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**Rhode Island Developmental Disabilities Council  
Five Year State Plan**

**Fiscal Years 2007 – 2011**

**Prepared and Submitted by**

**The Rhode Island Developmental Disabilities Council**

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## The Rhode Island Developmental Disabilities Council Five Year Plan 2007-2011

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## Introduction

### **Purpose & Role of Rhode Island Developmental Disabilities Council**

The Rhode Island Developmental Disabilities Council (RIDDC) promotes the implementation of an individual and family-centered, comprehensive system of a wide array of options for services and supports that will assist persons with developmental disabilities to achieve self-determination, and maximize independence, productivity, integration, inclusion and quality of life. RIDDC achieves its goals through advocacy efforts directed at systems change, capacity building, and public education. RIDDC aims to bring together representatives from state government, provider agencies, local school districts, persons with disabilities, and family members focusing on policy change and development to improve quality of life. Through its state plan process, RIDDC reviews services and supports throughout the state, identifies barriers and needs for new or additional supports, and develops a state plan with long range goals and objectives to address those barriers and needs. RIDDC does not provide any direct services to individuals with developmental disabilities.

### **Federal Definition of Developmental Disability**

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402) defines a developmental disability as: "a severe, chronic disability of an individual that :

- Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- Is manifested before the individual attains age 22;
- Is likely to continue indefinitely;
- Results in substantial functional limitations in 3 or more of the following areas of major life activity:
  - *Self-care.*
  - *Receptive and expressive language.*
  - *Learning.*
  - *Mobility.*
  - *Self-direction.*
  - *Capacity for independent living.*
  - *Economic self-sufficiency; and*
- Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

Or, an individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (a) through (e) above if the individual, without services and supports, has a high probability of meeting those criteria later in life.

### **Rhode Island Definition of Developmental Disability**

The Rhode Island Developmental Disabilities Council (RIDDC) is established by RI General Law 40.1-1-9, which includes the Federal definition of "developmental disability."

In 1988 the "Right to Service Law" (R.I.G.L. 40.1-21-1 et seq) took effect and changed the former State Department of Mental Health, Retardation and Hospitals – Division of Retardation (MHRH-DOR) to the Division of Retardation and Developmental Disabilities (MHRH-DOR/DD), and expanded the renamed Division's service coordination role to include persons with developmental



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disabilities other than mental retardation, using the federal definition of “developmental disabilities,” changing to a functional rather than a categorical definition. In 1993, the Division’s name was again changed (R.I.G.L. 40.1-21-2.1) to the Division of Developmental Disabilities (MHRH-DDD) better reflecting its expanded mission under the functional definition.

The “Right to Service” law set the stage for the evolution of a new system of services that would be individually-directed rather than agency directed. Under this new system, persons with disabilities and their families would initiate and make decisions regarding their supports.

In 1993, R.I.G.L. 40.1-21-4.4 authorized MHRH-DDD to “plan and implement a system of service delivery through a managed care system for developmentally disabled adults.” At the time Rhode Island was developing its CHOICES Title IX Waiver proposal, which would combine acute and long-term care supports in a single, managed care system that would provide flexibility, individual control and cost containment. MHRH-DDD later withdrew its Title IX Waiver Proposal but committed to implement the CHOICES initiative within the existing Title IX system.

### **Estimated Prevalence of Developmental Disabilities in Rhode Island**

Determining the prevalence of developmental disabilities among Rhode Island residents is a critical problem. Census data is not available that uses the Federal functional definition of developmental disabilities to track population.

The RIDDC uses the prevalence estimate of 1.8% developed by Gollay and Associates, based upon their analysis of the National Survey of Income and Education.

Rhode Island had a population of 1,076,189 in 2005, according to U.S. Census Bureau, 2005 Population Estimates. Using the Gollay prevalence factor, RIDDC estimates the number of Rhode Island citizens with developmental disabilities to be 19,371.

### **Organizational Structure**

The Rhode Island Developmental Disabilities Council (RIDDC) is a planning and advisory body composed of twenty-four (24) members including persons with developmental disabilities; immediate relatives or guardians of persons with developmental disabilities; and representatives of the principal State agencies, higher education and training facilities, local agencies, non-governmental agencies and groups concerned with services and supports to persons with developmental disabilities. At least 50% of the Council members must consist of persons with developmental disabilities or the parents/guardians of such persons. Of that 50%, one third must be persons with developmental disabilities and another one third must be immediate relatives or guardians of persons with developmental disabilities, which cause cognitive impairment.

The Council has 3 permanent employees:

- An Executive Director (full time) – Marie V. Citrone
- An Associate Director (full time) – Mary E. Okero
- An Administrative Assistant (full time) – Gail Votolato

