task Force (http://www.c-c-d./org) and the Technical Assistance Collaborative, Inc. (http://www.tacinc.org) offer many housing resources on their web sites. Among these is the Opening Doors newsletter, a quarterly newsletter discussing current housing issues, strategies, and resources.

7). CHANCE. The web site of the center on Community Housing and New Community Economics (CHANCE) contains a variety of reports that discuss strategies and resources to promote homeownership and to increase affordable housing (http://chance.unh.edu/).

8). CMS Website. The Centers for Medicare & Medicaid Services (CMS) web site includes a section on promising practices, which includes a subsection on housing (http://www.cms.hhs.gov/promisingpractices). This includes, for example, information about a housing alliance in Indiana; information about the Massachusetts accessible housing registry; information about Wisconsin's supported housing initiative and the supported housing specialist; and information and lessons learned from the Texas Home of Your Own initiative.

9). Clearinghouse for the Community Living Exchange Collaborative. (http://www.hcbs.org/). This site provides in-depth information on topics relevant to state systems change, including housing, workforce issues, employment, and consumer direction.

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AREA OF EMPHASIS

EMPLOYMENT

Summary Information

Challenges

- Skill Building and Skill Maintenance Not Supported After Leaving School
- Inadequate Infrastructure
- Low Rates for Supported Employment
- Transportation Barriers
- Need More Support for Support Coordinators
- Not Enough Training Available
- Lack of Quality Jobs
- Concerns Over Loss of Benefits
- Lack of Continuing Education for Adults
- Diverse Efforts of One-Stops Needed
- Need for Small Business Incubation
- Need Improved Statewide Date System
- Employer Attitudes
- Need for Coordinated Planning

Strengths/Resources

- BRTF Implementation Working Group
- The Able Trust
- Florida Business Leadership Network
- Employment in State Government
- Winter Haven, FL One-Stop Center, Polkworks, which Features Physical Co-Location
- Florida Freedom Initiative
- Training Curriculum Developed by Training Resource Network
- New Training Curriculum to be Developed
- Additional Florida Resources
- Helping People Succeed, Inc.
- Youth Leadership Forum
- University Efforts Related to Employment

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AREA OF EMPHASIS: EMPLOYMENT

Description of Existing Employment System

Stakeholders in Florida place a high value on integrated employment for people with developmental disabilities. Governor Jeb Bush, state agencies such as the Agency for Persons with Disabilities and the Florida Developmental Disabilities Council, providers, advocacy organizations, activist parents, and people with disabilities, to name a few, have endorsed a major shift in the system from segregated day services to integrated employment. Planning efforts such as the Blue Ribbon Task Force Implementation Work Group planning process, initiatives such as APD's 5-year initiative to divert 25% of the people receiving Adult Day Training Services into competitive employment opportunities by 2009, public pronouncements by Governor Bush and other officials, survey results, and other statements, have endorsed this shift.

In this section, therefore, we focus primarily on integrated employment, which includes supported employment, competitive employment, and customized employment. Because transition from studenthood to adulthood was covered in the education section, we do not focus on that here, though we acknowledge that for many students, the transition period should result in employment as an adult, and that the issues facing young people in the transition period are not unlike those facing older adults with developmental disabilities.

First, we provide some definitions. *Competitive employment* is regular work, obtained through such means as are used by other job seekers, and performed without intensive support or extended services. *Supported employment* is defined as "competitive work in integrated settings for individuals with the most severe disabilities for whom competitive employment has not traditionally occurred; or for whom competitive employment has been interrupted or intermittent as a result of a severe disability; and who, because of the nature and severity of their disability, need intensive supports or extended services in order to perform such work" (Rehabilitation Act). In supported employment, the supports can often be faded so that the person receives minimal support from an outside entity, along with internal support from the employer. *Customized employment*, a term used by the Office of Disability Policy (ODEP) within the U.S. Department of Labor and by the National Center on Workforce and Disability, www.onestops.org, refers to a flexible blend of strategies, services, and supports designed to increase employment options for job seekers with complex needs through voluntary negotiation of the employment relationship. In this process, the job seeker is viewed as the primary source of information and drives the customized employment process. Customization should be a feature of all employment activities and is certainly crucial to supported employment: It involves creative solutions, knowledge of the job seeker, whose wishes and skills direct the activities, and attention to the needs and desires of the employer.

Several state departments and offices are responsible for providing employment services in Florida, as noted in the Education section. Following is a brief description of

these departments and offices and of the services and funding they provide relating to employment.

Agency for Persons with Disabilities (APD)

APD provides funding for long-term day and employment supports to waiver-enrolled adults with developmental disabilities who are not competitively employed. At present, Adult Day Training (ADT) services throughout the state provide training for adults with developmental disabilities in non-work areas such as activities of daily living, self-advocacy, and "work-like" activities, as well as some community-based employment services. Mobile work crews and enclaves can be included as ADT services, as can microenterprise or entrepreneurial services. Supported employment services, which include individual and group models, are primarily provided under the Medicaid waivers (DD/HCBS and FSL), and are provided through the ADT services or by stand-alone supported employment agencies that contract with the APD to provide these services.

In 2003, APD (formerly, the Developmental Disabilities Program) announced a five-year initiative to divert 25% of the people receiving Adult Day Training Services into competitive employment opportunities by 2009. Each district subsequently submitted its own plan; almost all planned to... "Enable at least 50% of adults, age 18-55, receiving DDP funded services to achieve Integrated Employment by 1/1/09" (taken from the District 15 Plan, but the language was similar in almost all of the plans).

One measure of the progress of APD in fulfilling the promise of this initiative is the spending on supported employment over the years, while another is a count of the number of participants in supported employment. The latest national data from the Coleman Institute (see Section I of this report), show that in actuality, supported employment spending and participation in Florida dropped significantly between 2001 and 2004, even though total spending for day and supported employment programs increased every year. Both spending and participation, according to this source, dropped back to the levels of effort of the mid-1990s. Since 2001, when $11,126,140 was spent to support 4,298 individuals in supported employment, there was a significant drop to 2004, when $6,691,702 was spent to support 2,958 individuals. During the same period, the number of people in day (non-supported employment) programs actually rose, from 10,954 in 2002 to 11,390 in 2004 (Coleman Institute and Department of Psychiatry, University of Colorado, 2005, preliminary data). By these measures, the initiative could be seen as having failed during its first years, unless there have been larger numbers of people engaged in competitive employment who have not, therefore, been counted as part of the supported employment programs. *(Note: the Coleman Institute figures for 2001 are not consistent with the figures supplied by AHCA to the authors of "Promises Made, Promises Kept," published in 2003 by the Mailman Center and the Florida Developmental Disabilities Council.)*

According to national experts we consulted, this is not inconsistent with the national picture, which shows state DD agencies' supported employment spending and participation decreasing or staying "flat," rather than increasing significantly. A recent

article reports that segregated employment for people with severe disabilities receives four times the financial resources as integrated employment services (Rusch & Braddock, 2004). Further, the authors conclude that the trend is toward continued growth in segregated adult services. There are variations, of course, with some states doing much more than others to promote and fund integrated employment.

Department of Vocational Rehabilitation

The Department of Vocational Rehabilitation (DVR) provides "an employment program assisting individuals with disabilities, including Floridians with the most severe disabilities, to pursue meaningful careers commensurate with their abilities and capabilities" (from http://www.rehabworks.org, the website of DVR). It provides training, retraining, medical and psychological evaluation and treatment, supported employment, assistive technology, and rehabilitation technology services to individuals with physical or mental impairments or disabilities. DVR uses the Rehabilitation Act's definition of supported employment, given above.

The following table, taken from DVR's 2006 Federal State Plan for Vocational Rehabilitation Services, provides DVR's estimates in regard to its 2005-2006 supported employment services and outcomes.

TABLE 4: ESTIMATED NUMBERS OF INDIVIDUALS PROJECTED TO BE DETERMINED TO BE ELIGIBLE AND SERVED DURING FEDERAL FISCAL YEAR 2005-2006 BASED ON THREE YEARS OF HISTORICAL DATA

TITLE	NUMBER ELIGIBLE	NUMBER SERVED	NUMBER ACHIEVING EMPLOYMENT OUTCOME	TOTAL COST
Title I-General	26,000	19,635	10,000	$94,050,460[2]
Title VIB-Supported Employment		550	233	$1,674,963[3]
Total	**26,000[1]**	**20,185[1]**	**10,2335[1]**	**$96,725,423**

[1]Data used to make projections in this attachment are calculated on a different timeframe (i.e., the federal fiscal year) than the state performance based program budgeting projections. Therefore, these numbers can be expected to differ from projections or estimates calculated on the state fiscal year.

[2]Source: Conference Report on HB 1838-SFY 2004-2005. Page 15, Category 35: Purchased Client Services (General Revenue Fund and Federal Rehabilitation Trust Fund). DVR/FRC began the planning process earlier; consequently, the 2005-06 Legislative Appropriations were not available during the state plan development. Cost projections are estimated at the same level as last year.

[3]This amount represents the cumulative amount ($1,626,178) from the grant award notification received January 05, 2005 (plus a 3% increase).

Later in the plan, DVR states that it anticipates that the ADT programs will refer 2,566 people to DVR during this time. Supported employment services provided by DVR are time-limited; if a person needs ongoing support, this must be provided through organizations funded by APD.

DVR has cooperative agreements with agencies and other entities, and with entities in the Workforce Investment System. These include agreements between DVR and: The Able Trust, Division of Blind Services, Department of Children and Families Mental Health Program, Florida School for the Deaf and Blind, and others. In addition, DVR has formalized new agreements with agencies such as the Department of Juvenile Justice and the Florida Alliance for Assistive Services and Technology, Inc. (FAAST).

Agency for Workforce Innovation and One-Stop Centers

Employ Florida links all of Florida's workforce services--state and local--to each other. The state partners are Workforce Florida, the state policy and oversight board, and the Agency for Workforce Innovation (AWI), the state agency which administers workforce funds. At the local level there are 24 regional workforce boards, which administer close to 100 One-Stop Career Centers. Together these organizations represent the Employ Florida network of workforce services and resources. The state and local boards are composed of educational, governmental and private business resources to address local workforce needs.

One-Stop Centers provide the following core information services to anyone seeking a job: information on unemployment insurance, pension benefits and health insurance, job search assistance, job referral, résumé assistance, and job training. If the core services do not produce results, job seekers may be eligible for one-on-one assistance, group career workshops, and other assistance. Part of the centers' mandate is to be accessible and to assist people with disabilities. According to the National Center on Workforce and Disability (www.onestops.info), "each state's public vocational rehabilitation (VR) agency is a mandated partner in the One-Stop system. As a mandated partner, VR must make available via the One-Stop system, the core services applicable to VR."

The Blue Ribbon Task Force Report speaks of Florida's One-Stop Centers as another opportunity for generating employment for individuals with developmental disabilities. Early in July 2005, Workforce Florida, Inc. (WFI) was notified that Florida will receive $400,000 from the U.S. Department of Labor to train selected One-Stop staff to give more effective services to individuals with disabilities. Except for the Florida-based Disability Navigators and this grant application there is relatively little evidence of attention paid by AWI and Florida's One-Stops to provision of appropriate support to individuals with disabilities. For example, the Agency for Workforce Innovation (AWI), which states that it is "an equal opportunity program that provides auxiliary aids and services to individuals with disabilities upon request," offers little or no specific information about supported or customized employment or job seekers with disabilities in the documents and web pages we searched (note: two examples, one of a promising collaboration in Winter Haven and the second a completed project by the

FDDC to work with One-Stops, were found, though not on AWI's site). The inclusion of people with disabilities among the customers of the One-Stops remains as a promising opportunity that has not been developed to its full potential.

What Is Known about Successful Systems Change

A national study highlights activities and policies that state VR directors deemed most important in creating systems change (Novak, Rogan, Mank, & DiLeo, 2003). The study noted five policies or practices that encouraged the implementation of supported employment in states. The five "include (a) initiatives that tie funding to people (such as Choice Demonstration Projects and Robert Wood Johnson Self-Determination Projects), (b) funding for services and resources managed at the state level, (c) court-ordered deinstitutionalization, (d) organized state efforts for accessible transportation, and (e) state-mandated minimum qualification requirements for direct employment services staff."

Additionally, the study found that "Activities perceived to be most important to the implementation and expansion of state supported employment programs were training, technical assistance, capacity building, and policy and funding initiatives." Ongoing, consistently available training of providers, vocational rehabilitation staff, and developmental disabilities staff was crucial, as was technical assistance to those organizations interested in working to convert to or implement supported employment. States built capacity by encouraging providers to expand their service options and to convert their operations from segregated to integrated employment choices for consumers. They built incentives into their rate structures, for example, rewarding support for employment.

Employment: Stakeholder Perspectives on System Challenges

This section describes themes represented by stakeholders about the challenges they experience in the current system.

Forum participants and professionals we interviewed voiced many concerns about the continued segregation of most of the people receiving developmental disability services. They said:

1). Skill Building and Skill Maintenance not Supported After Leaving School. Young adults are leaving school without the skills needed to function at their maximum potential and as responsible adults. Without support to continue developing and refining their skills, and without support to obtain employment, their transition to adult life often means that they stay at home, idle during the day. Most provider agencies have waiting lists for the supported employment programs they operate. Because people who need ongoing support must usually join the waiting lists for adult services when they leave the education system, they cannot gain access to the services provided by DVR after graduation, and lose many skills during the waiting period.

2). Inadequate Infrastructure. The provider and community service infrastructure is not sufficient to support those who would like to be engaged in competitive, supported, or customized employment, or to start their own microenterprise or business. For example, ongoing funding for supported employment training has not been established, and in-depth technical assistance for organizations interested in change is not readily available.

3). Low Rates for Supported Employment. Providers are not paid adequately for supported employment—the rate should be raised. Consideration should be given to creating incentives for providers to offer supported employment.

4). Transportation Barriers. Transportation options are very limited and are inadequate to support the needs of adults who have jobs or who are seeking jobs, because they have no consistent way to get to work.

5). Need More Support from Support Coordinators. Support coordinators do not have the training, experience, and time needed to promote employment/supported employment for and with the people with whom they work. With high caseloads, they do what they can; however, employment is not often a priority.

6). Not Enough Training Available. In order for a provider to offer supported employment in Florida, the worker must have 18 hours of preservice training. This is a good requirement, but the training is not readily available. The live trainings offered by the Training Resource Network are filled one day after they are announced. More training is needed.

7). Lack of Quality Jobs. Most people with developmental disabilities who have jobs are employed in the food service, landscaping, and custodial industries, and most do not have full time work. Many work in crews or enclaves, which can be almost as segregated as a facility-based program. A "quality" job, where one has work he/she enjoys as well as a good benefit package, is not common.

8). Concerns Over Loss of Benefits. Many people are concerned about losing their benefits (Medicaid, housing subsidy, SSI or SSDI, food stamps) if they earn much money. They are not aware of the work incentives that have been established by Social Security to protect benefits (see http://www.ssa.gov/pubs/10095.html#part2 for a description of these incentives), and are not aware of the Florida Freedom Initiative (see below).

9). Lack of Continuing Education for Adults. There are very few opportunities for continuing education and vocational training for adults with disabilities.

10). Diverse Efforts of One-Stops Needed. Goodwill Industries has connected to the One-Stops in Florida, but people with disabilities are more interested in regular community employment than in jobs with Goodwill Industries.

11.) Need for Small Business Incubation. Some of the smaller supported employment providers have had difficulty with the business part of providing the service. There is a need for a "business incubation" program to support small providers, which are proliferating in Florida but may need assistance if they are to sustain themselves and to grow. Such a program would provide them with how-to's for running a small business, and would focus on marketing, bookkeeping, human resource areas having to do with selection/training/retention of staff, benefits, taxes, etc.

12). Need Improved Statewide Data System. There is a need for a better statewide data system at APD. Such a system would require providers to give simple, regular reports how many people are working, how much they are making, etc. If this information were available online, people who are looking for a provider could make informed comparisons.

13). Employer Attitudes. In general, employers do not view persons with disabilities as a potential pool of qualified workers to fill their employment needs, and need to be approached in a positive manner, by people who talk their language rather than the language of human services.

14). Need for Coordinated Planning. While it is good that people are now talking about community employment, there has not yet been enough action to shift the system in that direction. There are many scattered initiatives, but not one comprehensive and multi-faceted plan. Stronger, closer planning is needed between APD, DoE, FDDC, and DVR, toward the development of a solid, coordinated approach to supported employment.

Florida Strengths and Resources

There are many aspects of the system in Florida that are positive and that may be seen as foundational pieces of an emerging infrastructure. Solid infrastructure will be needed to make and sustain the changes that so many are calling for. Some of these positive examples include:

1). The Blue Ribbon Task Force Implementation Working Group. The Blue Ribbon Task Force made many comprehensive recommendations, which, if implemented, will result in sustainable change in the employment system that affects people with developmental disabilities in Florida. The BRTF Implementation Working Group is a collaborative effort involving many partners who are now working together to implement the recommendations.

2). The Able Trust. The Able Trust, also known as the Florida Governor's Alliance for the Employment of Citizens with Disabilities, was established by the Florida Legislature in 1990. The Trust is a public-private partnership that engages in fundraising, grant programs, public awareness and education in order to promote employment of people with disabilities. The Able Trust has awarded over $14 million to individuals with disabilities and nonprofit agencies throughout Florida for employment-related purposes since 1992. Able Trust programs have enabled approximately 2,000

Florida citizens with disabilities to enter the workforce each year, including some who have developmental disabilities. For example, two organizations that promote employment of people with developmental disabilities are recent recipients of Able Trust grants. The Able Trust supplied the following information for the most recent two years of their grant-awarding activity (some grants are still open from each of these years, and their data is not included in this tally).

TABLE 5: THE ABLE TRUST GRANT-AWARDING ACTIVITY

FISCAL YEAR	NUMBER SERVED	NUMBER EMPLOYED
2003	2,191	693
2004	2,015	297
Total	5,206	980

3). Florida Business Leadership Network. The statewide Florida Business Leadership Network (BLN), which is part of a national network of BLNs in 37 states, is an employer-led venture that is sponsored in Florida by The Able Trust. The Florida Business Leadership Network is a peer-to-peer membership group of employers seeking resources to recruit, hire and market to persons with disabilities. Members include small and large businesses who recognize that success in the 21st century hinges on a diverse workforce that includes employees with disabilities. For more information about the Florida BLN, visit www.floridabln.org. The FDDC provides funds to three local BLN chapters, which are dedicated to promoting employment of qualified workers with disabilities and assisting employers in recruiting, hiring, training, and retaining people with disabilities.

4). Employment in State Government. Florida was selected as a "best practice" state (by the U.S. Equal Employment Opportunity Commission—see www.eeoc.gov) for its efforts to employ people with disabilities within state government. EEOC cited a number of practices that have increased access to state jobs by people with disabilities:

a). Several state departments (AHCA, Transportation, and State) provide ADA training to personnel involved in hiring;

b). Some state agencies have adopted written reasonable accommodation procedures that clarify the process for making requests, and explain how agency officials should respond to requests for reasonable accommodation;

c). AHCA's cultural diversity training was expanded to include disability and explores issues other workers may have with regard to disability;

d). The Able Trust, the Blue Ribbon Task Force, the ADA Working Group, and other important initiatives reinforce the state's support for employment;

e). DDP/APD's five-year initiative, adopted in 2003, expands the emphasis on employment by working to divert 25% of people receiving ADT services into competitive employment opportunities.

5). The Winter Haven, FL One-Stop Center, Polkworks, which Features Physical Co-Location. The National Center on Workforce and Disability highlights a Winter Haven effort as a promising practice, saying "The partners who are co-located at the One-Stop Center include: Vocational Rehabilitation (VR); the local school board; Center for Independent Living; the Welfare/Transition agency; Veteran Services; Job Corps; Mental Health and Substance Abuse counseling services; the Department of Children and Families; and several community agencies serving people with disabilities, non-custodial parents, and others. The center has an on-site child care facility where customers can leave their children while utilizing center resources and services. The resource center is fully accessible, as VR has played a large role in making recommendations to the One-Stop Operator to improve the accessibility of space and equipment."

6). Florida Freedom Initiative (FFI). The Florida Freedom Initiative is a demonstration program that was set up to allow people with disabilities were permitted to protect their benefits while increasing their private resources through savings. It was felt that the quality of their lives would be enhanced: they would be more likely to pursue employment or additional education; buy homes of their own or personally-owned means of transportation; purchase adaptive equipment and assistive technologies; or purchase and develop a small business. In this way, the FFI is intimately tied to other employment strategies, and is a foundation block for infrastructure change. The FFI is open to all people who are involved in the CDC+ waiver who receive Social Security and wish to work or own a small business. Individual Freedom Accounts (IDAs) will be created for each person, and will be matched up to $8 for every $1 saved. A Savings Plan will be created by each person, with purchases from the Freedom Account tied to the goals in the plan. A participant is permitted to save up to $10,000, and to have Medical Continuing Disability Reviews suspended. More information about the FFI can be found on the APD website.

7). Training Curriculum Developed by Training Resource Network. The Training Resource Network (Dale DiLeo) has developed nationally-recognized curricula in supported employment, viewed by national experts as among the best available. Information on both the live training offerings and the web-based curricula can be accessed through the website, http://www.flse.net/.

8). New Training Curriculum to be Developed. The FDDC just funded a five-year grant to develop a curriculum in supported employment; this project includes national

experts David Guido, Michael Callahan, Cary Griffin, and Dale DiLeo. The curriculum will be available in three to four years.

9). Additional Florida Resources. Florida has many resources, such as Project Connect and the Transition Center at the University of Florida, in the employment arena; additionally, there are some supported employment providers that are critical resources for building and strengthening infrastructure and capacity.

10). HPS, Helping People Succeed, Inc. HPS, Helping People Succeed, Inc. (formerly Tri-County TEC), is an agency that has converted from a sheltered workshop/work activity center to a totally community based organization. HPS talks about, and teaches others about, customized employment. HPS President/CEO Suzanne Hutcheson is President of APSE (Association for Persons in Supported Employment) and is well-connected with T-TAP (see national resource section, below), which hosts several papers and workshops by Hutcheson on its website. HPS serves citizens of Martin, St. Lucie, Indian River and Okeechobee Counties. The agency's goal is to help each person achieve success so they may have a successful future, enjoying their life fully participating as productive taxpaying citizens. During 2002-2003, they helped 250 adults who have significant disabilities obtain and maintain employment, making competitive wages with benefits in many cases.

11). Youth Leadership Forum. The Florida Youth Leadership Forum (YLF) is a unique career leadership-training program for high school juniors and seniors with disabilities. The Forum offers peers with common challenges and experiences the opportunity to learn from one another. It is sponsored annually by The Able Trust, and funded entirely by corporate sponsorships, grants and private donations. By serving as delegates from their communities at the four-day event in Tallahassee, students cultivate leadership, citizenship and social skills. This Forum includes students with developmental disabilities, and builds confidence and awareness that adult employment is within their reach. One of its purposes is to make the young people aware that they have both a right and a civic responsibility to secure the highest form of employment for which they are qualified, and that they can and should think in terms of career exploration.

12). University Efforts Related to Employment. Florida's universities are working in the area of career development and employment of students with disabilities. For example, the University of North Florida is linked with the Center on Disability and Employment, College of Education, Health and Human Sciences, at the University of Tennessee to work on disability-related projects. On September 15, 2005, the Department of Labor's Office of Disability Employment Policy announced that Florida ranks seventh in the number of college students and recent graduates with disabilities who have been placed nationwide in summer and permanent jobs since the Labor Department's Workforce Recruitment Program (WRP) was announced in mid-April. Five students and recent graduates with disabilities from the University of West Florida have been placed through the WRP, the Secretary said, while other educational institutions with students in the WRP include Pensacola Junior College (four), Seminole CC, Lynn University and Florida Atlantic University (two each), and Florida A&M

University (one). This is a good start, in that the program is only a few months old. The universities' experience in career development and placement for students with disabilities is a resource for those wanting to expand employment opportunities in the state for people with developmental disabilities.

National Promising Practices and Resources

There are many promising employment practices nationally that benefit adults with developmental disabilities. Following are a few that were recommended to us as we interviewed national experts:

1). Initiatives Involving the One-Stops in the State of Washington. The State of Washington's DD Council has funded a project with a statewide association of community providers to expand the capacity of the One-Stop system to serve persons with developmental disabilities. This project looks at current barriers (in the One-Stops) to people with disabilities, how to blend funding, how developmental disabilities agencies and One-Stops can work together, and so forth. The coordinator of this project is Karen Hoffman, who can be reached at karenhoffman@earthlink.net. In addition, as a result of a Workforce Incentive Grant, a state-level network called the Washington Disability Network was established, which called for cabinet-level people to come together to work on barriers and state planning to increase employment opportunities for persons with disabilities.

2). Disability Navigators. The Social Security Administration (SSA) and the Employment and Training Administration (ETA) of the Department of Labor (DOL) are jointly funding approximately 200 "Disability Navigator" positions in 17 States, including Florida. Disability Navigators are located in the One-Stop Career Centers and are able to assist individuals with disabilities and the One-Stop staff with a variety of employment related services; their purpose is to help people with disabilities and the other WorkSource partners to work productively together to further employment of people with disabilities (go to this web site for a description: http://www.ssa.gov/disabilityresearch/navigator.htm). In Washington, as an example, the Disability Navigators have been very effective and have made a difference. There, many of the One-Stops had ordered assistive technology equipment, but did not understand its use or purpose. The Disability Navigators have helped to straighten out these and many other issues to make the One-Stops much more accessible to people of all abilities.

3). Tennessee Customized Employment Partnership (TCEP). The Tennessee Customized Employment Partnership (TCEP) is a part of the initiative to incorporate workforce development services for people with significant disabilities into One-Stop Career Centers. TCEP has developed an impressive and active group of partners in this endeavor, and has an informative website (http://www.tceponline.org/) that provides customized employment information and a wide range of resources that Career Centers and disability employment providers may use in delivering employment services to people with significant disabilities. Through their web site, one can learn about the customized employment concept and process, read stories of how people with very

significant and varying disabilities have worked with TCEP, and much more. TCEP was developed through a lengthy process of initiatives, beginning five years ago when the Office of Disability Policy (ODEP) funded a grant proposal by the University of Tennessee Center on Disability and Employment, which partnered with the Knoxville Career Center to develop a customized employment approach within the Career Center (a One-Stop center). With the help of additional grant funds, a number of partners have worked together to expand the approach and services developed in Knoxville to three other centers. The partnership is now working on a fifth center. As they see it, customized employment is a very person-centered approach that also assumes that generic centers (the One-Stop centers) can serve people with significant disabilities. The local partnerships developed at each of the sites are especially valuable in creating a discussion that has had a ripple effect on the entire network of employment systems that have traditionally served people with disabilities (VR, DMR, MH). The University of Tennessee's Center for Disability and Employment is already working with Florida supported employment providers under another initiative, and is an excellent resource for those wishing to develop customized employment in Florida. The Director of the Center Debra Martin Luecking, Ed.D., can be reached by emailing dlueckin@utk.edu or calling (865) 974-9068.

4). Vermont's Sheltered Workshop Closure and Outcomes. The State of Vermont (VR and Developmental Services) stopped funding sheltered workshops years ago, and all of their sheltered workshops have closed. Instead, every adult receiving developmental services has the option of seeking employment. The outcomes of this policy change have been positive. According to the 2005 annual report of the Vermont Developmental Services office, 37% of working age Vermonters receiving developmental services are supported to work. In FY 2002, Vermont was ranked # 1 in the nation in the number of people with developmental disabilities per 100,000 of the state population who received support to work (Coleman Institute, 2004). In 2004, the number of adults receiving support to work was 766, up from 536 in 1998; this does not include those who are self-managing their own work supports, or those who are working competitively and no longer using follow-along supports. In addition to those who are working, some Vermonters receiving developmental services choose to spend their day in other ways. For more information on what was done to make this major change in Vermont, one may contact Jennie Masterson at Jennie.Masterson@dail.state.vt.us.

5). APSE. The Network on Employment is a membership organization formed in 1988 as the Association for Persons in Supported Employment to improve and expand integrated employment opportunities, services, and outcomes for persons experiencing disabilities. Suzanne Hutcheson, director of Helping People Succeed (formerly Tri-County TEC), is the new president of APSE. APSE's teletraining curriculum, SE 101, is recommended by national experts who were consulted for this report. One can register for the training at http://www.apse.org/, APSE's web site.

6). ODEP Resources. The U.S. Office of Disability Employment Policy has developed Education Kit 2001, Supported Employment for Persons with the Most Significant Disabilities, found at http://www.dol.gov/odep/archives/ek01/support.htm.

7). Vermont Resource. A good resource, Vermont's Work-Based Learning Manual, can be found at http://www.state.vt.us/stw/wblm/2H0supported.pdf.

8). ICI Resources. The Institute for Community Inclusion (ICI) supports the rights of children and adults with disabilities to participate in all aspects of the community. This institute has many good resources on employment (look at its publications list, or type in "employment" in its search engine), including a new publication, The 30-Day Placement Plan: A Road Map to Employment. Another among its many services and resources is "Access to Integrated Employment: National Data Collection on Day and Employment Services for Citizens with Developmental Disabilities," a project with many downloadable publications. The Institute for Community Inclusion, http://www.communityinclusion.org/, is affiliated with the University of Massachusetts Boston and Children's Hospital Boston, and also operates the two programs whose descriptions follow (T-TAP and NCWD).

9). T-TAP. T-TAP, Technical Assistance for Providers, provides technical assistance on organizational change from group or congregate facility-based programs to supported employment, on customization of employment, on self-determination in employment, and on supported employment in general. A cooperative agreement from The U.S. Department of Labor (DOL), Office of Disability Employment Policy (ODEP) to Virginia Commonwealth University (VCU) in partnership with the Institute for Community Inclusion (ICI) at the University of Massachusetts in Boston established T-TAP. Its website is http://www.t-tap.org/.

10). NCWD. NCWD, National Center on Workforce and Disability, provides training, technical assistance, policy analysis, and information to improve access for all in the workforce development system. NCWD's areas of expertise include: designing access for all; accommodations and assistive technology; developing employer relationships; helping customers find jobs; job-related support; legal requirements and guidelines; partnerships and funding; disability policy; marketing and outreach. Their website, www.onestops.info, is a rich source of information on people with disabilities and the workforce development system.

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AREA OF EMPHASIS: QUALITY ASSURANCE

Quality Assurance for the Developmental Disabilities Home and Community Based (HCBW) program in Florida is provided through a contract with the Delmarva Foundation. The Quality Assurance program is performance outcome oriented, and supports quality improvement through technical assistance, training, resource materials, and analysis of patterns or trends which are identified from the aggregate data collected. The 2003/04 Annual Report issued by the Delmarva Foundation on the Florida program identifies continuing efforts to focus program measurements on the responsiveness of the system to the people who are being served.

In Florida there are seven core personal outcomes that are legislatively mandated which form the foundation for the quality assurance program. These include: freedom from abuse, personal safety, connections to natural support networks, fair treatment, has the best security, expression of personal rights, and optimal health. The performance program includes two outcome components. The first looks at person centered outcomes, and the second, provider effectiveness in producing the results which reflect consumer choice and preferences. Consumer outcomes are assessed from the perspective of the person served. Provider measures assess the delivery systems used and whether results are being achieved. Information is tracked by individual, agency, type of agency, and APD district. Reports are issued by Delmarva quarterly and annually which publish the activities and findings. The information from both the person centered and provider outcome assessments is used to promote performance improvement through the use of technical assistance, training, and other resources available through the Delmarva Foundation. These follow-up activities are targeted to persons with disabilities, providers, families, and APD staff. In addition to these follow-up activities quality improvement initiatives are undertaken based on trends identified from the growing pool of data being collected. Analysis of the aggregate data enables Delmarva staff to target specific areas for review and to quantify information which can be used to promote system performance improvements.

The program approach to quality in Florida is consistent with the direction set by the Council on Quality Leadership for Persons with Disabilities. The shift from an organizational compliance oriented system to one which focuses on organizational responsiveness to people reflects the definition of quality as adopted by the Council. The May 2003 report A Blueprint for Self Determination in Florida by the Center for Self-Determination recommended that in keeping with the State's expressed core values which support self determination, personal outcome measures used in the State's Quality Assurance program should be expanded to "reflect as nearly as possible what all Americans desire in their lives" (p. 14). Specific measurement standards were outlined in the life areas of home, community relationships, transportation, and business and commerce.

In addition, a National Core Indicator collaboration has been established among 25 states who have state agency membership in the National Association of State Directors of Developmental Disabilities Services. Florida is not one of the participating states. The purpose of this collaboration is to develop a uniform approach with common

performance outcome measures which enable participating states to share information with the overall goal of understanding and improving public developmental disability agency performance. Approximately 100 core indicators which co-related to the HCBS Quality Framework form the basis for the data collection system. Information sources include consumer surveys, family surveys, provider surveys, and data from the state system (expenditures, etc.). This is a unique multi-state effort to improve state agency performance.

SECTION III: OPPORTUNITIES FOR SYSTEMS CHANGE

There are distinct opportunities for systems change in Florida. Opportunities have been identified based on a confluence of events which are already occurring that are likely to support system change initiatives, and identifiable themes that represent an emerging consensus around challenges and a vision for the future. As the FDDC considers establishing strategic planning goals that promote a more inclusive quality of life for individuals with developmental disabilities, the identified opportunities may provide some directions which hold the most promise for change.

Education: Opportunity for Systems Change

The education system is experiencing unsatisfactory postsecondary outcomes with students who are leaving school and have few opportunities for employment and/or continuing education. Quality instruction that promotes achievement and skills development would be much more likely to result in postsecondary employment and outcomes which provide maximum opportunities for students to live fulfilling lives as responsible adults within the community.

Opportunity: Within the K-12 education system the "No Child Left Behind" Act establishes expectations for student achievement, and requires student assessment as the means for measuring school performance. This accountability system was established for all students. The language in the Act refers to the need for universal design of educational materials, including both assessments and instruction, for use by the widest number of people including students with disability. Further, NCLB gives states the flexibility to design an alternate assessment system for students with the most severe cognitive disabilities. The Blue Ribbon Task Force Implementation Work Group has identified improvement goals in connection with exceptional student education performance which include: a). student progress, b). dropout rates, c). graduation rates, and d). percent of students successfully transitioned to postsecondary education, competitive integrated employment, and or, vocational training. The attention which has been given to understanding this issue in Florida, and the commitment to system improvements expressed through the appointment of the BRTF Implementation Working Group, provides a unique **opportunity to address a significant systems performance issue: both instruction and the alternate assessment system in Florida's schools can be designed to include the general curriculum content as well as relevant functional and skill-building education that will contribute to improved postsecondary outcomes for students with developmental disabilities.**

Strengths: The political, professional, and family leadership in Florida has identified improved postsecondary outcomes for students with disabilities as a statewide priority at a time when overall school performance has emerged on the national agenda. There are technical assistance resources available to the State to provide support and assistance in the areas of universal curriculum design and alternate assessment systems. School transition planning has also received considerable attention in Florida. Most notable are the University of Florida Transition Center's activities, and the Partners in

Transition strategic planning project. The FDDC, Agency for Persons with Disabilities, and the Division of Vocational Rehabilitation have recognized the need and priority for improving the transition process. These initiatives suggest a promising opportunity for effecting systems improvements in the areas of student achievement, school transition, and postsecondary outcomes.