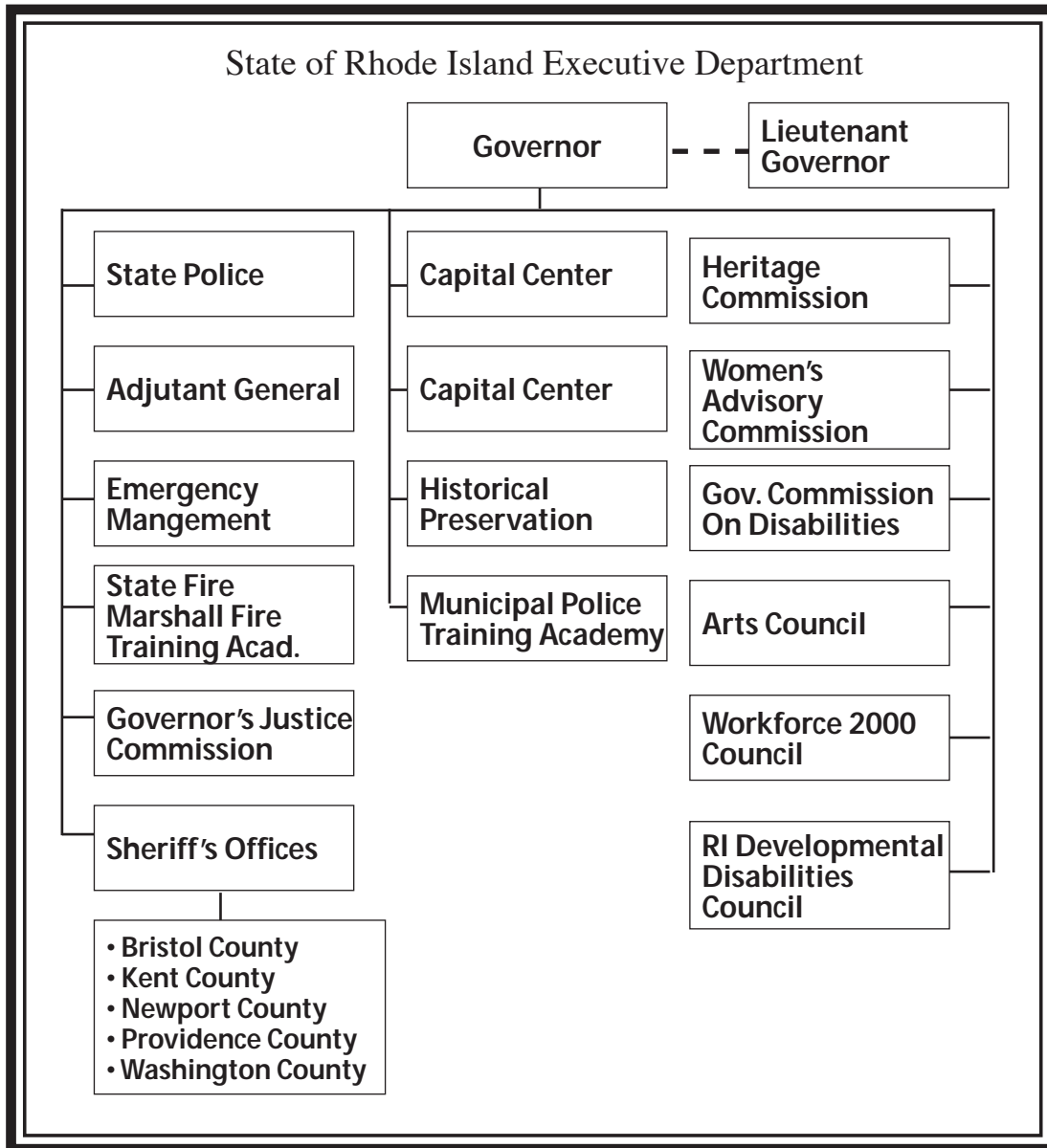
The Rhode Island Developmental Disabilities Council is located in the Executive Department of the State Government directly answerable to the Governor.

The Rhode Island Developmental Disabilities Council functions as the Designated State Agency (DSA) as defined in “*Developmental Disabilities Assistance and Bill of Rights Act 2000.*” A liaison is appointed by the Governor’s Office to work with the RIDDC Executive Committee and the RIDDC Executive Director on Council matters. The name and address of the Governor of the State of



Rhode Island and Providence Plantations is:  
The Honorable Donald L. Carcieri, Governor  
State of Rhode Island & Providence Plantations  
State House, Room 115  
Providence, RI 02903-1196  
(401) 222-2080

**State Structure: Services and Supports**





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The Division of Developmental Disabilities (DDD), RI Department of Mental Health, Retardation & Hospitals (MHRH) is responsible for planning, providing and administering supports for adults (21+ years of age) with developmental disabilities and their families.

The Office of Special Needs, RI Department of Education (RIDE), in conjunction with the local school districts, is responsible for planning, providing and administering educational services and supports for students with developmental disabilities aged 3-21.

The RI Department of Human Services is responsible for planning, providing and administering early intervention services and supports for children with developmental disabilities or at risk from birth to 3 years of age.

Rhode Island Budget Article 44, effective July 1, 2004, transferred the administration of the State's Early Intervention (EI) System from the Rhode Island Department of Health (DOH) to the Rhode Island Department of Human Services (DHS). The transition was officially complete as of January 2005.

### **Role of the Council Within the State's Structure**

The Council is responsible for developing and administering the State Plan in such a way that its activities and accomplishments promote systemic change, policy reforms, capacity building and advocacy to address the identified needs of Rhode Islanders with developmental disabilities. The Council also engages extensively in the training, education and provision of information to individuals with developmental disabilities, family members, service providers and the general public.

#### ***Development of an Individual--Controlled Service System***

- **Partners in Policymaking:** The Council has funded Partners in Policymaking projects, informing individuals and families of service options and supporting increased decision making on the part of individuals and families.
- **Inclusive Education:** Through training, technical assistance and advocacy, the Council has supported the efforts of parents, educators and administrators to maximize and focus on inclusion when planning educational services and supports for students with developmental disabilities.

#### ***Transportation:***

Through grants for evaluation of the transit system, needs assessments, training, technical assistance, and advocacy, the Council has attempted to collaborate with the RI Public Transit Authority (RIPTA) to continue to improve transit options for individuals with developmental disabilities.

#### ***Housing:***

Through collaborating with other community agencies focusing on housing issues, the Council has advocated for the inclusion of the needs of individuals with disabilities in planning for affordable housing (ownership/rental) and accessible housing.

#### ***Human Rights and Civil Rights:***

The Council has focused on providing technical supports, training and materials to Human Rights Committees. In 2006, the Council undertook a survey of agency administrators and human rights committee chairs to identify needs and accomplishments in this area.



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***Development of Self-Advocacy:***

The Council has funded several Partners in Policymaking training courses which provide individuals with disabilities and family members with leadership skills and explore such topics as networking, influencing the political process, accessibility in everyday life, assertiveness training, accessing the media, assistive technology, whole life planning, supported employment, etc.

***Public Awareness & Education:***

- The Council maintains an ongoing public information/education initiative to provide information regarding the possibilities for individuals with developmental disabilities to be valued and contributing members of the community.
- The Council has focused on supporting service learning opportunities for young people as a way of influencing the attitudes and behaviors regarding integration and full inclusion of people with disabilities in their community.

***Employment:***

The Council has researched and disseminated information on the federal Ticket to Work/ Work Incentives Improvement Act to foster the development of meaningful employment for individuals with disabilities.