Early Childhood Education and Health: Opportunity for Systems Change

There is a great deal of overlap between health services and educational services, an overlap that is acknowledged in the fact that Children's Medical Services is responsible for both health care and early intervention for young children at risk for or diagnosed with special health care needs. While there are many strengths in the early childhood (birth to school age) health and education systems in Florida, there are also a number of gaps that present great difficulties for families and children, especially because resources are shrinking and the need is increasing.

Opportunity: Several factors are producing change in how things have been and will be done: 1). the mandate in federal and state legislation that young children are to be served in natural environments; 2). the resulting need for specialists to develop models in partnership with child care providers including parents and preschool programs, and to design implementation approaches which address the associated needs for training and support within these environments; 3). the Medicaid reform legislation, which promotes self-direction and builds on the family-centered approach already followed by CMS and other entities; 4). the advent of universal pre-kindergarten programs in Florida; and 5). the striking awareness of how much remains to be done. The confluence of these factors can be seen as providing **an opportunity for stakeholders in Florida to come together to engage in strategic planning to examine and align the early childhood health, early intervention, and education (Part B) systems, build infrastructure, and enhance and maximize the resources that exist for children and families.** This planning could be modeled on the work done by the Blue Ribbon Task Force on Inclusive Community Living, Transition, and Employment.

Strengths: In its early childhood and health systems, Florida has many strengths: these include the many expert and caring early childhood people in Florida, the state agencies that are fulfilling their difficult responsibilities as conscientiously as possible, the already-existing state-level systems for interagency collaboration, the nationally recognized centers and institutes dealing with early childhood health and education issues, the requirements that early intervention programs must ensure that a strong connection is maintained between all local programs that serve vulnerable infants and toddlers and must engage in collaborative activities on a regular basis, the many excellent reports on the needs of Florida's children, and the families with experiences and energy to engage in strategic planning of this kind.

Adult Health Care: Opportunity for Systems Change

While the Medicaid package for children is generous, when they reach the age of 18 the health care package changes. The DD/HCBS waiver recognizes and addresses this by including health care services that are not available to those not enrolled. Additionally, whether or not adults with disabilities are enrolled in a waiver, health care concerns persist.

Opportunity: Medicaid reform is on the horizon, and the legislature has mandated that special delivery mechanisms for children with chronic medical conditions and persons with developmental disabilities must be designed and recommended to the legislature to implement the part of the reform that affects these groups. This presents a prime **opportunity to develop and recommend a model for Medicaid reform to meet the needs of persons with developmental disabilities.** The FDDC has already initiated a process to study this area in partnership with AHCA, and thus has an opportunity to effect systems change. A primary issue for persons with developmental disabilities in Florida's Medicaid reform will be to insure that health care benefits, and the services provided under the Medicaid waivers, are sufficiently protected within the new model to meet their needs and support an inclusive and improved quality of community life. There will be a need for vigilance in regard to the pilot projects' effects on people who are not on the DD/HCBS, FSL, and CDC+ waivers.

Strengths: The Medicaid reform initiative is aimed at giving the person enrolled in the waiver more control over health care decisions; self-determination has the same goal. A strength in Florida is that so many stakeholders have come to understand and embrace the philosophy and suggested mechanisms for making the kinds of change needed to enable people with developmental disabilities to live meaningful lives in the community. Another strength is that many have gone the next step, with the CDC+ waiver, to take responsibility for managing the services they receive. The knowledge base and experience of these families and other stakeholders will be invaluable in developing recommendations for the Medicaid reform delivery system for people with developmental disabilities.

The need is for vigilance in regard to the pilot projects' effects on people who are not on the DD/HCBS, FSL, and CDC+ waivers; for careful attention to the types of health care services adults with disabilities need, and to how current services could be improved; and for creation of a proposal for a delivery system under the reform waiver that will address all of the health care needs of people with developmental disabilities.

Inclusive Community Living for Adults: Opportunity for Systems Change

The waiting lists for inclusive living opportunities are very long in Florida. Many young and middle-aged adults want to live outside of the family home and in the community. Many others want to leave congregate facilities. And, there are increasing numbers of aging caregivers who will soon be unable to care for their loved ones. Therefore, Florida's developmental disabilities system faces a need to continue its rapid

growth, especially in regard to inclusive community residential services. As important as this, however, is the understanding that inclusive living also means adequate support for meaningful participation in the community.

Opportunity: Florida has a significantly lower rate of persons with developmental disabilities receiving residential services than the national average. Its rate for settings housing 1-6 persons is less than half that of the national average; and seventy percent of developmentally disabled people who live outside of their family home live in intermediate care facilities or group homes. At the same time, there are very strong efforts to increase community living opportunities, especially through the FSL waiver. The BRTF report emphasizes inclusive community living for all persons and makes many recommendations for systems change, especially in regard to expansion of already-existing initiatives. With the BRTF Implementation Work Group's recent efforts to prioritize and ensure implementation of these recommendations, there is **an opportunity for stakeholders to unite around the goal of expanding funding and increasing the numbers of people who are supported to live in homes they have chosen in the community, with people with whom they want to live or by themselves, and with both formal and informal supports.** This should include attention to those still living in institutions and other congregate facilities (ICFs/MR and nursing homes, for example), to those whose caregivers are aging or who are aging themselves, and to those who will soon be unable to live with their families. It should also include attention to the possibility of allowing all adults, including those not enrolled in the waivers, access to support coordination.

Strengths: Since it was developed, Florida's supported living program specified that a supported living provider could not be responsible for the support and at the same time own or lease the person's home. Other important principles in the program are choice of where, with whom and what lifestyle the person will live, and individual support based on an individual support plan that can change as the individual's needs change. These principles are important for many reasons, and are a strength in the Florida system. The Family and Supported Living waiver was based on an awareness that supported living is preferred by many people and an important direction in which the community residential system needs to move if people are to be included in the community. The rate of increase in supported living in recent years (over 2000 since 1999) is another strength, even though the spending per participant is low in comparison to average national spending ($7,374 vs. $21,021 U.S., according to Braddock et al., 2005, preliminary). Finally, the expertise of APD's Community of Landmark discharge planning team is a strength that could be utilized not just in the closure of public institutions but in training of discharge planners working in private settings.

Housing: Opportunity for Systems Change

Safe, affordable, accessible housing is a great need for low income adults and families in Florida. For those adults with disabilities who want to own or rent their own homes, many barriers exist. At the same time, there are many organizations and resources that already exist to address these barriers, both in Florida and nationally.

Opportunity: Because so much thinking and organizing has been done to address the housing shortage, the **opportunity exists to develop a new initiative to increase availability of safe, affordable, accessible housing for people with developmental disabilities in Florida.** Some of the activities that could be undertaken by those concerned about housing include: 1). working together to convince every PHA to consider disability in its needs assessments and plans; 2). advocating that more of the housing resources coming to the state should be reserved to meet the needs of people with disabilities; 3). a planned effort to combine resources such as the low income tax credit and rent subsidies, to better assist those with the lowest incomes; and 4). assisting individuals who have had success in creating individualized options of homeownership and rental for people with disabilities, who have knowledge and connections with housing organizations, to train a small pool of individuals in other communities within both disability and housing organizations on how to do the same. A statewide leadership group, perhaps a Task Force on Housing or a subgroup of the Blue Ribbon Task Force Implementation Work Group could address the housing issues detailed in this report.

Strengths: Some of the strengths in Florida include the housing organizations, especially the Florida Supportive Housing Coalition and the Florida Housing Coalition; the opportunities created by the Florida Freedom Initiative; the many legislative priorities endorsed by the Florida Developmental Disabilities Council (and the analysis and awareness that went into development of these priorities); the Blue Ribbon Task Force Implementation Work Group work on housing, which is ongoing; and Florida-based housing resources such as the website cited in the housing section and the recommendations in A Blueprint for Self-Determination.

Employment: Opportunity for System Change

The Blue Ribbon Task Force on Inclusive Community Living, Transition, and Employment of People with Disabilities (BRTF) underscored that most people with developmental disabilities who live in Florida want to work at competitive, integrated employment, while very few actually have community jobs.

Opportunity: An opportunity exists in the coming together of many forces in Florida: 1). the findings of the BRTF and the subsequent follow-up efforts by the BRTF Implementation Working Group demonstrate a clear commitment to address the systems factors which can improve employment opportunities for persons with developmental disabilities throughout the State of Florida; 2). both the Agency for Persons with Disabilities, and the Division of Vocational Rehabilitation have made increasing supported employment opportunities as a priority within their respective strategic plans; 3). the Partners in Transition Project has on a statewide basis brought to the table the key stakeholders around the issue of school transition, and has produced a strategic plan to address the challenges young people face when moving from school to work; 4). the Florida Freedom Initiative and other work incentive programs are in place to help workers retain their benefits as they enter the workplace; and 5). there are many best practice resources within and outside the State of Florida which can provide technical support and assistance to systems change efforts in the areas of employment

and transition. All of these give evidence that **the system is ready to respond to the opportunity for increasing competitive employment outcomes for persons with developmental disabilities.** Major areas for consideration include: building the infrastructure and the incentive system that will sustain the change that is envisioned, increasing awareness by families and people with disabilities of the advantages and supports involved in getting and keeping employment in the community, and incorporating the concept of customized employment into the system as it develops.

Strengths: There are many other strengths in the Florida employment arena, as evidenced by the interagency collaborative work that went into production of the BRTF Report and is now involved in the Implementation Work Group. A key strength is the family advocates who have spoken out for integrated employment for many years. Keeping these strong forces together and moving forward will be crucial if the employment system infrastructure is to be developed to the extent needed to achieve the desired outcomes.

Family Preservation and Permanency Planning: Opportunity for Systems Change

Significant numbers of children with developmental disabilities in Florida are at risk of being placed into congregate settings, or are already in institutions, nursing homes, group homes, and foster homes. Nationally, the most current trends and promising practices in child welfare recognize the child development and public policy benefits to family preservation and permanency planning for all children; these same benefits are beginning to be recognized in some states' developmental disabilities systems.

Opportunity: There are many indications that family preservation and permanency planning are valued in Florida's systems: 1). the recent changes to the Family and Supported Living waiver demonstrate a commitment to supporting families as the primary caregivers to children with developmental disabilities; 2). the child welfare system in Florida has already demonstrated that even the very high needs of children can be met in family settings through the existing medical foster care program, many of whom pursue adoption of the children they foster; and 3). the July 2004 change to Florida's Part C program requiring that children be served in "natural environments" is further evidence of the State's recognition of the importance for every child to be nurtured within family settings. Families throughout the state are seeking additional support as represented in their comments about how the system currently functions and about the unmet needs they have. Florida has the **opportunity to embed family preservation and permanency planning into the value base of its service system, by considering new ways of supporting families, and by instituting mechanisms that ensure that children remain with their primary caregivers or in other long term family relationships.** To do this, Florida will need to engage in the kind of coordinated and systematic effort that was put in place in Michigan (see Formal and Informal Supports section) to ensure permanency planning for children with developmental disabilities. This includes 1). examining beliefs about

children and families; 2). putting in place a concentrated and collaborative effort to create a system that says, "Children belong in families;" 3). examining the pathways by which children are placed in group settings; 4). developing policies and practices that result in the closing of these pathways; 5). bringing needed services to family homes; and 6). developing new ways of thinking about family choices, among other things. Such an effort will require work by family advocates and by all relevant departments at the state and local levels. But first, it requires making a commitment that children belong in families.

Strengths: As in other areas, Florida has many strengths that could come together in the realm of family preservation and permanency planning. There are many excellent organizations focusing on the needs of families and children: some are named in the sections on Health and Informal and Formal Supports. To name one, the Positive Behavior Support Project at the University of South Florida works with schools, families, and foster families to implement strategies for positive behavior support. There are also some national resources that are invaluable for states that undertake policy and practice change in the area of family preservation and permanency planning for children with developmental disabilities.

Workforce Issues: Opportunity for Systems Change

Both nationally and in Florida, for individuals with disabilities to live, work, learn, and socialize in inclusive community places, there is an enormous need for trained direct support professionals. However, high turnover rates, ill-trained workers, and unfilled positions mean that people with disabilities and their families are and will increasingly be less able than they could be to participate fully in community life.

Opportunity: The emphasis on person-centered planning and self-determination presents an opportunity to Floridians concerned about the workforce shortage, in that studies show that when people with disabilities select and manage their own support workers (with or without assistance), they and the workers are more likely to be satisfied. To direct attention to the coming workforce crisis in supporting individuals with disabilities to live, work, learn, and socialize in inclusive community places, **stakeholders in Florida could come together to determine the extent of workforce retention and recruitment problems in the state, and develop strategies to address them.** Florida's unemployment rate is quite low (3.6% in August, 2005); competition for good workers is strong. There is a need to face these issues squarely and to put in place mechanisms to address the problem.

Strengths: Many excellent training organizations are operating within Florida, addressing training in specific areas such as supported employment, health care, early childhood care, education, etc., and curricula developed in many areas through the FDDC grant programs. The Advocacy Center also trains families and support coordinators in regard to many. Additionally, there are national training curricula that could be examined for use with direct support workers in Florida. There are also studies of recruitment, retention, and compensation nationally, and suggestions made by

organizations such as the National Association of Direct Support Professionals, as well as by Florida organizations, that can assist with this effort.

APPENDIX A

Florida Stakeholders Interviews

Daniel Armstrong, Ph.D., Associate Chair, The Mailman Center
Dennis Baxley, Representative
Nila Benito, Parent, CARD-USF; Vice Chair, FDDC
Wil Blechman, M.D. (retired)
Shelly Brantley, Director, Agency for Persons with Disabilities
Karen Clay, Parent, FDDC
Jeremy Countryman, Family Cafe
Guenevere Crum, The Able Trust
Dale DiLeo, Training Resource Network
Jackie Frost, Shriner's Hospital
Lori Fahey, Family Cafe
Susan Gold, Ed.D., The Mailman Center, Dept. of Pediatrics; FDDC
Lyndi Gordon, Senior Attorney, Advocacy Center for Persons with Disabilities
Ted Granger, United Way of Florida
Sheila Gritz, Transition Center, University of Florida
Janet Hess, Director, Hillsborough Coalition for Children and Youth with Special Needs
Steve Holgren, Program Director, FDDC
Patty Houghland, PADD, Pensacola
Elizabeth Jennings, Real Choice Partnership Project, United Way of Palm Beach County
Beth Kidder, Bureau Chief, Medicaid Services, AHCA; FDDC
Roberta Kelley, Bureau Chief for Health Systems Development, AHCA
Stephanie Kovacks, Consumer, FDDC
Ann Millan, Chair, Family Care Council
Phyllis Sloyer, Ph.D., Division Director, Early Steps, Children's Medical Services, DOH, FDDC
Mimi Graham, Ed.D., FSU Center for Prevention and Early Intervention
Charles Liem, Staff Director, House Elder and Long-Term Care Committee
Susan Redmon, R.N., M.P.H., Children's Medical Services; FDDC
Sue Ross, Children's Mental Health
Jean Sherman, Director, Center on Aging and Disability, University of Miami
Sylvia Smith, Director of Protection and Advocacy Programs for the Developmentally Disabled, Advocacy Center for Persons with Disabilities
Ann Swerlick, Deputy Director, Florida Legal Services, Inc.
Charm Thometz, Parent, FDDC
Gary Weston, Executive Director, Advocacy Center for Persons with Disabilities, Inc.
Beverly Whiddon, Staff Director, Senate Children and Family Committee

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APPENDIX C

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APPENDIX D

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APPENDIX E:

FORUM SUMMARY INFORMATION

The Florida Developmental Disabilities Council, Inc. (FDDC) Five Year Strategic Planning Process is committed to ensuring a significant participatory role by persons with developmental disabilities, parents, and other family members. Among the activities employed by the Council to insure the next Five Year Plan is responsive to the needs of the people who will be directly impacted by the plan was the use of six public forums which were held in separate geographic locations most proximate to the population centers throughout the State of Florida, and an internet based participation option. The forums where held during July and August 2005, and the internet option was available during the same time period. Notices about the FDDC five year planning initiative, and the opportunity to participate in the forums were widely distributed to stakeholder groups utilizing both an extensive internet based notification, a hard copy mailing, and newspaper announcements. The purpose of the forums was to gather current information on the issues significant to persons with developmental disabilities including what services are needed to achieve an improved quality of life; perspectives on current services; perspectives on barriers to services; and recommendations for improvements of the service and support system. A total of 166 people participated in the forums including 71 family members, 16 persons with disabilities, 48 providers, 2 public officials, and 29 advocates. The comments received from forum participants included the identification of barriers they have experienced, and suggestions for improvements. Themes which emerged from the forums have been incorporated into the appropriate area of emphasis section of the report along with the improvement suggestions. The outline which follows highlights the input received from forum participants.