## Section I: Council Identification

**A. Five Year State Plan Period:**

2007 – 2011

October 1, 2006 to September 30, 2010

**B. State Code**

Rhode Island

**C. Chairperson's Appointment Date:** 3/23/2005

**D. Council Establishment Date:** 10/01/71

**Authorization:** State Statute

**Statute:** RIGL 40.1-1-9

### Council Membership

Last Name	First Name	Agency Name	Code	Appt.Exp. 9/30
Bandusky	Ray	RI Disability Law Ctr.	A6	2006
Beazley	Frank		C1	2006
To be Named		UCEDD Sherlock Ctr.	A5	N/A
Colantuono	Maya	RI Dept. Of MHRH – Div. of DD	A9	N/A
Connor	Regina	RI Dept of Hum. Ser. – Office of Rehab. Ser.	A1& A4	N/A
Cummiskey	Elizabeth		B2	2007
D'Agostino	Joan	RI Dept. of Elderly Affairs	A3	N/A
Feole	William		C1	2008
Garneau	Deborah	RI Dept. Of Health	A10	N/A
Leonard	Kathleen		B1	2007
Lowe	Claudia		B3	2008
Martinelli	John		B1	2008
O'Connor	Kathryn		A8	2008
Rule	Anne		A8	2008
Sebesta	Helen		B2	2006
Singleton	Christine		B1	2008
St. Pierre	Frank		B3	2007
Stuckey	Alton		B1	2007
Susa	John		B2	2006
Susa	Mark		B1	2007
Thibeault	Andre		B2	2008
Vandall	Lori		B1	2007
Woolman	Ina	RI Dept. of Education	A2	N/A
Zawacki	Charles		B1	2007



### **Council Membership Plan for Compliance**

**Provide a brief plan for compliance if the Council cannot fulfill the new membership requirements by the due date of this plan:**

The Council currently has twenty-three (23) members, with one (1) vacancy in the UCEDD category (A5) We are awaiting notification from the UCEDD Sherlock Center at Rhode Island College. Fifteen (15) members (62.5%) represent individuals with developmental disabilities. Appointments and re-appointments are usually made by the Governor prior to the new fiscal year.

## **Section II: Designated State Agency (DSA)**

A. DSA is The Council

**Agency Name:** RI Developmental Disabilities Council

**State DSA Official's Name:** Citrone, Marie V.

**Address:** 400 Bald Hill Road, Suite 515  
Warwick, RI 02886

**Phone:** 401 737 1238 (V/TDD)

**Fax:** 401 737 3395

**E-mail:** riddc@riddc.org

B. DSA is Not Another Agency

C. Direct Services (If DSA is other than Council)

Not applicable

D. Does your Council have a Memorandum of Understanding/Agreement with your DSA?

Not applicable, Council is the Designated State Agency.

E. DSA roles and responsibilities related to the Council, if DSA is other than the Council.

Not applicable, Council is the Designated State Agency.

F. Calendar Year Council or Agency was designated as DSA.

01/01/89

## **Section III – Comprehensive Review and Analysis**

A. Prevalence of Developmental Disabilities in the Rhode Island – see page 4.

B. Environmental Factors Affecting Services

*Describe how economic, social, political, and litigative factors affect persons with developmental disabilities and their families in Rhode Island.*

**1.Children's Issues: According to "2005 RI Kids Count"**

**Early Intervention**

2,870 children ages birth to 3 who had a developmental delay or were at-risk received Early Intervention services through RI's five regional Early Intervention programs in 2004. This number represents 8% of the state's 37,775 children aged birth to three based on the 2000 census.



### **Special Education**

During 2003-04 school year 32,925 school children in RI (21% of students) received special education services. The number of children receiving special education services has increased 6% since the 1999-2000 school year.

#### **Special Education Enrollment by Disability 2003-04**

Learning disability.....	43%
Speech disorder .....	22%
Health impairment .....	13%
Emotional disorder.....	10%
Developmental delay (pre-school only) .....	4%
Mental retardation .....	4%
Autism .....	2%
Other disability.....	2%

The percentage of students with a health impairment has increased from 8% in the 1999-2000 school year to 13% in the 2003-04 school year. The percentage of students with a learning disability decreased from 53% to 43% during the same time period.

### **Poverty**

Children in poverty, especially those in poverty for extended periods of time, are more likely to have health and behavioral problems, and experience difficulty in schools. In the population of children with developmental disabilities these factors further impair development. Between 1990 and 2000 the percentage of children in poverty decreased nationally. However, in Rhode Island the percentage of children living below the poverty threshold increased from 14% in 1990 to 17% in 2000 or 41,162 children. Rhode Island has the largest percentage of Latino children (47%) living below the federal poverty threshold in the country, compared to the national rate (28%). Rhode Island also has the highest percentage of African American children (38%) living below the federal poverty threshold in New England. Families with income below 50% of the federal threshold are considered to be living in extreme poverty. Children who live in extreme, long term poverty experience poor health outcomes, such as childhood asthma and malnutrition, as a result of their family's income status. In 2000, of the 41,162 children living below the poverty threshold in Rhode Island, nearly half (48%) lived in extreme poverty.

Research shows that increased exposure of young children to risk factors associated with poverty obstruct children's emotional and intellectual development. Risk factors associated with poverty include: inadequate nutrition, environmental toxins, maternal depression, trauma and abuse, lower quality child care and parental substance abuse.<sup>1</sup> In 2000, 19% (14,548) of Rhode Island Children under age six were living below the poverty threshold. Of these children, 7,230 (50%) were extremely poor. As of December 1, 2004 47% (9,938) of the children receiving cash assistance from the Family Independence Program in RI were under the age of six, with 55% of these children being under the age of three.

More recent figures released by RI Kids Count in January 2006 show that childhood poverty has continued to increase in Rhode Island. Between 2000 and 2004 the childhood poverty rate rose from 17% to 21% with 50,390 children underage of 18 in Rhode Island living below the federal poverty threshold. Rhode Island was the only state in New England that did not see an increase in

1 National Center for Children in Poverty, (2002). Early childhood poverty: A statistical profile. New York, NY: Columbia University, Mailman School of Public Health.



real median wage between 2000 and 2004. The percentage of minority children living in poverty also continued to escalate between 2000 and 2004 with Latino children rising from 47% to 52%, African American children rising from 38% to 48% and Asian children rising from 22% to 38%; while the percentage of white children living in poverty remained constant at 13%.<sup>2</sup>

### **Family Structure**

Children in single-parent households are five times more likely than children in two-parent families to be living in poverty. According to the 2000 Census, compared to the rest of New England, Rhode Island has the highest percentage of families with children headed by a single parent (32%). While the percentage of children in single-parent families continues to grow nationally, Rhode Island is out-pacing this national growth. From 1990 to 2000 the percentage of children living in single-parent families grew 25% nationally, but in Rhode Island it increased 39%.<sup>3</sup>

## **2.Housing**

Rhode Island was one of the first states to provide all services to adults with developmental disabilities solely in community settings. In March 1994, the Ladd Center was closed and Rhode Island joined New Hampshire and Vermont as the first states to close their institutions.