Education

- Children are slipping through the cracks of the early intervention system, particularly within low income, non English speaking, and other minority sectors of the community.

- Changes in the Part C Early Intervention services and delivery system, for example, day care not covered, natural environment requirement; are presenting a problem for working parents, and lack the out of home inclusive child care resources.

- Care Coordinators have high caseloads and operate in more of a “gate keeper” capacity.

- Transition from Part C to Part B is a difficult period due to changes in systems, assessment criteria, and providers.

- Statewide funding is insufficient to meet the need.

- Service access is restricted to authorized providers, and not sufficiently available in rural geographic areas.

- Insufficient information available to parents about service options.

- Service continuity is not reliable.

- Respite is either unavailable or very limited.

- Schools are not held accountable for the progress of exceptional education students.

- The role of parents in the IEP process is often not supported by school personnel. This results in an adversarial relationship.

- When educationally related resources are not available to a school district services are not provided.

- Diploma decisions limit a child's exposure to general education expectations and opportunities.

- The exceptional student education curriculum does not provide practical skill development, sufficient emphasis on academics, nor vocational training to adequately prepare students for adult life.

- Transition planning and postsecondary opportunities are inadequate, and limited by the long waiting list for the DD/HCBS waiver.

- The coordination across the Department of Education, Division of Vocational Rehabilitation, and Agency for Persons with Disabilities systems is either not apparent, or not working.

- Parent to parent support should be available in all school districts, and this should include training in the parental role in IEP development, rights and due process procedures, transition planning, and diploma decision making considerations.

Health

- Rural areas of the state do not have an adequate supply of health care professionals to meet the need.

- Service determination under the Medicaid programs is based on a medical necessity standard which does not provide an accurate assessment of need, and results in changes to the types and frequency of services.

- The Medicaid health care system appears to be managed based on suspicion of fraud, cost containment, and "managed access" versus "managed care."

- There is a structural conflict of interest in the Medicaid health care system in that the people who are responsible for reviewing and authorizing services are also responsible for managing utilization.

- Many health care providers will not accept Medicaid due to the low rates.

- Choice is limited to the Medicaid approved provider unless the individual is covered by private third party insurance.

- The Children's Medical Service Medicaid program provides a comprehensive package of health care services for children with disabilities, however, when children reach adulthood and their coverage changes there is not comparable coverage leaving gaps in access to health care. Although the HCBSW addresses some of these adult service deficiencies, there is a long waiting list for the HCBSW thus creating differential levels of health care and service based on program enrollment vs. need.

- The due appeals process is stacked against consumers of the Medicaid health care system in the State uses professional legal representation from the Attorney General's office against poor and low income self advocates who are not skilled in due process procedure and lack resources to obtain professional representation.

Child Care

- Child Care is not a covered service under the Part C program.

- There are very few child care providers who provide inclusive services.

- Many child care providers have entrance criteria which are exclusive, for example, toilet training, behavior support needs.

- The universal Pre-K program does not make provisions for children with special needs.

- The first line in child care is the family, however, there are not sufficient supports available to support to families care for their special needs children at home. Respite needs are high with few options.

Formal and Informal Community Supports Including Housing, Employment, & Transportation

- There is an extensive and multi year waiting list for the DD/HCBS waiver. Individuals on the waiting list and their families do not have sufficient information about how long they can expect to be on the waiting list, and how their needs are being considered in decision making around who does and does not get served.

- The new FSL waiver does not provide sufficient resources to support the needs of most of the individuals who are on the DD/HCBS waiting list.

- There is confusion and suspicion around how acceptance of the FSL will impact a person's status on the DD/HCBS waiting.

- Services are not reliable under the waiver due to changes in the medical necessity judgment, availability of providers, and knowledge and skills of the Support Coordinator.

- The current support system for adults promotes poverty and dependence.

- Young adults are leaving school without the skills needed to function at their maximum potential and as responsible adults.

- The provider and community service infrastructure is not sufficient to meet the adult community living needs for adults with disabilities (for example, supported employment, housing, adaptive technology, home modification, transportation, and social/leisure time opportunities).

- There are very few opportunities for continuing education and vocational training for adult persons with disabilities.

- In general, employers do not view persons with disabilities as a potential pool of workers to fill their employment needs.

- Housing rental and purchase costs are beyond the means of most persons with disabilities.

- Transportation options are very limited and inadequate to support the needs of adults who have community living employment, medical, and social commitments.

- The notion of "independent living" is being heavily promoted; however, parents are reluctant to support this direction in the absence of a sustainable infrastructure to support this direction. Many parents do not trust the current system and believe their adult children would be at risk of living in unsafe situations and in isolation.

- Parents identify the lack of information as a significant obstacle in negotiating the system on behalf of their family member.

- There are not sufficient supports for long term futures planning in the areas of guardianship, estates planning, trusts, and health care decision making.

- Aging parents are concerned that the service and support system will not be available when they are no longer able to support their adult children in the family home.

- The shift in emphasis away from Adult Day Training should be tempered taking into consideration the range of needs of individuals. Day training programs which offer productive habilitation experiences should continue to be a part of the system, and used in combination with supportive employment opportunities as appropriate to the needs of individuals.

- The provision of home modification services under the waiver program is hampered by the ability to engage contractors as Medicaid vendors. The five year limitation period on eligibility is too restrictive.

- Every county in the State should have a housing plan which includes how the housing needs of persons with disabilities will be meet through a range of rental and home ownership options.

Recreation

- Access to religious, social, cultural, and recreational opportunities for persons with disabilities including after school activities for young people is hampered by lack of transportation and personal supports.

- Existing groups and organizations for example, Girl Scouts of America and VSA Arts of Florida, encourage the participation of persons with disabilities. These inclusive resources which provide opportunities for self expression, learning, and socialization should be actively supported.

- Public transportation is very limited, and when available often operates at a reduced schedule during evenings and weekends when people are have the time to participate in leisure and social activities.

- Inclusive “play groups” could be an effective approach to socialization of toddlers and preschool children with disabilities and their non disabled peers. In addition parents would have the opportunity to network during the time their children are playing together.

Quality Assurance

- There is a need for increased provider performance accountability within the system.

- There is variability in the skills, knowledge and performance among Support Coordinators.

- There is no coordinated local planning structure to insure the developmental disabilities system and infrastructure develops to meet the service and support needs of persons with developmental disabilities.

Summary of Forum Participant Satisfaction Survey

A Forum Participant Satisfaction Survey Form in both English and Spanish was distributed to all participants. Participants were asked and reminded to complete and return the form before leaving, or to mail responses to project staff. The mailing address, internet site address, and toll free telephone number were included on the printed form. A total of 54 forms were completed by participants and returned. Forty of the participants rated the event as "very satisfied, 11 somewhat satisfied, and 3 did not give an overall rating. No respondents indicated that they were not satisfied. The significant comments were as follows:

- Additional forums are needed and should be held in more dispersed geographic locations to increase participation.
- More advance notice would have resulted in increased participation.
- Forums should be scheduled at varying times to increase participation including earlier in the day, evening hours, and weekends.
- The availability of support services including transportation and respite would have increased participation.
- Feedback to participants should be provided on past forums as well as the Dare to Dream Forum.
- The Orlando facility was difficult to find and due to the construction occurring around the facility made access very difficult.
- Written material was not available in Braille on the day of the event.
- Family Care Councils could have helped with participation.
- Too much time spent on education and not enough attention to transportation and other adult service needs.

APPENDIX F

COORDINATION AMONG DISABILITIES SERVICE ENTITIES

The analysis of the Florida systems for providing services and supports to persons with developmental disabilities included the identification of current efforts to coordinate activities across state agencies and organizations. The findings which are outlined below indicate that there are many identifiable efforts to coordinate within the State and across agency lines.

Statewide Councils and Work Groups

The Office of Program Policy Analysis and Government Accountability (OPPAGA) issued a report in July 2005 (No. 05-39) discussing the issue of coordination among statewide entities which address the interests of persons with disabilities. Overall the findings indicated that duplication was not a significant problem, however, while there is some coordination occurring further improvements are needed. OPPAGA identified 25 different entities of which 12 were created by state law or executive order, 11 are non profit entities, and 2 are councils or committees within state agencies. The charts below taken from the OPPAGA report provide information about each of these entities. One significant activity not included on this list is the recently formed Blue Ribbon Task Force Implementation Working Group (BIWG). The BIWG is comprised of State agency heads and organizations responsible to insure the coordinated implementation of the recommendations made by the Governor's Blue Ribbon Task Force in the areas of inclusive community living, effective transition services, and competitive integrated employment for persons with developmental disabilities. The charts below provide detailed descriptive information about each of the entities included in the OPPAGA review.

Interagency Agreements

Formal inter agency agreements were also identified as follows:

- Agreement Between The Medicaid Office, Economic Services, Children, Youth, and Families Program Services Office, Children's Medical Services Program Office, Developmental Services Office, Alcohol Drug and Mental Health Program Office, and the State Health Office for the Early Periodic Screening, Diagnosis, and Treatment of Medicaid eligible children under 21

- Agreement Between the Medicaid Office and the Developmental Services Office

- Agreement Between the Medicaid Office and the Department of Aging and Adult Services

Source: Office of Program Policy Analysis and Government Accountability. (2005, July). *Disabilities groups should improve coordination, but duplication of activities appears to be low* [OPPAGA Report No. 05-39]. Tallahassee: The Florida Legislature. Retrieved from http://www.oppaga.state.fl.us/reports/pdf/0539rpt.pdf

Appendix A

Entities That Address the Interests of Persons with Disabilities

To identify statewide entities that address the interests of but do not directly provide services to persons with disabilities, we obtained information from the Agency for Persons with Disabilities, Agency for Health Care Administration, Department of Children and Families, Department of Education, and Department of Health, and reviewed entity documents and reports. Based on this information, we identified 25 statewide entities listed below that address the interests of persons with disabilities.

Entity	Established/ Administered	Mission	Activities
All Persons with Disabilities			
Abilities of Florida, Inc.	Nonprofit organization	Provide vocational evaluation, skills training, accessible housing, and job placement services to persons with disabilities.	Activities include providing job placement and skills training to persons with disabilities and financial assistance to low-income persons with disabilities who need housing.
The Advocacy Center for Persons with Disabilities, Inc.	Nonprofit organization	Advance the dignity, equality, self-determination, and expressed choices of individuals with disabilities, and ensure and expand the human and legal rights of people through the use of information and advocacy. Designated by executive order as the Protection and Advocacy System for the State of Florida.	Activities include implementing federally mandated programs that provide protection and advocacy for persons with developmental disabilities, mental illnesses, and traumatic brain injuries; also provides protection and advocacy for individual rights and voting access.
The Americans with Disabilities Act Working Group (ADAWG)	Executive Orders 97-56 (created); 99-80, 01-161, 03-137 (expanded)	Provide information, referrals, education, and recommendations for compliance and implementation of the Americans with Disabilities Act (ADA) in order to increase the independence and quality of life for citizens of Florida of all ages with disabilities.	Activities include maintaining a statewide information and referral system for all disability related services, programs, assistance, and resources; identifying and recommending methods to remove barriers to the delivery of and access to services for people with disabilities; and acting as the entity to coordinate the implementation of the ADA.
The Family Café	Nonprofit organization	Ensure that individuals with special needs or disabilities and their families have an opportunity for collaboration, advocacy, friendship, and empowerment by providing information, resources, and support in a family-centered environment.	Primary activity is holding an annual conference with participation by and support from state agencies and disabilities groups across the state, providing free registration and assistance with lodging and mileage, to educate families regarding available services. Presents a series of several small versions of the annual conference with region-specific information regarding programs and services.
Family Network on Disabilities of Florida, Inc.	Nonprofit organization	Ensure through collaboration that Floridians have full access to family-driven support, education, information, resources, and advocacy.	Activities include sponsoring support and self-help groups, providing parental training, and maintaining a family resource center.
Florida Alliance for Assistive Services and Technology, Inc. (FAAST)	Nonprofit organization	Enhance the quality of life for all Floridians with disabilities by promoting the awareness of, access to, and advocacy for assistive services and technology.	Activities include providing information and referral services, evaluation, and testing of assistive technologies, and financial assistance.

Source: Office of Program Policy Analysis and Government Accountability. (2005, July). *Disabilities groups should improve coordination, but duplication of activities appears to be low* [OPPAGA Report No. 05-39]. Tallahassee: The Florida Legislature. Retrieved from http://www.oppaga.state.fl.us/reports/pdf/0539rpt.pdf

Entity	Established/ Administered	Mission	Activities
Florida Association of Centers for Independent Living (FACIL)	Nonprofit organization	Through advocacy and coordination, lead, strengthen, and support the member Centers for Independent Living, which serve persons with disabilities.	Serves as the statewide association for numerous Centers for Independent Living throughout the state. The centers provide four core services: information and referral, independent living skills training, peer counseling, and individual and systems advocacy.
Florida Endowment Foundation for Vocational Rehabilitation, Inc. (The Able Trust)	s. 413.615, *F.S.* Nonprofit public-private partnership	Provide Floridians with disabilities fair employment opportunities through fundraising, grant programs, public awareness, and education. Designated by executive order to serve as the Florida Governor's Alliance for the Employment of Citizens with Disabilities.	Activities include supporting projects that provide on-the-job coaching, supported employment, job skills training, job development, employer outreach, ADA facility compliance, and skills evaluation. Only projects for which funding cannot otherwise be provided through a state agency are considered for funding. Also promotes awareness of abilities of persons with disabilities, serves as liaison to the Office of Disability Employment Policy, and recommends policies to the Governor.
Florida Independent Living Council, Inc. (FILC)	s. 413.395, *F.S.* Department of Education Nonprofit organization	Promote, in response to the Federal Rehabilitation Act of 1973, Title VII and as mandated by the ADA, independent living opportunities for persons with disabilities of all ages throughout the state of Florida. This includes the promotion of a direct service philosophy that is consumer controlled and directed.	Activities include developing a state plan for independent living; providing oversight to centers throughout the state; monitoring, reviewing, and evaluating implementation of the state plan; and coordinating activities with state councils that address the needs of specific disability populations.
Florida Rehabilitation Council	s. 413.405, *F.S.* Department of Education	Increase employment, enhance independence, and improve the quality of life for Floridians with disabilities, ages 16 through 64 years, through evaluation, planning, and coordination of services.	Activities include serving as the federal oversight body responsible for reviewing vocational rehabilitation services in Florida and reporting to the Governor and Legislature.
Florida Statewide Advocacy Council	s. 402.165, *F.S.* Executive Office of the Governor	Safeguard the health, safety, welfare, and rights of the clients of programs and services provided by the State of Florida health and human services delivery system from conditions or individuals that constitute a threat to clients' civil and human rights.	Activities include processing complaints, conducting investigations, and monitoring programs. This statewide network of services is performed by the Florida Local Advocacy Councils that are composed of approximately 370 Governor-appointed volunteers.
Special Needs Shelters Interagency Committee	s. 381.0303(5), *F.S.* Department of Health	Resolve problems related to special needs shelters not addressed in the state comprehensive emergency medical plan and serve as an oversight committee to monitor the planning and operation of special needs shelters.	Activities include developing and negotiating any interagency agreements and submitting recommendations to the Legislature.
Persons with Developmental Disabilities			
Family Care Council	s. 393.502, *F.S.*	Advocate, educate, and empower individuals with developmental disabilities and their families, partnering with the Agency for Persons with Disabilities to bring quality services to individuals for dignity and choice.	Activities include providing outreach and information to families about accessing supports and services, developing written recommendations for enhancing community and family supports and services, and monitoring the effectiveness of supports and services to ensure that the full range of family needs are addressed.

Source: Office of Program Policy Analysis and Government Accountability. (2005, July). *Disabilities groups should improve coordination, but duplication of activities appears to be low* [OPPAGA Report No. 05-39]. Tallahassee: The Florida Legislature. Retrieved from http://www.oppaga.state.fl.us/reports/pdf/0539rpt.pdf

Entity	Established/ Administered	Mission	Activities
Florida Developmental Disabilities Council (FDDC)	s. 393.002, *F.S.* Nonprofit organization	Encourage and advocate opportunities for persons with developmental disabilities (as defined in federal law, P.L. 106-402, section 102) and their families to enhance their quality of life within their communities. Designated by executive order as the agency to receive federal funds to implement on behalf of the State of Florida, Part B of the Federal Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402).	Activities include coordinating efforts of federal, state, and local agencies to provide health care, vocational training, community living opportunities, and case management for persons with developmental disabilities and their families, enhancing independence, productivity, integration, inclusion, and self-determination in all facets of community life. Funds programs for prevention, identification, and alleviation of developmental disabilities in children.
Southern Movement for Independence	Nonprofit organization	Promote the self-determination of individuals with developmental disabilities.	Activities include supporting legislation, programs, and policies; promoting public awareness; and providing mini-grants to local chapters.
Persons with Brain and/or Spinal Cord Injuries			
The Brain and Spinal Cord Injury Advisory Council	s. 381.78, *F.S.* Department of Health	Provide all eligible Florida residents who sustain a moderate to severe brain or spinal cord injury the opportunity to obtain the necessary services enabling them to return to their community.	Activities include providing advice and expertise to the Department of Health for the preparation, implementation, and periodic review of the Brain and Spinal Cord Injury Program, including on-site visits to transitional living facilities identified by the Agency for Health Care Administration as being in possible violation of the statutes and rules regulating such facilities.
Brain Injury Association of Florida, Inc.	Nonprofit organization	Improve the quality of life for persons with traumatic brain injuries and their families by creating a better future through brain injury prevention, research, education, support services, and advocacy.	Activities include providing case management services to persons with traumatic brain injuries, providing support for their families, and implementing public education programs.
Florida Spinal Cord Injury Resource Center	Nonprofit organization	Serve as the statewide clearinghouse of spinal cord injury (SCI) resource information for persons who have survived an SCI, their families and friends, healthcare professionals, support groups, the media, and the general public.	Activities include providing new survivors with information to expand their awareness about SCI, offering peer mentors and information and referral services for all survivors of SCI and their families and friends, making public awareness presentations, and sponsoring support groups.
Persons with Hearing Impairments			
The Florida Coordinating Council for the Deaf and Hard of Hearing (FCCDHH)	s. 413.271, *F.S.* Department of Health	Recommend policies and direct program development to address the needs of persons who are deaf, hard of hearing, late deafened, and deaf-blind, as well as methods that improve the coordination of services among public and private entities, and to provide technical assistance, advocacy, and education.	Activities include providing information and referral services; advice regarding coordination of interpreter services, captioning services, and assistive listening devices; and information and assistance to the Legislature. Conducts public hearings and reviews federal and state statutes, rules, and regulations that establish requirements with which agencies must comply.
Persons with Visual Impairments			
Florida Rehabilitation Council for the Blind	s. 413.011, *F.S.* Department of Education	Assist the Florida Division of Blind Services in the planning and development of statewide rehabilitation programs and services and recommend improvements to such programs and services on behalf of Floridians with visual impairments.	Activities include recommending policies to the Department of Education and conducting an annual client satisfaction survey that evaluates the Division of Blind Services.

Source: Office of Program Policy Analysis and Government Accountability. (2005, July). *Disabilities groups should improve coordination, but duplication of activities appears to be low* [OPPAGA Report No. 05-39]. Tallahassee: The Florida Legislature. Retrieved from http://www.oppaga.state.fl.us/reports/pdf/0539rpt.pdf

Entity	Established/ Administered	Mission	Activities
Persons with Mental Illnesses			
National Alliance for the Mentally Ill (NAMI) Florida, Inc.	Nonprofit organization	Eradicate severe brain disorders and improve the quality of life of persons of all ages who are affected by these disorders.	Activities include sponsoring support groups and education programs for persons with mental illnesses and their families; service referral; assessing, reviewing, and monitoring services; and supporting legislation, programs, and policies.
Substance Abuse and Mental Health Corporation	s. 394.655, *F.S.* Nonprofit organization, Department of Children and Families	Oversee the state's publicly funded substance abuse and mental health systems and make policy and resource recommendations to improve the coordination, quality, and efficiency of the system.	Activities include making recommendations to the state's substance abuse and mental health programs, Governor, and Legislature to improve services for individuals with mental illnesses and chronic substance abuse.
Persons with Special Needs (Birth through Age 21)			
Florida Institute for Family Involvement (FIFI)	Nonprofit organization	Enhance, facilitate, and support family and consumer involvement in the development of responsive, family-centered, and community-based systems of care for children and youth with special health care needs, based on the federal definition, and their families.	Activities include providing information and leadership training to families of children and youth with disabilities; supporting legislation, programs, and policies; and providing grant funding.
Florida Interagency Coordinating Council for Infants and Toddlers (FICCIT)	Required by federal law (Individuals with Disabilities Education Act, [IDEA], Part C, P.L. 105-17), Department of Health	Assist public and private agencies in implementing a statewide system of coordinated, comprehensive, multidisciplinary, interagency programs providing appropriate early intervention services to infants and toddlers, birth to five years, with disabilities and risk conditions and their families.	Activities include recommending procedures for distribution of funds and priorities for program support under IDEA, Part C, and obtaining public comment on the Florida State Plan as required by IDEA, Part B; assisting and advising the lead agency in developing and reporting information and evaluations of programs; and seeking information from service providers, coordinators, and parents about any federal, state, or local policies that impede timely service delivery.
State Advisory Committee for the Education of Exceptional Students	Department of Education	Advocate for students with disabilities (ages 3 through 21).	Activities include advising the department of unmet needs in the education of children with disabilities, and commenting publicly on any proposed rules or regulations regarding the education of children with disabilities. Other activities include advising the department in developing evaluations and reporting on data, and advising on the education of eligible students with disabilities who have been convicted as adults or incarcerated in adult prisons.

Source: State and federal laws, Governor's executive orders, entities' websites, responses to Office of Program Policy Analysis and Government Accountability surveys, and communications from the Department of Education and the Department of Health.

Source: Office of Program Policy Analysis and Government Accountability. (2005, July). *Disabilities groups should improve coordination, but duplication of activities appears to be low* [OPPAGA Report No. 05-39]. Tallahassee: The Florida Legislature. Retrieved from http://www.oppaga.state.fl.us/reports/pdf/0539rpt.pdf

Appendix B

Coordination Among Entities That Address the Interests of

We asked a representative of each entity we surveyed to identify other entities with which they had coordinated their efforts on behalf of persons with disabilities during the past 12 months. In the table below, a box marked with an "X" indicates that the entity listed in the column on the left reported that it coordinated with an entity listed in the top row.

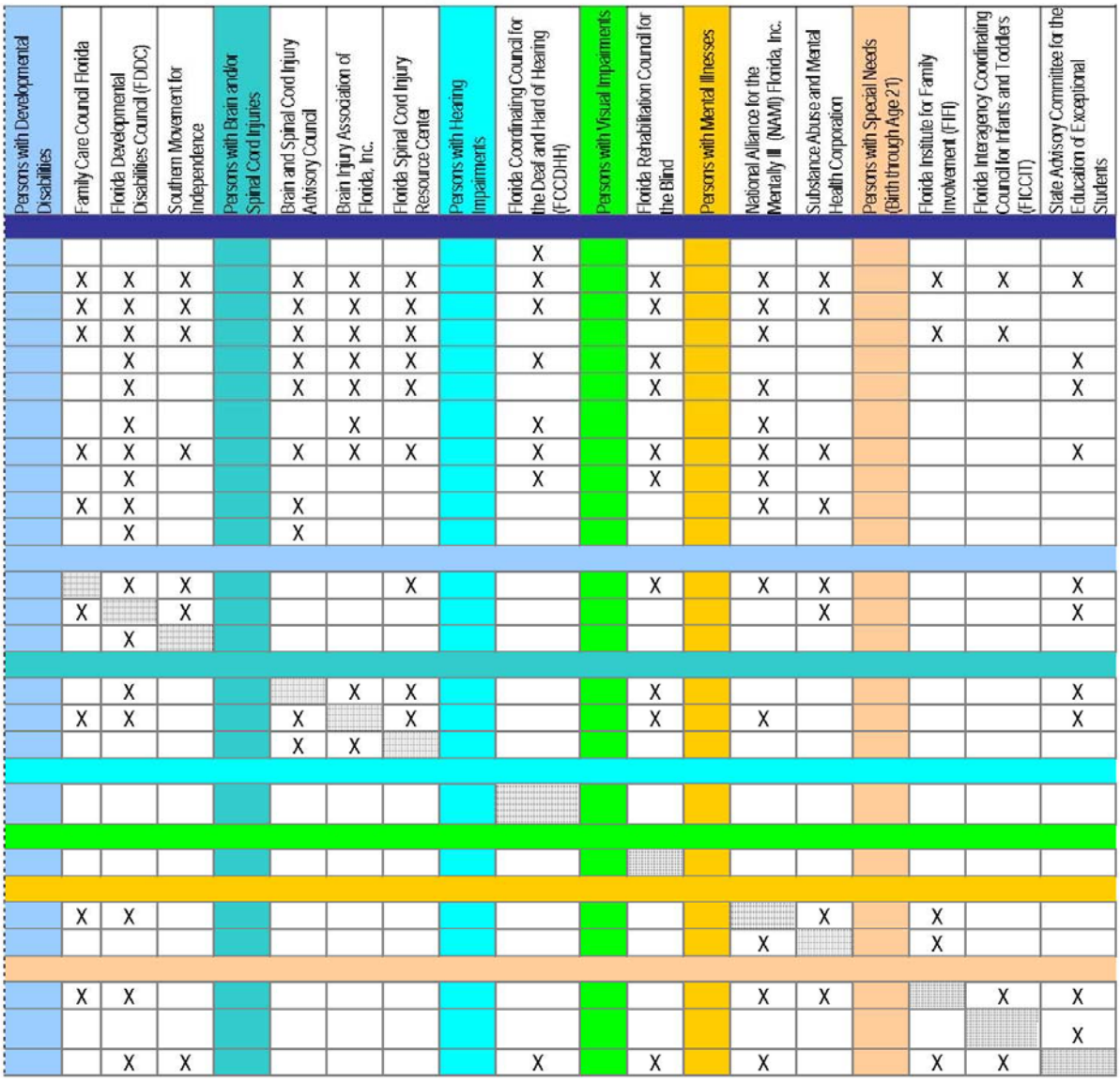
	All Persons with Disabilities	Abilities of Florida, Inc.	The Advocacy Center for Persons with Disabilities, Inc.	The Americans with Disabilities Act Working Group (ADAWG)	The Family Café	Family Network on Disabilities of Florida, Inc.	Florida Alliance for Assistive Services and Technology, Inc. (FAAST)	Florida Association of Centers for Independent Living (FACIL)	Florida Endowment Foundation for Vocational Rehabilitation, Inc. (The Able Trust)	Florida Independent Living Council, Inc. (FILC)	Florida Rehabilitation Council	Florida Statewide Advocacy Council	Special Needs Shelters Interagency Committee
All Persons with Disabilities													
Abilities of Florida, Inc.			X				X	X	X		X		
The Advocacy Center for Persons with Disabilities, Inc.		X		X	X	X	X	X	X	X	X	X	X
The Americans with Disabilities Act Working Group (ADAWG)		X	X		X	X	X	X	X	X	X	X	X
The Family Café			X	X		X	X	X	X	X	X	X	
Florida Alliance for Assistive Services and Technology, Inc. (FAAST)		X	X	X	X	X		X	X	X		X	
Florida Association of Centers for Independent Living (FACIL)			X	X	X	X	X		X	X			
Florida Endowment Foundation for Vocational Rehabilitation, Inc. (The Able Trust)		X	X	X	X	X	X	X		X			
Florida Independent Living Council, Inc. (FILC)			X	X	X	X	X	X	X		X		
Florida Rehabilitation Council				X	X	X			X	X			
Florida Statewide Advocacy Council			X	X	X	X	X	X	X	X	X		
Special Needs Shelters Interagency Committee			X	X				X		X			
Persons with Developmental Disabilities													
Family Care Council Florida			X	X	X	X	X	X	X	X	X	X	X
Florida Developmental Disabilities Council (FDDC)			X	X	X	X	X	X	X	X	X	X	
Southern Movement for Independence													
Persons with Brain and/or Spinal Cord Injuries													
Brain and Spinal Cord Injury Advisory Council		X	X	X	X		X	X	X	X	X	X	X
Brain Injury Association of Florida, Inc.		X	X	X	X	X	X	X	X				
Florida Spinal Cord Injury Resource Center			X	X	X		X	X	X	X		X	
Persons with Hearing Impairments													
Florida Coordinating Council for the Deaf and Hard of Hearing (FCCDHH)				X						X			
Persons with Visual Impairments													
Florida Rehabilitation Council for the Blind			X							X			
Persons with Mental Illnesses													
National Alliance for the Mentally Ill (NAMI) Florida, Inc.			X	X	X			X	X	X	X	X	X
Substance Abuse and Mental Health Corporation			X	X								X	
Persons with Special Needs (Birth through Age 21)													
Florida Institute for Family Involvement (FIFI)			X	X	X	X	X	X	X		X	X	X
Florida Interagency Coordinating Council for Infants and Toddlers (FICCIT)					X								
State Advisory Committee for the Education of Exceptional Students			X	X	X	X	X		X		X		X

[1] The Family Network on Disabilities of Florida, Inc., did not respond to our survey, but is included in the table since other entities reported coordination

Source: Responses to Office of Program Policy Analysis and Government Accountability surveys.

Source: Office of Program Policy Analysis and Government Accountability. (2005, July). *Disabilities groups should improve coordination, but duplication of activities appears to be low* [OPPAGA Report No. 05-39]. Tallahassee: The Florida Legislature. Retrieved from

Persons with Disabilities



with that organization.

- Agreement Between the Medicaid Office and the Department of Education
- Memorandum of Agreement Between the State Health Office and the Medicaid Program Office regarding the Healthy Start Initiative
- Cooperative Agreement Between the agency for persons with Disabilities and the Agency for Health Care Administration
- Cooperative agreement between the Agency for Persons with Disabilities and the Department of Children and Families
- Cooperative Agreement between the Division of Vocational Rehabilitation and the Department of Education
- Cooperative Agreement between the Division of Vocational Rehabilitation and the Agency for Persons with Disabilities
- Cooperative Agreement between the Division of Vocational Rehabilitation and the Division of Blind Services
- Cooperative Agreement between the Division of Vocational Rehabilitation and the Department of Children and Families Mental Health Program
- Cooperative Agreement between the Division of Vocational Rehabilitation and the Florida School for the Deaf and Blind
- Cooperative Agreement between the Division of Vocational Rehabilitation and the Department of Juvenile Justice
- Cooperative Agreement between the Division of Vocational Rehabilitation and the Florida Alliance for Assistive Services and Technology, Inc.

APPENDIX G:

COMPREHENSIVE NATIONAL RESOURCES

Note: the following resources each provide information on a wide variety of topics related to community inclusion. Many other resources that pertain to specific topics are listed throughout the report under the topical area.

Center for Self-Determination (http://www.self-determination.com). The Center "is a working collaborative of individuals and organizations committed to the principles of self-determination." The website includes numerous general resources related to self-determination, as well as state specific resources and information.

Centers for Medicare & Medicaid Services, Promising Practices (http://www.cms.hhs.gov/promisingpractices). The Centers for Medicare and Medicaid Services "has sponsored the development of a series of promising practices reports on home and community-based services to assist states, in partnership with their disability and aging communities, to strengthen their community long term support systems." This site contains case study reports on a wide variety of issues, such as systems reform, caregiver support, moving from institutions, quality, self-directed services, workforce and employment, and others.

Center on Human Policy (http://thechp.syr.edu/). The Center on Human Policy at Syracuse University has an extensive website that contains dozens of downloadable papers, as well as issue statements, descriptions of projects and activities, and other information for professionals, parents, people with disabilities, and advocates.

Clearinghouse for the Community Living Exchange Collaborative (http://www.hcbs.org). The Community Living Exchange Collaborative is a joint effort of ILRU (Independent Living Research Utilization), a program of The Institute for Rehabilitation and Research (TIRR), and Rutgers Center for State Health Policy (CSHP). The Exchange is funded by the Centers for Medicare and Medicaid Services (CMS). The Clearinghouse, which is one aspect of the Community Living Exchange Collaborative, provides in-depth information on topics that are of particular interest to Real Choice Systems Change grantees and others. Information is provided on the themes of: Aging and Disability Resource Centers, Direct Service Workforce, Housing Coordinated with Services, and Quality Assurance and Improvement.

Coleman Institute for Cognitive Disabilities (http://www.colemaninstitute.org). The Coleman Institute's mission is "to catalyze and integrate advances in science, engineering and technology to promote the quality of life and independent living of people with cognitive disabilities." The Coleman Institute is located at the University of Colorado, and produces The State of the States in Developmental Disabilities.

Human Services Research Institute (http://www.hsri.org). HSRI "established in 1976 with the express purpose of assisting states and the federal government to enhance services and supports to people with mental illness and people with mental retardation,

and to support the development of alternatives to congregate care facilities." The HSRI website contains reports, evaluations, and other materials related to a broad range of topics including family support, self-advocacy, quality assurance, employment and workforce, deinstitutionalization, and others.

The Institute for Community Inclusion (ICI) (http://www.communityinclusion.org/) The Institute for Community Inclusion, located at the University of Massachusetts Boston, "supports the rights of children and adults with disabilities to participate in all aspects of the community. As practitioners, researchers, and teachers, we form partnerships with individuals, families, and communities. Together we advocate for personal choice, self-determination, and social and economic justice." Their website includes materials on health, employment, recreation, education, transition, and many other areas.

Institute on Community Integration (http://ici.umn.edu/). The Institute on Community Integration at the University of Minnesota is a rich source of information on community integration. Its mission is to improve the community services and social supports available to individuals with developmental and other disabilities, and their families throughout the United States and abroad. They fulfill this mission through research, professional training, technical assistance, and publishing activities.

Institute on Disability (http://www.iod.unh.edu/). The Institute on Disability/UCED (IOD) at the University of New Hampshire was established in 1987 to provide a coherent university-based focus for the improvement of knowledge, policies, and practices related to the lives of persons with disabilities and their families. The IOD envisions a future where all persons, including those living with disabilities, are fully engaged members of communities, a future where culturally appropriate supports are available across the life span to individuals and families that lead to independence, productivity, and a satisfying quality of life. To that end, they advance policies and systems changes, promising practices, education, and research that strengthen communities and ensure full access, equal opportunities, and participation for all persons.