The Department of Mental Health, Retardation and Hospitals, Division of Developmental Disabilities (The Division) provides services and supports to approximately 4,000 adults with developmental disabilities. The Division provides a variety of housing options in over 1000 community settings for approximately 2,000 adults. Settings include apartments, adult foster care placements, condos, group homes, etc. and range from 24-hour care to minimal care based on the individual's needs. The remaining approximately 2000 adults with developmental disabilities receiving services and supports from The Division continue to live with their families.<sup>4</sup>

There has been a continued growth in the number of families willing to have their adult family member with developmental disabilities who receives supports from The Division live outside the family home. Additionally, The Division reports that approximately 40% of the parents who have adult sons/daughters with developmental disabilities living at home are over the age of 60, up ten percent over the past five years. Each of these factors plays a significant role in the increasing need for housing units with supports provided by The Division.<sup>5</sup>

The Division is interested in expanding the array of integrated housing options available to include more opportunities for supported living arrangements and set-aside units in HUD-assisted housing. While the total number of housing units needed by persons receiving services from the Division is unclear, the following provides some indicators:

The Division estimates that approximately 110 people with developmental disabilities "turn 21" each year and request supports from the Division.

In November 2004, Division staff reported approximately 200 current requests from families for residential support. Of these, approximately 30 were aged 18-21 and the remaining 170

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2 Providence Journal, (1/10/06), More R.I. children living in poverty; Jordan, Jennifer D.

3 Children at risk: State trends: 1990-2000. (2002) Baltimore, MD: Population Reference Bureau for The Annie E. Casey Foundation.

4 State of Rhode Island 5 Year Consolidated Plan 2005-2009, (2004) Providence, RI: Rhode Island Housing and Mortgage Finance Corporation for HUD

5 Ibid



individuals were over the age of 21. Most of those over-21 requesting supports have been in the adult DD service delivery system for years.

The federal Preadmission Screening and Annual Review (PASSAR) requirements result in the Division continuing to identify individuals with developmental disabilities living in nursing homes that meet the criteria for group home living.

Many adults with developmental disabilities require varying levels of support to successfully live independently and have meaningful opportunities for community participation and contribution. Historically, agencies that provide residential supports for The Division to people with developmental disabilities have done so in group settings. Currently most available units are three-to-six-person units with double and single rooms. In an effort to provide greater choice and a wider array of residential possibilities for people to select from, The Division would need access to apartments, efficiencies, condos, co-ops, and other options. To accomplish this, development of smaller integrated housing models, as well as accessing existing housing such as HUD assisted housing, would need to be pursued<sup>6</sup>

In 2002, an estimated 97,000 households in Rhode Island were paying too much for housing. About 30,000 renters (20% of all rental households) and 18,807 homeowners (9% of all homeowners) were paying more than 50% of their incomes for housing.<sup>7</sup>

Approximately 155,000 households in Rhode Island have incomes insufficient to pay for the average advertised rent on a two-bedroom apartment. From 1999 to 2002, house prices grew by 35.9% and the average rent on a 2BR apartment grew by 35.3%. Over the same period of time, the median household income in Rhode Island grew by 8.4%. Since home prices and rents are growing more than four times faster than incomes, this number, as well as the number of families paying too much for housing, will likely grow substantially by 2011.<sup>8</sup>

There are about 10,000 more low-income households in Rhode Island than there are housing units they can afford.<sup>9</sup>

### **3. Health Care**

Rite Care, Rhode Island's Medicaid managed health care program, has been lauded by many as a comprehensive, accessible health insurance/health care system that has provided health coverage for many poor and working families. Based on the 2000 Census data, the percentage of Rhode Islanders of all ages who lacked health care coverage was the lowest in the 50 states and the District of Columbia.<sup>10</sup>

<sup>10</sup>On January 1, 2006, Medicare Part D (prescription drug coverage) went into effect, with mandatory participation required for all Medicaid participants (a large percentage of the DD population).

### **4. Employment**

Historically, persons with developmental disabilities have not enjoyed access to, or benefited from, participation in the competitive labor force. Most vocational services for people with

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6 Ibid

7 Affordable Housing for Rhode Island (2004), Providence, RI: i2 Community Development Consulting

8 Ibid

9 Ibid

10 Disparities in Health Insurance Coverage among Adults in Rhode Island (2002), Providence, RI: Health Policy Brief, Issue 02-1; Rhode Island Department of Health



mental retardation or other cognitive disabilities continue to be provided in sheltered employment settings. During the past two decades, however, significant progress has been made toward the inclusion of people with cognitive disabilities as well as those with significant physical disabilities in the competitive labor force. Public policy initiatives, including the ADA and the Ticket to Work and Work Incentive Improvement Act of 1999, attempt to address commonly cited barriers to competitive employment for this group. These include workplace discrimination and potential loss of cash and health insurance benefits for persons eligible for Social Security Disability Benefit programs.

Between 1994 and 2002, the number of Rhode Island adults with developmental disabilities receiving day or work supports (including supported employment) increased from 1,824 to 2,826 (55%). During the same period the number of individuals receiving supported employment services increased from 245 to 545 (122%). The emphasis on supported employment went from 13.4% in 1994 to 19.3% in 2002.<sup>11</sup>

The Rhode Island One-Stop Delivery System created under the Work Force Investment Act has established four One-Stop Centers in Rhode Island. This delivery system, called netWorkri (where people and jobs connect), streamlines access to training and other human resource services activities and programs. NetWorkri is intended to simplify and expand access to services for individuals with disabilities and employers.

### **Process of Review of Statewide Service Delivery System**

In preparing for the development of this 5-year state plan, in 2002-2003 the Council commissioned:

**Telephone interviews with a randomly selected sample of 232 adult individuals receiving services from The Division of Developmental Disabilities.**

**Telephone interviews with 6 heads of service provider agencies**

**8 school district special education directors.**

**Focus Groups with 67 participants, including:**

- 2 Focus Groups with adults with developmental disabilities
- 2 Focus Groups with Special Education staff
- 3 Focus Groups with day and residential support staff
- 1 Focus Group with family members

In addition, the Council is continually updating information on the service delivery system and the Council's impact on services and supports through data gathering activities of the Council's Executive Committee.

In 2006, the Council conducted telephone interviews with Human Rights Committee Chairs and Provider Agency Administrators to identify the effectiveness and needs for Human Rights Training for individuals, families, provider agency staff and human rights committee members.