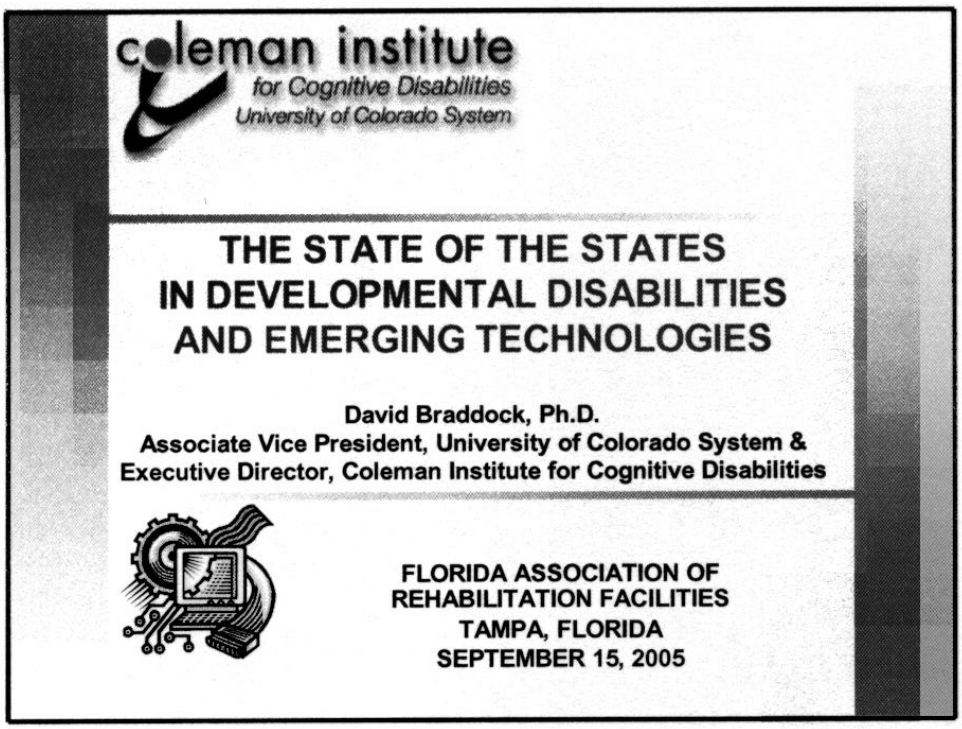
National Association of Directors of Developmental Disability Services (NASDDDS) (http://www.nasddds.org). The goal of NASDDDS is "to promote and assist state agencies in developing effective, efficient service delivery systems that furnish high-quality supports to people with developmental disabilities." To do this, NASDDDS strives to provide the public and member state agencies with timely analyses of federal statutory and regulatory policies that affect people with disabilities; disseminate cutting edge information on state-of-the-art programs and service delivery practices; provide technical assistance and support; and offer a forum for the development of state and national policy initiatives.

National Conference of State Legislatures (NCSL) Report on Long Term Care (http://www.ncsl.org/programs/health/forum/ltc/LTC_draft.htm***)***. This NCSL report examines specific measures taken by each state in their efforts to reform long-term care.

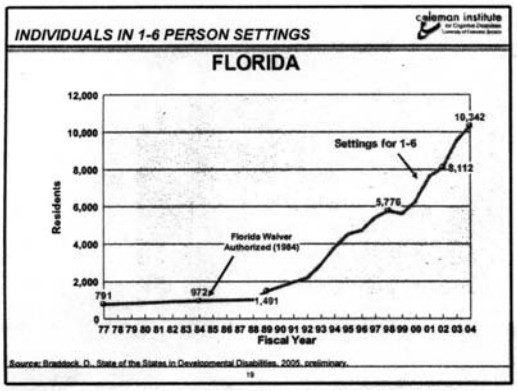
Quality Mall (http://www.qualitymall.org). Quality Mall is a web-based "mall" where one can find lots of free information about person-centered supports for people with developmental disabilities. Each of the mall "stores" has departments that offer information about positive practices that help people with developmental disabilities live, work and participate in their communities and improve the quality of their supports.

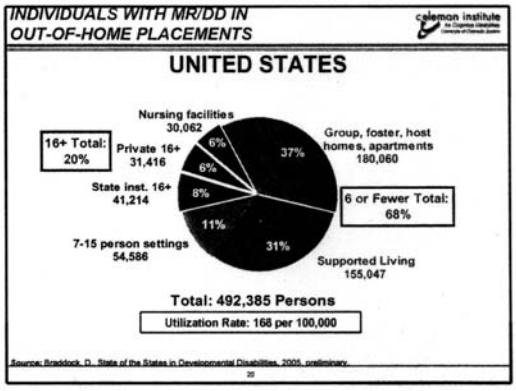
APPENDIX H

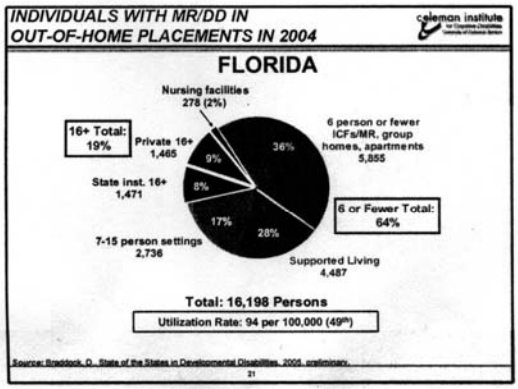
Relevant Sections of a PowerPoint Presentation
Given by David Braddock, Ph.D.
Associate Vice President, University of Colorado System &
Executive Director, Coleman Institute for Cognitive Disabilities
To Florida Association of Rehabilitation Facilities, Tampa, Florida, September 15, 2005

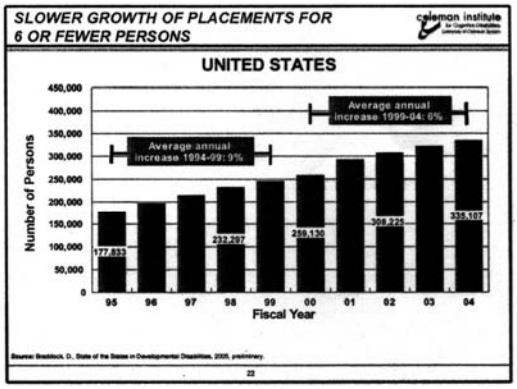


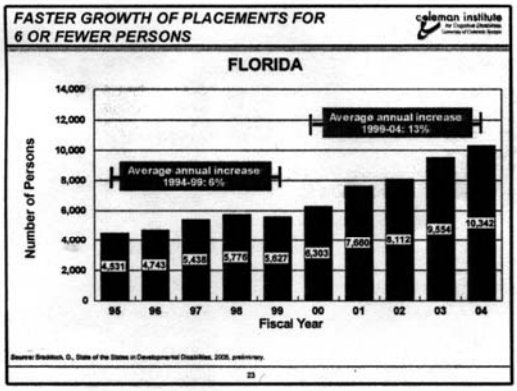
The project team wishes to express its gratitude to David Braddock and the Coleman Institute for permission to reproduce these slides.

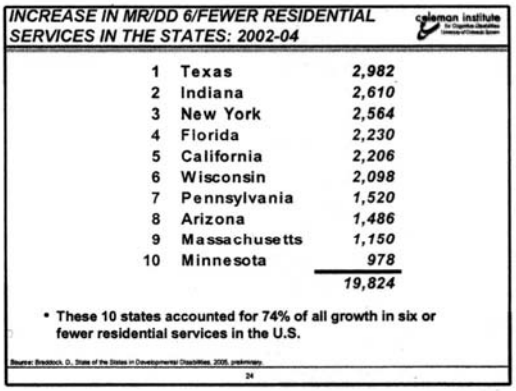

INDIVIDUALS IN 1-6 PERSON SETTINGS
FLORIDA
Residents
Fiscal Year
Settings for 1-6
Florida Waiver Authorized (1984)
791
972
1,491
5,776
8,112
10,342
Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.
19


INDIVIDUALS WITH MR/DD IN OUT-OF-HOME PLACEMENTS
UNITED STATES
16+ Total: 20%
Nursing facilities 30,062
6%
Private 16+ 31,416
6%
State inst. 16+ 41,214
8%
7-15 person settings 54,586
11%
Supported Living 155,047
31%
Group, foster, host homes, apartments 180,060
37%
6 or Fewer Total: 68%
Total: 492,385 Persons
Utilization Rate: 168 per 100,000
Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.
20

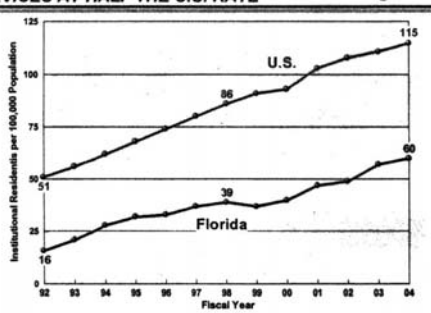

INDIVIDUALS WITH MR/DD IN OUT-OF-HOME PLACEMENTS IN 2004
FLORIDA
Nursing facilities 278 (2%)
16+ Total: 19%
Private 16+ 1,465
9%
State inst. 16+ 1,471
8%
7-15 person settings 2,736
17%
Supported Living 4,487
28%
6 person or fewer ICFs/MR, group homes, apartments 5,855
36%
6 or Fewer Total: 64%
Total: 16,198 Persons
Utilization Rate: 94 per 100,000 (49th)
Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.
21


SLOWER GROWTH OF PLACEMENTS FOR 6 OR FEWER PERSONS
UNITED STATES
Number of Persons
Fiscal Year
Average annual increase 1994-99: 9%
Average annual increase 1999-04: 6%
177,833
232,297
259,150
309,225
335,107
22


FASTER GROWTH OF PLACEMENTS FOR 6 OR FEWER PERSONS
FLORIDA
Number of Persons
Fiscal Year
Average annual increase 1994-99: 6%
Average annual increase 1999-04: 13%
4,531
4,743
5,438
5,776
5,627
6,503
7,600
8,112
9,554
10,342
23


INCREASE IN MR/DD 6/FEWER RESIDENTIAL SERVICES IN THE STATES: 2002-04
1 Texas 2,982
2 Indiana 2,610
3 New York 2,564
4 Florida 2,230
5 California 2,206
6 Wisconsin 2,098
7 Pennsylvania 1,520
8 Arizona 1,486
9 Massachusetts 1,150
10 Minnesota 978
19,824
• These 10 states accounted for 74% of all growth in six or fewer residential services in the U.S.
24

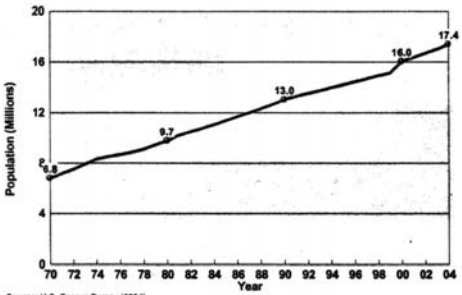
FLORIDA USES 6/FEWER RESIDENTIAL SERVICES AT HALF THE U.S. RATE



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

25

FLORIDA'S POPULATION GROWTH WAS 34% DURING 1990-2004: TWICE THAT OF THE U.S.



Source: U.S. Census Bureau (2004).

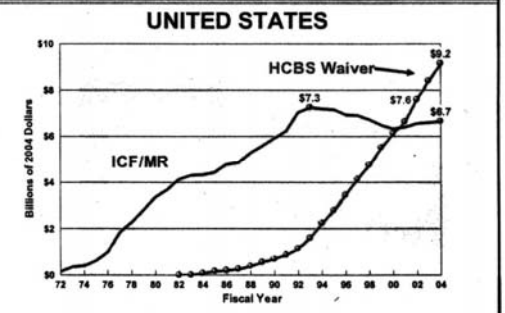
26

PUBLIC SPENDING FOR MR/DD LONG-TERM CARE

IMPORTANCE OF THE HOME AND COMMUNITY BASED SERVICES (HCBS) WAIVER

27

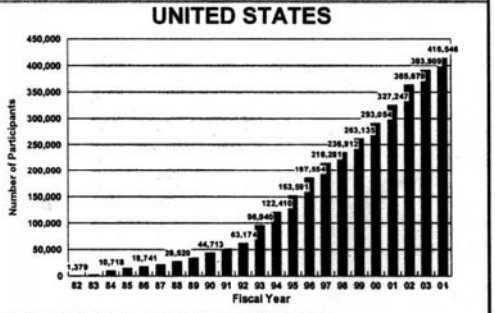
FEDERAL HCBS WAIVER SPENDING SURPASSED ICF/MR SPENDING IN 2001



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

28

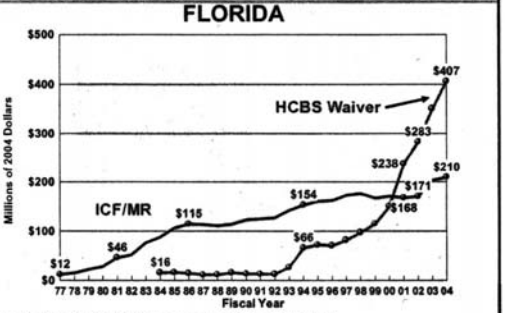
HCBS WAIVER PARTICIPANT GROWTH: 1982-2004



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

29

FLORIDA FEDERAL WAIVER SPENDING ALSO SURPASSED ICF/MR SPENDING IN 2001



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

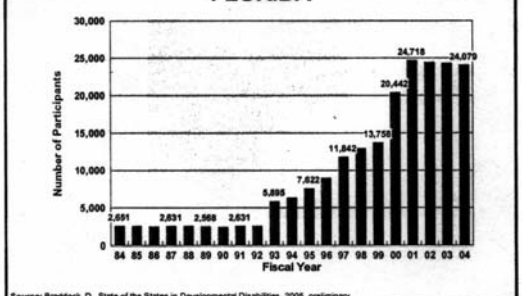
30

ODE TO RUDYARD KIPLING'S "IF"

- "If"....Florida's Waiver spending equaled the average state's on a per capita/general population basis, an additional $208 Million in state-federal MR/DD funds would have been available in FY 2004.
- A 31% increase over actual ($667 M).

31

HCBS WAIVER PARTICIPANT GROWTH: 1984-2004



Source: Braddock, D. State of the States in Developmental Disabilities, 2005, preliminary.

32

FEDERAL-STATE HCBS SPENDING PER CAPITA IN 2004*

1	Rhode Island	$203	18 West Virginia	$67	35 Florida	$39
2	Minnesota	$161	19 Arizona	$63	36 Idaho	$38
3	Maine	$143	20 Delaware	$62	37 Alabama	$38
4	Wyoming	$141	21 Maryland	$62	38 Ohio	$37
5	New York	$140	22 Oregon	$61	39 South Carolina	$36
6	Vermont	$137	23 Indiana	$61	40 Georgia	$36
7	Connecticut	$113	24 Oklahoma	$61	41 Virginia	$33
8	New Mexico	$111	25 Louisiana	$61	42 California	$33
9	New Hampshire	$97	26 Montana	$60	43 North Carolina	$31
10	Alaska	$94	27 Iowa	$58	44 Kentucky	$30
11	South Dakota	$89	28 Colorado	$55	45 Michigan	$29
12	Pennsylvania	$87	29 Hawaii	$52	46 Illinois	$24
13	Massachusetts	$85	30 Tennessee	$50	47 Arkansas	$22
14	North Dakota	$84	31 Washington	$47	48 Nevada	$15
15	Kansas	$76	32 Utah	$44	49 Texas	$14
16	Nebraska	$75	33 New Jersey	$42	50 Mississippi	$11
17	Wisconsin	$73	34 Missouri	$41	51 Dist. of Columb.	$9

*Per capita of the general population

UNITED STATES $54

Source: Braddock, D. State of the States in Developmental Disabilities, 2005, preliminary.