### **C. The State Service System(s)**

*Provide a summary of the results of the Council's review and analysis of the State service system for people with developmental disabilities. Include reference to relative interagency initiatives and any specific eligibility barriers to service.*

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<sup>11</sup> The State of the States in Developmental Disabilities: 2005, by David Braddock, Richard Hemp, Mary C. Rizzolo, and Diane Coulter, Laura Haffer, Micah Thompson; Boulder, CO, Coleman Institute, University of Colorado



## 1. Community Supports

RI Department of Mental Health, Retardation & Hospitals (MHRH) Division of Developmental Disabilities (DDD)

In Rhode Island, MHRH DDD is responsible for planning, providing and administering supports for adults with developmental disabilities and their families. DDD contracts with service providers, collects federal reimbursement, monitors and investigates complaints, undertakes quality assessment and provides training. DDD also coordinates service provision with other state, local and federal agencies.

Services and supports are provided to persons with developmental disabilities and their families which support these individuals living in the community, including:

- Residential Programs
- Supported Employment
- Transportation
- Respite Care
- Family Supports
- Health
- Education
- Rehabilitation

DDD provides community supports through a state-operated program, RI Community Living and Supports, as well as by funding private not-for-profit agencies' provision of community support services through contractual arrangements.

Updated statistical and future planning information from DDD was unobtainable despite numerous requests, phone calls and emails to DDD's Acting Executive Director. Wherever possible information on DDD was gathered from other sources, as noted in the footnotes.

## 2. Comprehensive Evaluation, Diagnostic, Assessment, Referral, Reevaluation Services and Supports (CEDARR)

- RI Department of Human Services (DHS)
- RI Department of Health (DOH)
- RI Department of Education (RIDE)
- RI Department of Children, Youth & Families (DCYF)
- RI Department of Mental Health, Retardation & Hospitals (MHRH)

In Rhode Island, CEDARR Family Centers are intended to serve as family-centered, comprehensive sources of information, clinical expertise, connection to community supports and assistance to aid the family in meeting the needs of their child.

Each child and his or her family have the opportunity to voluntarily utilize a CEDARR Family Center to help identify and understand their child's strengths and needs, develop a Family Care Plan for the child and family, and help with referrals, and related services and supports.

Services provided through the CEDARR Initiative are designed to improve the appropriateness of care, support a more positive family-centered system of care, promote clinical excellence, improve outcomes and promote overall cost effectiveness for Medicaid eligible children with special needs. In addition, the CEDARR Initiative establishes the means to support new and expanded services in critical areas that currently do not exist or are limited.



A family may choose to use a CEDARR Family Center for assessment, evaluation, and referral only; or to maintain an ongoing relationship using different supports as their needs change over time.

It is hoped that CEDARR Family Center services will ultimately be available to all children regardless of whether or not they are eligible for Medicaid. It is expected that, in the future, CEDARR Family Centers will establish sliding scale fee arrangements based on income for families who are not Medicaid eligible.

Other state agencies which provide services to children with special health care needs are collaborating with DHS in the ongoing development and implementation of the CEDARR Family Centers. The goal is to create, to the greatest degree possible, a unified, coordinated and integrated system of services and supports.

In FY 2004, three CEDARR Family Centers were in operation around the state. The CEDARR Family Centers assisted 829 children and their families. Of the children accessing a CEDARR Family Center in FY 2004, 559 (67%) were male, and 402 (49%) were under age 8 at first contact. CEDARR Family Centers served children and families from 39 cities and towns in Rhode Island.

One of the key responsibilities of the CEDARR Family Center is to identify gaps in the current array of services available to meet children and families' needs, as well as to identify capacity shortfalls. When fully implemented, CEDARR direct services will improve access to a wider continuum of care for children with special health care needs. The following CEDARR direct services are being made available when included in a CEDARR Family Care Plan.

### ***Home Based Therapeutic Services***

Since the mid-1990's, Medicaid eligible children with special health care needs have been receiving Home-Based Therapeutic Services (HBTS) under the provisions of Early Periodic Screening, Diagnosis and Treatment. In February of 2003, the Department of Human Services (DHS) issued certification standards for provider agencies of home-based services. Currently, there are 14 certified HBTS provider-agencies across the state. DHS continues to maintain an open application process for any interested party wishing to become certified as an HBTS provider agency. HBTS represents an array of therapeutic services designed to reduce and/or ameliorate deficits in cognitive, communication, psychosocial, and physical functioning in children with special health care needs. This therapeutic service is intended to maintain, stabilize and/or improve adaptive functioning of these children.

HBTS is often indicated because children diagnosed with moderate to severe physical, developmental, behavioral or emotional conditions require health and related services beyond those required by children generally. HBTS is unique in that services are provided in children's homes and community settings by paraprofessionals under the direction of licensed health care professionals. Treatment is therapeutically based upon identification of treatment objectives, specified methods of intervention, and measurable objectives. Participation of parents or caregivers is required.

HBTS provider-agencies are an important resource for CEDARR Family Centers. Typically, families are referred to HBTS following a CEDARR Family Center assessment and treatment recommendation. In 2004, HBTS provider agencies served about 416 children. The maximum hours of HBTS authorized each week cannot exceed forty hours per client. The average client received seventeen hours of HBTS services per week. A treatment plan lasts for 6 months and can be renewed as necessary. The age distribution of children receiving HBTS has remained relatively constant over the years.



Categorized by age group, in 2004 the program was utilized as follows: 0 - 4 years old represent 8%; 5 - 9 years old represent 35%; 10 - 14 years old represent 42%; and 15 - 19 years old represent 15% of the caseload. Their special health care needs were as follows: 11% have medical/physical conditions; 7% have developmental conditions; 52% have behavioral health conditions; and 30% have autism spectrum conditions.

### ***Therapeutic Child and Youth Care***

Therapeutic Child and Youth Care provide Medicaid funding for specialized therapeutic supports to allow children with significant physical, developmental, behavioral or emotional conditions to participate in typical child and youth care settings. This program features an “inclusive” model, allowing children with special needs to participate in child and youth care settings with peers who are typically developing. DHS released certification standards for its Therapeutic Child and Youth Care Program in spring of 2003. Two providers were certified in 2004 and DHS is recruiting additional providers. The DHS goal is for Therapeutic Child and Youth Care to be available on a statewide basis for all Medicaid-eligible children and families needing this service.<sup>12</sup>

## **3. Education**

### ***Early Intervention***

Rhode Island Budget Article 44, effective July 1, 2004, transferred the administration of the State’s Early Intervention (EI) System from the Rhode Island Department of Health (DOH) to the Rhode Island Department of Human Services (DHS). The transition was officially complete as of January 2005. In addition to Article 44, an insurance mandate was passed in the 2004 legislative session (Article 22). Article 22 mandated that all commercial insurers licensed in Rhode Island reimburse certified EI providers for all EI services provided to eligible children and families to a maximum of \$5,000 per calendar year per child. Also mandated was that this benefit would not include co-payments or deductibles for families and would not be applied to any annual or lifetime maximum benefit contained in the policy or contract.<sup>13</sup>

DHS reports that in 2005 the number of children receiving EI Services has risen to 2,063,<sup>14</sup> an increase of 69% from the 1,244 children served by DOH in 1995. Programs such as Universal Newborn Screening and Home Visiting Risk Response, as well as Child Find activities on the part of EI Providers have contributed to the early identification and referral of children for EI.