33

FLORIDA HCBS WAIVER SERVICES

- Specialized mental health services
- Dietician, medication review
- Case management
- Foster care
- Specialized medical equipment, supplies
- Personal care, companion services, homemaker
- Habilitation (residential, day), adult day training
- Supported employment
- Transportation
- Respiratory therapy
- Adult dental services

34

FLORIDA HCBS WAIVER SERVICES (Continued)

- <u>Supported living Waiver (utilizes "coaches")</u>
- Skilled, residential and private duty nursing
- Psychological and therapeutic massage assessment
- Respite care
- In-home support & chore services
- Environmental accessibility
- PT, OT, & Speech, Hearing, and Language Services
- Behavior training, and
- Personal Emergency Response System (PERS)

35

FLORIDA "CASH AND COUNSELING" AND "INDEPENDENCE PLUS" WAIVERS

In addition to the Supported Living Waiver, other Waiver initiatives in Florida:

CASH AND COUNSELING (1998)

- Consumers self-direct their services and quality assurance
- Consumers can hire family members, friends
- Developed as a Medicaid Section 1115 "Research and Demonstration" Waiver
- A joint initiative of the Robert Wood Johnson Foundation and the Department of Health and Human Services (DHHS)
- Florida, AR and NJ first 3 states to implement

36

FLORIDA "CASH AND COUNSELING" AND "INDEPENDENCE PLUS" WAIVERS (Cont'd)

FLORIDA'S *INDEPENDENCE PLUS WAIVER*: "CONSUMER DIRECTED CARE PLUS"

- Statewide for children, in selected counties for adults
- Florida received December 2003 DHHS approval to convert Cash & Counseling Waiver to "Independence Plus"
- The R&D Waiver experimental design is no longer required and Waiver was extended through February 2008
- Consumer Directed Care Plus serves 5,000 Aged/Disabled and approximately 1,000 adults and children with DD

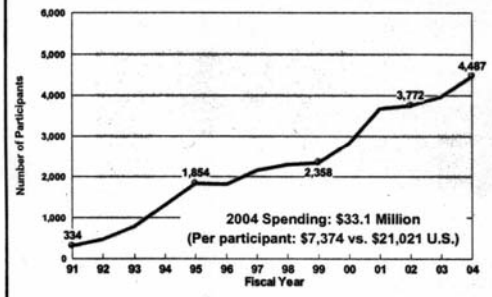
37

TRENDS IN COMMUNITY SUPPORTS

- Supported Living
- Family Support
- Supported Employment

38

NUMBER OF FLORIDA SUPPORTED LIVING PARTICIPANTS HAS GROWN STEADILY: 1991-2004



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

39

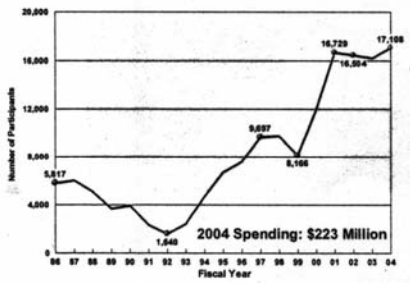
PRINCIPLES OF SUPPORTED LIVING/ PERSONAL ASSISTANCE

1. CHOICE
   - Where to live, with whom and which lifestyle
2. OWNERSHIP BY OTHER THAN THE SERVICE PROVIDER
   - Individual owns or rents;
   - Family owns or holds lease;
   - Housing cooperative owns
3. INDIVIDUAL SUPPORT
   - Focus on individual's changing needs over time;
   - Individualized support plan or support contract

Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

40

FAMILIES SUPPORTED IN FLORIDA PLATEAUS



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

41

FAMILY SUPPORT DEFINED

Family Support Includes

- Respite
- Family counseling
- Architectural adaptation of the home
- In-home training, education, behavior management
- Sibling support programs, and
- Purchase of specialized equipment

"Cash subsidy family support" includes

Payments or vouchers directly to families; families determine what is purchased

Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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CASH SUBSIDY FAMILY SUPPORT STATES, 2004

	State	Susbsidy Per Family
1	Illinois	$11,739
2	North Dakota	$6,300
3	South Carolina	$4,596
4	Iowa	$4,239
5	Florida	$3,886
6	Nevada	$3,661
7	Rhode Island	$3,497
8	Arizona	$3,373
9	Alaska	$3,000
10	Louisiana	$2,738
11	New Mexico	$2,600
12	Michigan	$2,585
13	Minnesota	$2,480
14	Oklahoma	$2,418
15	Delaware	$2,379
16	Kansas	$2,291
17	Washington	$2,143
18	Texas	$1,870
19	New Jersey	$1,405
20	Connecticut	$1,028
21	Arkansas	$773
22	Utah	$567
	U.S.	$2,853

	State	# Families
1	New Jersey	6,485
2	Michigan	6,307
3	Connecticut	3,188
4	Texas	2,674
5	Illinois	2,360
6	Washington	2,101
7	Louisiana	1,793
8	Oklahoma	1,735
9	Minnesota	1,653
10	Kansas	1,422
11	Alaska	1,003
12	South Carolina	735
13	Arizona	442
14	Nevada	386
15	Iowa	378
16	Florida	137
17	Arkansas	120
18	Utah	117
19	North Dakota	94
20	New Mexico	80
21	Delaware	74
22	Rhode Island	50
	U.S.	33,334

Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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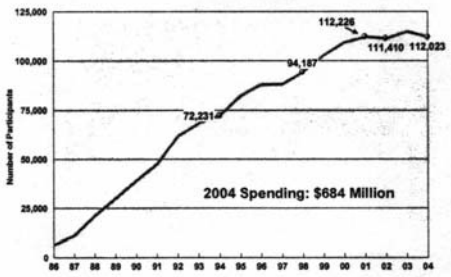
SUPPORTED EMPLOYMENT WORKERS IN THE U.S.: 1986-2004



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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SUPPORTED EMPLOYMENT LOSES MOMENTUM

- "While supported employment has made significant gains since its formal introduction in 1984 (P.L. 98-527), segregated services continue to outpace the growth of supported employment."

(Rusch & Braddock, *Research and Practice for Persons with Severe Disabilities*, 2004)

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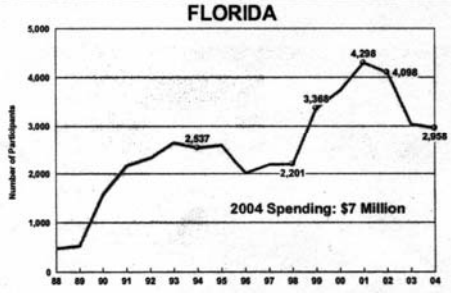
SUPPORTED EMPLOYMENT LOSES MOMENTUM



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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SUPPORTED EMPLOYMENT: LEADING STATES

In 2004, the percentage of day/work clients in MR/DD agency Supported Employment exceeded 40% in:

Oklahoma	71%
Washington	55%
Connecticut	51%
New Hampshire	49%
Indiana	48%
Louisiana	44%
Massachusetts	43%
Vermont	43%
Alaska	41%

FLORIDA:	21%
U.S.:	24%
FLORIDA RANK:	32nd

Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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SUMMARY: MEASURING FLORIDA'S GROWING COMMITMENT TO DD SERVICES

Fiscal effort is a ratio that can be utilized to rank states according to the proportion of their total statewide personal income devoted to the financing of MR/DD services.

Fiscal effort is defined as a state's spending for MR/DD services per $1,000 of total statewide personal income.

Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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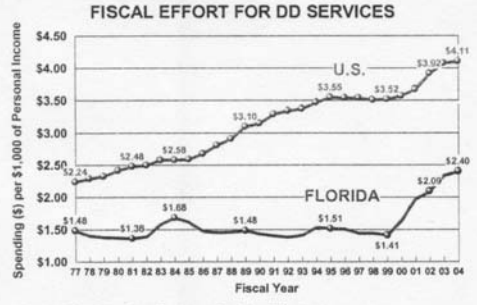
FLORIDA IS CLOSING THE GAP: 1999-2004



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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FLORIDA CLOSES THE GAP: 1999-2004

- Florida led the nation in community fiscal effort increase 1999-2004: 117% vs. U.S. 28%.
- Florida's overall MR/DD fiscal effort (community & institutional spending) increased 70% for 1999-2004. The U.S.: 17%.
- Florida was second nationally in % increase in fiscal effort over the past 5 years.

Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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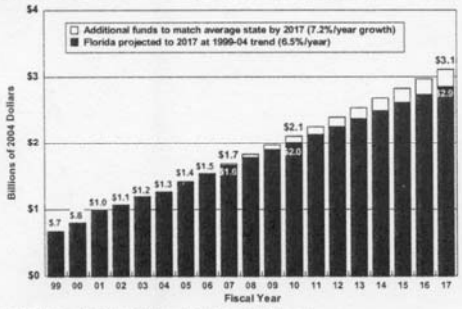
CONTINUING TO CLOSE THE GAP OVER THE NEXT DECADE



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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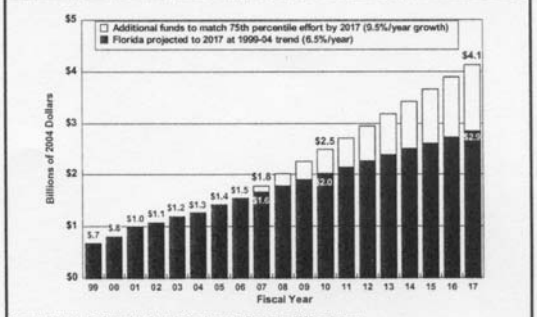
ALTERNATE PROJECTION



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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III. FACTORS INFLUENCING DEMAND FOR MR/DD SERVICES IN FLORIDA AND THE U.S.

1. Fiscal conditions in the States
2. Aging caregivers
3. Increased longevity of people with MR/DD
4. Litigation/waiting lists
5. Workforce poverty

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1. FISCAL CONDITIONS IN THE STATES IN FY 2006

- Health care/Medicaid costs keep rising
- Medicaid matching enhancements ended 6/30/04
- Overall State General Fund spending dropped -1.4%, -2.5% and -0.3% during 2002-04
- 2006 state GF spending to increase +0.5% (vs. the 2% average increase 1979-2005)

Sources: NCSL (2004, April; 2003, April); National Association of State Budget Officers (2005, June).

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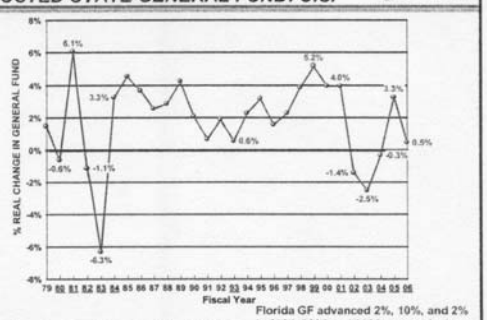
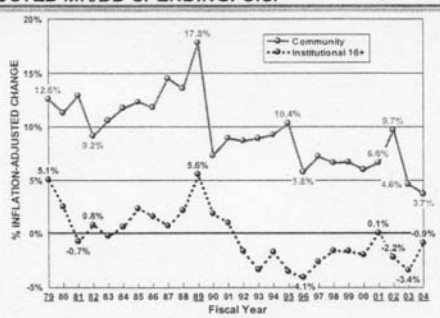
ANNUAL % CHANGE IN INFLATION-ADJUSTED STATE GENERAL FUND: U.S.



Florida GF advanced 2%, 10%, and 2% in 2004, 2005 and 2006, respectively

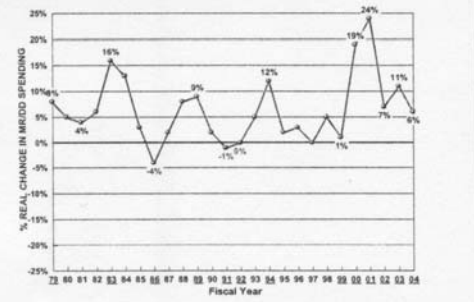
Source: National Association of State Budget Officers (2004, April).

ANNUAL % CHANGE IN INFLATION-ADJUSTED MR/DD SPENDING: U.S.



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

ANNUAL % CHANGE IN INFLATION-ADJUSTED MR/DD SPENDING: FLORIDA



Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

NUMBER OF STATES WITH INFLATION-ADJUSTED CUTS IN MR/DD SPENDING

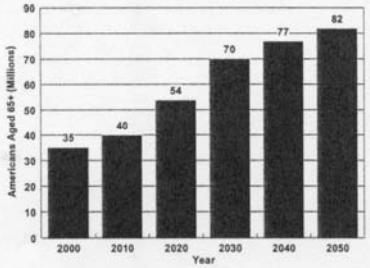
1979 – 6	1990 – 4	2001 – 10
1980 – 18	1991 – 6*	2002 – 5
1981 – 15	1992 – 10*	2003 – 12
1982 – 14	1993 – 16	2004 – 13
1983 – 17	1994 – 8	
1984 – 10	1995 – 5	
1985 – 5	1996 – 11	
1986 – 5*	1997 – 11	
1987 – 7	1998 – 3	
1988 – 6	1999 – 9	
1989 – 5	2000 – 5	

*Florida had cuts in:
1986 (-4%)
1991 (-1%)
1992 (-0.2%)

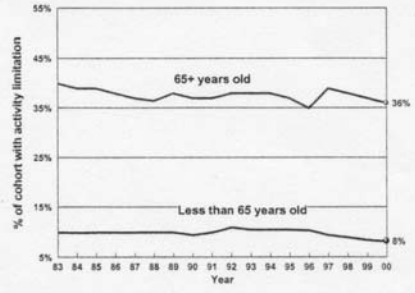
Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

2. THE IMPACT OF AN AGING POPULATION: U.S.

AGED 65+ YEARS: 2000-2050

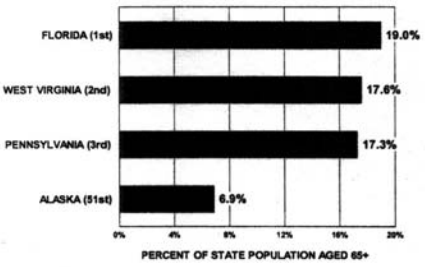


DISABILITY INCREASES WITH AGE



Sources: National Health Interview Survey; Fujiura, 2002.

STATES WITH GREATEST, LEAST PROPORTION OF RESIDENTS AGED 65+ YEARS, 2004



Source: U.S. Bureau of the Census, 2004

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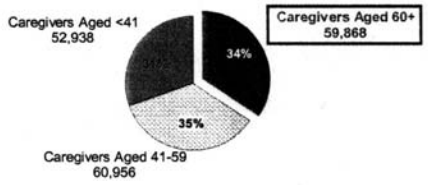
AN ESTIMATED 34% OF PERSONS WITH DD IN FLORIDA WHO LIVE AT HOME LIVE WITH AGING CAREGIVERS



Total Family Caregivers in 2004: 173,762

Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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3. LONGEVITY IS INCREASING FOR PERSONS WITH MENTAL RETARDATION

- 1970s: 59.1 years
- 1993: 66.2 years
- U.S. General Population: 70.4 years
- In the future "...those without severe impairment can be expected to have a life span equal to that of the general population."

Source: M. Janicki, (1996). Rehabilitation Research and Training Center on Aging and Mental Retardation, University of Illinois at Chicago.

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4. ROLE OF LITIGATION: STATES WITH ACTIVE/SETTLED CLASS ACTION CASES 2002-2005

Waiting List 22 Cases		*Olmstead* 9 Cases	Medicaid Access 15 Cases
ALABAMA	NEBRASKA	CALIFORNIA (2)	ARIZONA
ALASKA	NEW HAMPSHIRE	DELAWARE	ARKANSAS (2)
ARKANSAS	NEW MEXICO	FLORIDA	CALIFORNIA
COLORADO	OHIO	HAWAII	CONNECTICUT
CONNECTICUT	OREGON	MASSACHUSETTS	ILLINOIS
FLORIDA	PENNSYLVANIA	MONTANA	KANSAS
HAWAII	TENNESSEE (2)	PENNSYLVANIA (2)	MINNESOTA (2)
ILLINOIS	TEXAS		MONTANA
KENTUCKY	UTAH		OHIO
MAINE	WASHINGTON (2)		OKLAHOMA
			PENNSYLVANIA
			TENNESSEE
			TEXAS

Source: Braddock, D., State of the States in Developmental Disabilities, 2005, preliminary.

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NINTH CIRCUIT'S AUGUST 2, 2005, RULING AGAINST PLAINTIFFS IN SANCHEZ

Sanchez v. Johnson: California's low staff wages, high turnover violate Medicaid law that "payments for care and services...are consistent with efficiency, economy, and quality of care."

[42 U.S.C. Section 1396a(a)(30)(A), or "Section 30(A)"]

Ninth Circuit Ruling: Congress did not unambiguously create an individually enforceable right in Section 30(A)...for either recipients or providers of Medicaid services.

Furthermore, Sanchez's and the Providers' requested relief under Title II of the ADA and Section 504 of the Rehab Act would require the 'fundamental alteration' of a comprehensive, working plan for deinstitutionalization in contravention of *Olmstead*.

[United States Court of Appeals for the Ninth Circuit (D.C. No. CV-00-01593-CW), August 2, 2005]

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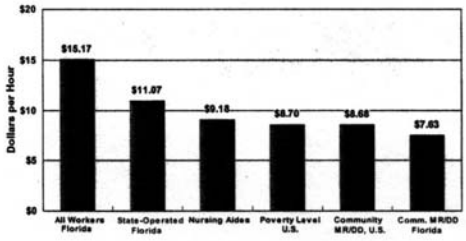
5. FLORIDA DIRECT SUPPORT STAFF AVERAGE WAGES HAVE BEEN BELOW THE POVERTY LEVEL



Sources: "All workers in Florida" for 2001 (Bureau of Labor Statistics, 2003); "state-operated and community MR/DD" for U.S. and Florida for 2002 (Lakin, Polister, & Prouty, 2003); "nursing aides" for 2001 (BDO Seidman, 2002); and "poverty level" for 2002 (ASPE, 2002).

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OLMSTEAD IMPLEMENTATION?

HOW MANY MORE MILES
TILL WE GET THERE?

Source: Braddock, D., National Study of Disability Finance, 2005, preliminary.

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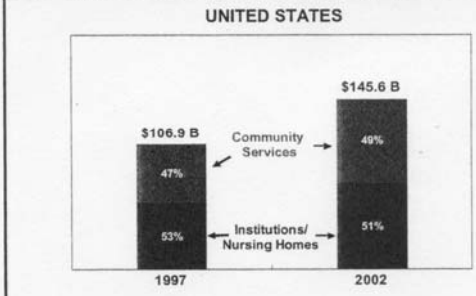
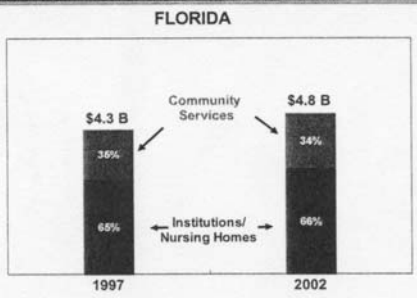
% OF DISABILITY LONG TERM CARE RESOURCES CONCENTRATED IN INSTITUTIONS & NURSING HOMES



Source: Braddock, D., National Study of Disability Finance, 2005, preliminary.

68

% OF DISABILITY LONG TERM CARE RESOURCES CONCENTRATED IN INSTITUTIONS & NURSING HOMES



Source: Braddock, D., National Study of Disability Finance, 2005, preliminary.

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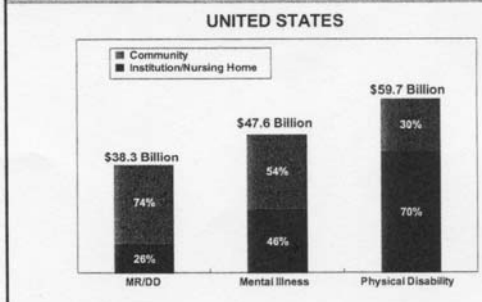
% CONCENTRATION OF LONG TERM CARE RESOURCES BY DISABILITY GROUP, 2002



Source: Braddock, D., National Study of Disability Finance, 2005, preliminary.

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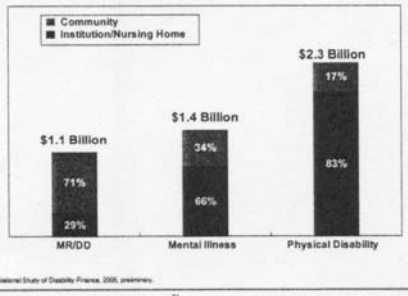
% CONCENTRATION OF LONG TERM CARE RESOURCES BY DISABILITY GROUP, 2002



Source: Braddock, D., National Study of Disability Finance, 2005, preliminary.

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IV. EMERGING TECHNOLOGIES AND DEVELOPMENTAL DISABILITIES

1. *The Coleman Institute*
2. *Engineering advances of the 20th Century*
3. *Personal support technologies*
4. *Smart homes/care*
5. *Neurotechnology*

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APPENDIX I: DATA SUMMARY SECTION

FLORIDA'S RESIDENTIAL SERVICE SYSTEM: 2004

- Served a total of 16,198 people with developmental disabilities in 2004.
- 19.8% or 3,210 people were served in public or private institutional settings:
  - 1,399 in state institutions
  - 1,465 in private residential facilities
  - 278 in nursing homes
- 63% or 10,432 people were served in settings for six or fewer people.

FLORIDA'S DEVELOPMENTAL DISABILITY SYSTEM SERVICES PROVIDED AS OF 2004

- 14,348 people with developmental disabilities were served in non-vocational day programs or work programs
- 2,958 persons benefited from supported employment programs
- 3,833 persons were in supported living situations
- 654 persons received personal assistance services
- 17,108 Florida families received family support services

SPENDING FOR DEVELOPMENTAL DISABILITY SERVICES IN FLORIDA

- Totaled $1,269,300,000 million in 2004, with a significant portion of services is funded through the federal-state Medicaid program.
- 96% of funds spent for services are matched by federal dollars.
- Federal Medicaid revenues were $628.9 million in 2004
  - $406.6 million for the Home and Community-Based Services (DD and FSL) Waivers
  - $210.1 million for public and private Intermediate Care Facilities for the Mentally Retarded (ICFs/MR)
  - $12.2 million for consumer directed care
  - $22,000 for the supported living waiver

RECENT TRENDS IN FLORIDA DATA

Positive Trends

- Spending for developmental disability services (adjusted for inflation) increased significantly between 2002 and 2004, approximately 17.9%.
- DD and FSL Waiver spending per recipient increased significantly between 2002 and 2004, from $20,500 to $27,713 or an increase of over 35%.
- The number of persons with developmental disabilities served in community settings for six or fewer people continues to steadily increase, from 9,554 people in 2003 to 10,342 people in 2004 or approximately 8.2%. Since 1999, the number has almost doubled, from 5,627.

- The number of persons served in supported living increased significantly from 3,464 in 2003 to 3,833 in 2004, an increase of almost 10.7%. Funding for supported living similarly increased from $22.6 million to $27.5 million, or approximately 21.5%.
- The number of persons receiving personal assistance services, while still small, increased from 525 in 2003 to 654 in 2004, or roughly 24.6%. Funding increased from $4.4 million to $5.6 million, an increase of 26.9%.
- The number of families receiving family support services increased from 16,248 in 2003 to 17,108 in 2004, or approximately 5.3%. Spending for family support services increased from $191 million to $222.1 million, or approximately 16.2%.

Negative Trends

- The number of people living in public and private institutions has remained relatively constant over the past five years. From 1999 to 2004, the populations of public and private institutions only declined from 3,295 to 3,210 the populations of state institutions only declined from 1,512 to 1,377. From 2003 to 2004, there was a negligible change in institutional populations; 46 fewer people lived in state institutions and 53 fewer people lived in both public and private institutions. However, Florida closed the Landmark facility in June 2005
- The number of people with developmental disabilities in supported employment has declined precipitously in recent years. This number reached a peak of 4,298 people in 2001. By 2004, this number had declined to 2,958, down from 3,040 in 2003.
- Spending on supported employment parallels trends in the number of people in supported employment. In 2001, approximately $11.1 million was spent on supported employment in Florida. By 2004, this number had dropped to slightly under $7 million, down $729,625 from 2003.
- Although DD and FSL waiver spending per recipient increased from 2002 to 2004, the number of waiver recipients declined from 24,443 to 24,079 during this time, a decrease of 364 persons.
- Per diem (per person per day) spending for state institutions increased from $252 in 2002 to $308 in 2004. This translates into an annual per person cost of $112,728 in 2004.
- The proportion of youth (0-21 years of age) among the state institution population jumped from 1% in 2002 to 7.7% in 2004.

STATE INSTITUTIONS: POPULATIONS AND TRENDS IN FLORIDA IN 2004

- Florida had 7.9 persons with developmental disabilities in large state facilities, or institutions, per 100,000 of its almost 17.4 million population.
- This compares with a national average of 14.3 per 100,000 population.

Decline in Populations of Florida's Institutions

1995-04	2000-04
8.2%	8.6%

- These percentages indicate that there was a negligible decline in the years 1995-2000.
- Florida admitted 139 persons with developmental disabilities to its institutions in 2004; 158 persons were discharged and 21 residents died.

Decline in Populations of Institutions Nationally
(States Operating State Institutions)

1995-04	2000-04
33.9%	12%

Decline in Populations of Institutions
Other Large States

	1995-04	2000-04
Texas	8.7%	8.2%
Michigan	66.1%	50.9%
New York	50.5%	8.6%
Ohio		8.2%

FLORIDA'S INSTITUTIONAL POPULATION: CHILDREN AND YOUTH

- Included a significantly higher percentage of children and youth (0-21) and persons with mild intellectual disabilities than the national average.
- In 2004, 7.7% of the residents of Florida institutions were 15-21 years of age (no children younger than 15 were reported).
- This compares with a national average of 4.3%.
- Among large states, only Michigan (7.8%) and New York (12.8%) had higher percentages of children and youth.

FLORIDA'S INSTITUTIONAL POPULATION: MILD INTELLECTUAL DISABILITIES

- Persons with mild intellectual disabilities accounted for 36.8% of the population of Florida's institutions, compared with the national average of 10.2%.
- Of the other seven large states, Michigan (45.8%) and New York (45.5%) had higher percentages of people with mild intellectual disabilities.

FLORIDA'S RESIDENTIAL SERVICES: 2004

- Florida had a significantly lower rate of persons with developmental disabilities receiving residential services per 100,000 of the overall state population than the national average.
- In settings of all sizes, Florida provided residential services to 75.4 persons per 100,000.
- This compares with a national average of 143.1 persons per 100,000 of the general population.

FLORIDA'S RESIDENTIAL SERVICES: COMPARISON TO OTHER LARGE STATES

- Each of the other large states served a higher number of persons.
- Texas had the closest rate, at 93.1.
- The other states had rates ranging from 127.9 (Ohio) to 235.1 (New York) per 100,000 of the general population.
- In settings housing 1-6 persons, Florida provided residential services to 48.5 persons per 100,000 of the general population, compared with a national average of 100.5.
- Of the other seven large states, only Ohio (22.7) served a lower number of persons.
- The other states ranged from 59.6 (Texas) to California (358.94).

FLORIDA'S RESIDENTIAL SERVICES: LARGE ICFs/MR

- Florida served 1,805 persons in 49 large (16 or more persons) non-state Intermediate Care Facilities for the Mentally Retarded in 2004.
- This was the fourth largest number of persons in large non-state ICFs/MR in the country, after Illinois (3,429), Ohio (3,076), and Texas (1,864).

FLORIDA'S RESIDENTIAL SERVICES: LIVING AT HOME

- In 2004, 30% of people receiving residential services lived in their own homes (i.e., homes owned or leased by the individual).
- This was higher than the national average of 26% and higher than all but two (California at 32% and Illinois at 31%) of the other large states.

FLORIDA'S RESIDENTIAL SERVICES: WAITING LIST AS OF 2004

- Florida had a waiting list for residential services of 15,278.
- This was the larges waiting list in the nation and almost double the size of any other state (Maryland at 7,666).
- Of 36 states reporting information on waiting lists, only three other states had more persons on waiting lists than the total number of current recipients of residential services.
- For the waiting list in Florida to be eliminated, the current residential service system would need to grow 116.4%. This was the second highest percentage in the nation.

AREA OF EMPHASIS: EDUCATION
Infants through Toddlers (Pre-K) Years

- In FY 2003-04, 36,265 infants and toddlers were enrolled in Early Steps (another 4,289 were served, but not eligible for enrollment).
- Of those who were enrolled:
    - 30,603 were in the IDEA, Part C program
    - 2,474 were in the Developmental Evaluation and Intervention program
    - 3,188 were enrolled in the DEI program and the IDEA, Part C program

THE EARLY STEPS PROGRAM
ENROLLMENT AND AMOUNT OF FUNDING PER CHILD

1994-95	2004-05
20,973 $1,265 per child	42,702 $883 per child

TOTAL STUDENT ENROLLMENT PRE-K THROUGH 12

	2003-2004	2001-2002	Increase
Total Enrollment Pre-K to Grade 12	2,598,231		3.8%
Exceptional Student Enrollment	398,721	376,074	26.6%

OSEP STATE REPORTED DATA ON ENROLLMENT OF STUDENTS WITH A MENTAL RETARDATION DISABILITY

- A total of 39,030 students with a mental retardation disability between the ages of 6 and 21 enrolled in the Florida education system for the 2003 school year.
- 91% of these students attended school in regular public school facilities, with more than half of these students spent in excess of 60% of their school day outside of the regular classroom.
- The remaining 9% of this group of students attended school in separate facilities.

DROP OUT RATE 2003-2004 SCHOOL YEAR

DISABLED STUDENTS	4.7%
NONDISABLED STUDENTS	2.6%

GRADUATION RATE 2003-2004 SCHOOL YEAR

DISABLED STUDENTS	64%
NONDISABLED STUDENTS	72.5%

POSTSECONDARY OUTCOMES AS REPORTED BY THE BLUE RIBBON TASK FORCE

- 55% of the students with a developmental disability exited school without a diploma or certificate of completion.
- 12% of all students with a developmental disability were enrolled in postsecondary education
- 17% were employed following graduation, with quarterly earnings of $3,700

FUNDING AND SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

- A total of 1,550,936 children were enrolled in Florida's KidCare as of June 30, 2004, and 1,479,613 as of June 2005.
- Of these, 7,728 (Title XXI) and 28,000 (Title XIX) were enrolled in CMS Network as of June 2005.
- While an estimated 13%-14% of Florida's children have special health care needs, 28% of children served through the various KidCare programs are identified as CHSCN.
- At the time of the Florida KidCare Evaluation Report 2004, 83% of children served through Children's Medical Services Network had special health care needs.
- Twenty-two percent (22%) of Medicaid HMO enrollees, 13% of MediKids enrollees, and 21% of Healthy Kids enrollees had special health care needs.
- Additionally, 32%-38% of enrollees in MediPass had special health care needs.

MENTAL HEALTH SERVICES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

23% of the families enrolled in CMS Network services said that they had moderate to extreme difficulty in getting mental health treatment for their children

HEALTH CARE FOR CHILDREN: DELAYS IN IDENTIFICATION

EPSDT screenings are provided to only 65%-70% of Florida's eligible children

CONCERNS REGARDING SERVICE COORDINATORS

The average size of Service Coordinators' caseloads: 136

ENROLLMENT IN THE THREE FLORIDA WAIVER PROGRAMS

WAIVER PROGRAM	ENROLLMENT AS OF JUNE 2005
Developmental Disabilities Home and Community Based Services Waiver (DD/HCBS)	23,998
Family and Supported Living Waiver (FSL)	1,197
Consumer Directed Care Plus Waiver (CDC+)	967

DD/HCBS WAIVER WAITING LIST

The waiting list for the DD/HCBS waiver exceeds 15,000 individuals

AGENCY FOR PERSONS WITH DISABILITIES (APD): PERSON'S SERVED

APD serves approximately 32,000 people

INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES WHO WERE LIVING OUTSIDE OF THEIR FAMILY HOME IN FLORIDA

Supported or independent living	30%
Intermediate Care Facilities	26%
Group homes	44%

CHILDREN AND FAMILIES

- During FY 2004-05, 593 children (under age 21) received medical foster care services
- As of August 2005, 361 children (under age 21) were in nursing homes

- In 2002 Florida ranked 9th nationally in the amount of family support spending with an average of $7,386 spent per family.
- 6,358 families are waiting for respite care

INCREASE IN FAMILY SUPPORT SPENDING

1994	2004
$18.3 million	$222.6 million
	Supported 17,108 families with these services: • cash subsidy payment ($532,377, for 137 families) • "other family support" ($222,112,102, for 17,108 families)

GROWTH IN THE SUPPORTED LIVING PROJECT

1995	2004
1,854	4,487

People participating in supported and independent living achieve 70.9% of their personal outcomes which is the highest performance level as compared with other residential settings.

CDC+ WAIVER ENROLLMENT VS. CAPACITY

Enrolled	Capacity
967	2,182

TRANSPORTATION DISADVANTAGED SUMMARY REPORT 2004

- 19,779,563 rides were provided for individuals with disabilities
  - 36% were for medical purposes
  - 19% for education/training/daycare
  - 14% for nutritional
  - 9% for employment
  - 22 % for "life-sustaining/other" trips

TRANSPORTATION DISADVANATED UNMET TRIP REQUESTS

2004	2003	2002
682,037	1,065,528	709,597

PERCENTAGE OF INDIVIDUALS CONSIDERED "TRANSPORTATION DISADVANTAGED" SERVED

2002	2004
9.9%	14.10%

REVENUE AND EXPENSES - 2004 TRANSPORTATION DISADVANTAGED COMMISSION

REVENUE	EXPENSES
$307 million	$303 million

HOUSING FOR INDIVIDUALS WITH EXTREMELY LOW INCOMES – 2003

The greatest unmet need for affordable housing in Florida is for individuals with extremely low incomes (e.g., at 30% and below area median income).

UNITS AVAILABLE	REMAINING NEED
131,210	217,315

In FY 2003,

- Florida received a total of $84.2 million in HOME funding from HUD
- Florida received a total of $190.8 million in CDBG funding
- Florida Public Housing Authorities (PHAs) had a total of 79,861 Section 8 vouchers
- Approximately 2,600 Section 8 voucher set-asides for people with disabilities have been awarded to 19 PHAs and 3 nonprofit disability organizations in Florida since 1997

PERCENTAGE OF SECTION 8 HOUSEHOLDS NONELDERLY AND DISABLED

Nationally	Florida
22%	16.8%

EMPLOYMENT

- Supported employment spending and participation in Florida dropped significantly between 2001 and 2004, even though total spending for day and supported employment programs increased every year.

EMPLOYMENT SPENDING IN FLORIDA

YEAR	AMOUNT SPENT	INDIVIDUALS SUPPORTED
2001	$11,126,140	4,298
2004	$6,691,702	2,958

NUMBER OF PEOPLE IN DAY PROGRAMS (NON-SUPPORTED EMPLOYMENT)

2002	2004
10,954	11,390

ESTIMATED NUMBERS OF INDIVIDUALS PROJECTED TO BE DETERMINED TO BE ELIGIBLE AND SERVED DURING FEDERAL FISCAL YEAR 2005-2006 BASED ON THREE YEARS OF HISTORICAL DATA

TITLE	NUMBER ELIGIBLE	NUMBER SERVED	NUMBER ACHIEVING EMPLOYMENT OUTCOME	TOTAL COST
Title I-General	26,000	19,635	10,000	$94,050,460[2]
Title VIB-Supported Employment		550	233	$1,674,963[3]
Total	**26,000[1]**	**20,185[1]**	**10,2335[1]**	**$96,725,423**

[1]Data used to make projections in this attachment are calculated on a different timeframe (i.e., the federal fiscal year) than the state performance based program budgeting projections. Therefore, these numbers can be expected to differ from projections or estimates calculated on the state fiscal year.

[2]Source: Conference Report on HB 1838-SFY 2004-2005. Page 15, Category 35: Purchased Client Services (General Revenue Fund and Federal Rehabilitation Trust Fund). DVR/FRC began the planning process earlier; consequently, the 2005-06 Legislative Appropriations were not available during the state plan development. Cost projections are estimated at the same level as last year.

[3]This amount represents the cumulative amount ($1,626,178) from the grant award notification received January 05, 2005 (plus a 3% increase).

THE ABLE TRUST (FLORIDA GOVERNOR'S ALLIANCE FOR THE EMPLOYMENT OF CITIZENS WITH DISABILITIES)
GRANT-AWARDING ACTIVITY

FISCAL YEAR	NUMBER SERVED	NUMBER EMPLOYED
2003	2,191	693
2004	2,015	297
Total	5,206	980