DHS reports that 94% of the children served receive services either at home or in an integrated day care setting.<sup>15</sup> Services are delivered elsewhere only when early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment.

### ***Special Education***

In the 2004-05 school year, 32,296 RI students (21%) were enrolled in special education. 41% had learning disabilities; 21% had speech disorders; 14% had health impairments; 10% had behavioral disorders; 4% had developmental delays; 4% had mental retardation; 3% had autism; and 3% had other disabilities, including, in order of prevalence, mental health, hearing, mobility, and vision impairments as well as deafness, TBI and deaf/blindness. The graduation rate was 73%, reflecting a dropout rate of 27%.<sup>16</sup>

12 Rhode Island Medicaid Program Annual Report, Fiscal Year 2004, Rhode Island Department of Human Services

13 Ibid

14 Rhode Island: Part C State Performance Plan (SPP) for 2006 - 2010, (2005) Providence, RI: RI Department of Human Services

15 Ibid

16 InformationWorks!, (2005) Providence, RI: Rhode Island Department of Elementary and Secondary Education



### **Secondary Transition Services**

The Rhode Island Department of Elementary and Secondary Education, Office of Special Needs has actively worked with students, parents, local school districts, and other state and local agencies to promote an effective statewide system of secondary transition services for students with disabilities.

Secondary Transition is defined in the Individuals with Disabilities Education Act (IDEA) as:

Transition Services are a coordinated set of activities designed within an outcome oriented process that promotes movement from school to post-school activities, including but not limited to:

- Post secondary education
- Vocational training
- Integrated competitive employment (including supported employment)
- Continuing and adult education
- Adult services
- Independent living, and
- Community participation.

Transition planning is part of the Individual Education Program (IEP) planning process for students beginning at 14 years old and is focused on the skills and services the student will need to successfully transition from school to adult life.

### **Adult Education**

Availability of Adult Education varies widely from community to community. In 2005 a statewide Director of Adult Education was appointed and tasked with improving the availability of Adult Education across the state. The RIDDC met with the newly appointed director and intends to work closely with him to improve access to continuing education for individuals with disabilities.

## **4. Employment**

### **Department of Human Services (DHS) Office of Rehabilitation Services (ORS)**

In Rhode Island, ORS provides a comprehensive program of rehabilitation, social, and independent living services to eligible Rhode Island residents who have a disability and apply for services. Each individual undergoes an evaluation to determine service eligibility.

Direct services are provided by vocational rehabilitation counselors and supervisors, social workers, rehabilitation teachers, peripatologists, and vending facility supervisors as well as staff support. ORS also develops partnerships with community resources to ensure appropriate services for individuals with disabilities.

- ORS is a partner in the RI One-Stop Delivery system created under the Workforce Investment Act, called netWorkri.
- ORS has developed the Supported Employment Pilot Project as a strategy to enhance the quality and quantity of employment outcomes for individuals with the most significant
- ORS has developed the Supported Employment Pilot Project as a strategy to enhance the Quality and Quantity of employment outcomes for individuals with the most significant disabilities.<sup>17</sup>

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17 Federal Fiscal Year 2006 Annual Update to State Plan, (2005) Providence, RI: Rhode Island Department of Human Services Office of Rehabilitation Services for US Department of Education Rehabilitation Services Administration (RSA)



- ORS reports that in FFY2005, 6,907 individuals with disabilities were provided vocational rehabilitation, training and employment services through ORS. 700 individuals with significant disabilities (100%) had successful employment outcomes.

### **Medicaid Buy-In**

On July 2, 2004, the Governor signed into law the Sherlock Act, which established a Medicaid Buy-In Program for Rhode Island. It will afford individuals with disabilities the opportunity to purchase Medicaid as their medical coverage, enabling them to secure employment while maintaining the medical services necessary to function independently. The Medicaid Buy-In Program took effect in January, 2006.<sup>18</sup>

### **DDD-Statewide Quality Consortium Employment Survey**

In 2004, the Division of Developmental Disabilities Statewide Quality Consortium surveyed 35 DD agencies about the number of people employed in community jobs. Thirty agencies provided the following information for each individual employed during 2003: Individual ID, Employer Name, Job title, Hours worked, monthly income and employment type, i.e. Individual Supported Employment, Group Supported Employment, and Competitive Employment. The Center for Medicaid Services, through a grant with the Human Services Research Institute, established the National Core Indicators, which defined types of employment.

According to DDD, 3,915 adults received services from them in 2003, of which approximately 3,365 received services from DD provider agencies.

The results of the employment survey show that 21% (699) of people receiving services from a DD agency held at least one job in 2003. 112 of those individuals reported having more than one job, for a total of 811 jobs. Ten individuals reported being self-employed.

Individuals are reported as working in the following support categories:

- Individual Supported Employment - 252
- Group Supported Employment - 428
- Competitive Employment - 131

Additionally, 80% or 648 jobs are less than 20 hours per week. 20% or 131 jobs are more than 20 hours per week; only 30 jobs (4%) are full-time, 35 hours or more per week.

Throughout the state, employed individuals worked for 199 companies, in 35 job titles with an average hourly wage of \$7.14.

The Office of Rehabilitation Services has entered into a Cooperative Agreement with MHRH to address the employment needs of individuals with developmental disabilities and those with behavioral health issues. In particular, the Cooperative Agreement enables ORS to capture more Federal funds to provide vocational rehabilitation services to individuals with developmental disabilities.<sup>19</sup>

## **5. Transportation**

Transportation remains a key issue for Rhode Islanders with disabilities, in terms of access to services, supports and activities; employment opportunities; and opportunities for community inclusion. Of the 232 individuals surveyed by telephone in a 2003 study commissioned by RIDDC,

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18 2004 -- S 2280 SUBSTITUTE a AS AMENDED." RI General Assembly Website. July 2004. RI General Assembly. 31 Mar. 2006 <<http://www.rilin.state.ri.us/PublicLaws/Law04/Law04354.htm>>

19 Ibid



91.1% stated that, “being able to get a ride where you need to go” was important to them.

### **Rhode Island Public Transit Authority (RIPTA)**

To help meet the mobility needs of individuals with disabilities, all RIPTA vehicles are equipped with wheelchair lifts. In addition, RIPTA buses and trolleys can “kneel”; lowering the front entrance of the vehicle to within inches from the ground for easy access by customers who have mobility impairments or difficulty using the front steps.

To assist passengers with visual impairments, RIPTA bus operators make ADA stop announcements in compliance with the Americans with Disabilities Act (ADA).

On RIPTA vehicles, there is priority seating for passengers with disabilities and seniors located directly behind the driver. Other passengers must make these seats available upon request.

Personal Care attendants for individuals with disabilities may ride RIPTA buses and trolleys free when accompanying a person who is carrying a RIPTA Disabled ID Pass that designates that a Personal Care Attendant is required.

For customers with certified physical, cognitive or visual disabilities who are functionally unable to independently use buses, RIPTA provides ADA Para transit Service. This service is limited to locations within 3/4 mile of RIPTA's fixed-route service.

RIPTA also coordinates and manages the statewide RIde Para Transit Program. RIde is a partnership of the RI Department of Elderly Affairs, the RI Department of Mental Health, Retardation and Hospitals, the RI Department of Human Services and RIPTA.<sup>20</sup>

To address the shortcomings of fixed route service, especially in suburban areas, RIPTA has initiated Flex Service which will take riders anywhere within a community's established Flex Zone, as well as connect with fixed bus routes. Flex Service is a new RIPTA pilot program designed to help serve the unmet mobility needs of communities across Rhode Island. Flex Service, shorthand for Flexible Service, offers passengers the option of calling for a ride or picking up the Flex Vehicle at one of its regularly scheduled Flex Stops.

## **6. Housing**

There is a critical lack of affordable housing throughout Rhode Island, including rental assistance for the general public and specific groups. The past five years have been marked by rapidly increasing housing costs statewide.

In 2005, each city and town was required to develop a plan to reach a minimum level of 10% of the housing units within their respective communities being affordable.

DDD provides a variety of housing options in over 1000 community settings for approximately 2000 of the 4000 adults with developmental disabilities DDD supports. The remaining 2000 adults with developmental disabilities continue to live with their families. Approximately 40% of these individuals are living with a parent over the age of 60.

### **D.Community Services and Opportunities**

Provide a summary of the extent to which community services and opportunities related to the area of emphasis directly benefit individuals with developmental disabilities. Include information on assistive technology and rehabilitation technology, current resources and projected availability

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20 RIPTA Transit Programs.” RIPTA. Rhode Island Public Transit Authority. 31 Mar. 2006 <<http://ripta.com/content574.html>>.



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of future resources to fund services, and health care and other supports and services received in ICF/MRs and through Home and Community Based Waivers.

Rhode Island was one of the first states to provide all services to adults with developmental disabilities in community settings. In March 1994, the Ladd Center was closed and Rhode Island joined New Hampshire and Vermont as the first states to close their institutions.

The federal Preadmission Screening and Annual Review (PASSAR) requirements continue the identification of individuals with developmental disabilities living in nursing homes that can be better served in a community setting.

TechACCESS of RI has been a significant contributing partner to the Assistive Technology Access Partnership since its inception in 1993, and continues to meet the needs of people with disabilities through its varied activities and collaborations.

### ***Assistive Technology and Rehabilitation Technology***

TechACCESS has been responsible for maintaining the statewide ATAP Information and Resource Center, which provides:

- Free information and resources to the public
- A tri-annual newsletter reaching over 3,500 individuals, family members, and service providers
- Free weekly AT demonstrations
- An adaptive computer lab, which provides an opportunity to the public to try out computer, related technologies.

Additionally, TechACCESS has coordinated the ATAP Assistive Technology Conference with the other ATAP subcontractors and disability agencies to foster public awareness and increase professional skills in the area of assistive technologies for home, school, work and community.

TechACCESS of RI, as a subcontractor of the Assistive Technology Access Partnership for Rhode Island, has operated the ATAP Demonstration Center since the inception of ATAP. The demonstration program is staffed with expert, experienced professionals including speech/language pathologists, occupational therapists, individuals with ATP (Assistive Technology Practitioner) certification, educators, and several assistive technology users who have many years of experience with blind/low vision technologies and hearing technologies. TechACCESS also utilizes licensed/certified consultants who have specific expertise in seating and positioning, as well as assistive listening devices. The Staff is not only knowledgeable about the wide variety of devices and their applications at home, in school, at work and in the community, but they are also able to assist individuals with making informed AT choices. The staff participates in ongoing vendor training several times a year to keep abreast of the newest technologies, and the close relationship with many local and regional vendors enables the staff to obtain the newest equipment available for self-training and demonstration. TechACCESS plans to expand the existing staff to include an additional communication specialist, an additional low vision specialist, and a general AT practitioner.

East Bay Educational Collaborative (EBEC) has, and will continue to provide services to children and youth statewide. East Bay Educational Collaborative is one of four regional education centers established legislatively to provide professional development, curriculum development, alternative learning programs, and parent support for eight local school districts in the East Bay region of the state. EBEC has been an ORS/ATAP subcontractor since 1995, employing the ATAP



Children and Youth Specialist. The ATAP Children and Youth Specialist has advanced training in speech and language pathology, as well as being certified by the Rhode Island Department of Education as a teacher assistant trainer. The ATAP Children and Youth Specialist conducts professional development for teachers in elementary and secondary education, as well as AT assessments for students with disabilities. In addition, the AT Children and Youth Specialist maintains a demonstration center and device loan program for children and youth.

The Sherlock Center will continue to refine and implement Assistive Technology Competencies for elementary and secondary educators in Rhode Island school districts.<sup>21</sup>

## **Protection & Advocacy System)**

### ***RI Disability Law Center (P&A Program)***

Rhode Island Disability Law Center (RIDLC) provides free legal assistance to persons with disabilities. Services include individual representation to protect rights or to secure benefits and services; self-help information; educational programs; and administrative and legislative advocacy. The agency administers eight federally funded advocacy programs, each of which has its own eligibility criteria.

#### ***1. Protection and Advocacy for Individuals with Developmental Disabilities***

Provides advocacy to remedy abuse or neglect of individuals with developmental disabilities and assistance accessing benefits and services (e.g. special education, day programs, and residential services). A developmental disability is a severe physical, cognitive, or emotional impairment, which begins before age 22, is likely to continue indefinitely, and interferes with three or more major life activities.

#### ***2. Protection and Advocacy for Individuals with Mental Illness***

Provides advocacy to remedy abuse or neglect of individuals with mental illness who are residents of certain care and treatment facilities (e.g., nursing facilities, community hospitals, assisted living facilities, and mental health facilities for children). The scope of this program was expanded recently to provide legal assistance to individuals with mental illness residing in the community.

#### ***3. Protection and Advocacy for Individual Rights***

Provides advocacy to individuals with disabilities who are not eligible for other advocacy programs (e.g., individuals disabled after the age of 22) and who require legal assistance to overcome discrimination or barriers to living independently. Assistance with accessing benefits and services, with emphasis on enforcement of rights under fair housing and anti-discrimination laws, is also provided.

#### ***4. Client Assistance***

Provides advocacy to individuals with disabilities applying for or receiving services from vocational rehabilitation, independent living, and services for the blind and visually impaired.

#### ***5. Assistive Technology***

Provides advocacy to individuals with disabilities seeking access to assistive technology devices and services, with emphasis on obtaining funding from vocational rehabilitation, special education, and Medicaid/Medicare.

#### ***6. Protection and Advocacy for Beneficiaries of Social Security***

Provides advocacy to individuals receiving Social Security benefits who are seeking to secure,

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21 FFY 2006-2008 State Plan for Assistive Technology. Rhode Island Department of Human Services, Office of Rehabilitation Services. Providence, RI, 2005. 2-6.



maintain, or regain employment, with emphasis on education and training about work incentives and the benefits available to beneficiaries who obtain employment.

### **7. Protection and Advocacy for Individuals with Traumatic Brain Injury**

Provides advocacy to individuals with traumatic brain injury, with emphasis on improving access to comprehensive, high quality health care services and increasing the quality, availability, and effectiveness of educational and community-based programs designed to improve the quality of life for this population.

### **8. Voting Accessibility**

Provides advocacy to individuals with disabilities in order to expand and improve access to and participation in the electoral process.

### **Paul V. Sherlock Center on Disabilities at Rhode Island College (UCEDD)**

The Paul V. Sherlock Center on Disabilities carries out the following functions:

- Interdisciplinary Training
- Community Outreach and Service
- Dissemination of Information
- Research

The Sherlock Center is currently pursuing the following programs and initiatives:

#### **1. Assistive Technology**

The Sherlock Center serves as evaluator for ATAP, the Rhode Island Tech Act Project. ATAP is directed through the RI Office of Rehabilitation Services, and has as its primary goal the development of improved, customer-responsive systems for AT acquisition and support for all Rhode Islanders with disabilities. The Sherlock Center gathers and analyzes discrete and descriptive data to reflect program progress, to identify gaps, and to use for program development and decision-making.

#### **2. Children & Youth Services**

This initiative provides family and professional support, coordination of services, information, technical assistance, and training to children with dual sensory impairments, from birth through 22 years of age.

#### **3. Early Childhood Transitions**

The purpose of this initiative is to strengthen and improve the Rhode Island transition system supporting children and their families moving from an Early Intervention Program to Special Education Services, or to other early care and education programs.

#### **4. Educational Advocate Program**

This program is responsible for making educational decisions for children with disabilities who are in the care of the state, and whose parents are unable to act on their behalf. The education advocate ensures a child receives an education that meets the special needs of the child in the least restrictive environment.

#### **5. Employment**

The Sherlock Center offers several comprehensive training programs specifically for direct support professionals, managers, job developers, and educators supporting individuals with disabilities to become meaningfully employed. Individualized technical assistance is also available by request in the following areas:

1. Person Centered Career Planning
2. Assessment Strategies



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3. Job Development & Placement

4. Job Support

5. Community Resources

6. Systems Change & Program Development

7. Family to Family of Rhode Island Family to Family of Rhode Island is a network created by families for families of children and adults with special needs. It offers opportunities for families to connect with one another to share experiences, information, and/or support.

### **6. Individual & Family Support**

This program promotes quality services by helping the service system regard the family as the unit receiving services and by recognizing and helping to meet the needs of parents, siblings and other family members of persons with disabilities.

### **7. Positive Behavioral Support**

This initiative provides information and training to help facilities, schools and provider agencies to identify the purpose of challenging behavior and to develop a capacity for implementing positive behavioral support.

### **8. Rhode Island State Improvement Grant (RISIG)**

The United States Department of Education, Office of Special Education Programs (OSEP) awarded Rhode Island a grant to improve student performance and increase access to general education for children with disabilities. The grant award process was highly competitive and funding was awarded for five years, effective November 1, 2002.

### **9. Teacher Recruitment**

Rhode Island is expected to face a shortage of more than 600 Special Educators over the next 5 years. Now, more than ever, RI children and youth with disabilities need highly qualified teachers who can make a difference in their lives. This initiative seeks to recruit and assist individuals who are interested in pursuing careers in Special Education and/or support services in Rhode Island.

### **10. Transition**

This initiative works in partnership with public and private organizations to improve transition services for students with disabilities as they move from school to adult life.

### **11. RI Vision Education and Services Program**

This program, supported by the Rhode Island Department of Education, provides teaching and consultation services to children who are blind or visually impaired, their families and educational staff within the school environment. The array of services available includes Early Intervention, Orientation and Mobility, and the instruction of specific compensatory skills to children from birth through 21 years.



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### **Collaborative Efforts of the DDC, P&A Program, and UCEDD**

In Rhode Island, representatives from the Developmental Disabilities Council, Protection & Advocacy Program, and the University Center on Disabilities are members of each other's governing bodies and review and comment on each other's State Plans.

#### **The three agencies plan to:**

Develop and jointly fund a plan for RI's implementation of the US Supreme Court's Olmstead Decision enabling individuals with disabilities to choose to live in the most integrated setting appropriate to their needs. This plan may include:

- Policy analysis
- Legal initiative
- Information dissemination
- Training and public education

Continue to support the Sherlock Center's Project of National Significance Grant to develop a comprehensive support system for parents with disabilities that will enable them to keep their children at home. Activities may include:

- Providing funding for local and regional conferences and training;
- Collaborating on building system infrastructure, providing technical assistance, and information and referral for families;

Continued participation in the New England Coalition for Supporting Parents with Cognitive Challenges.

Continue to collaborate on and support employment related activities such as the Sherlock Center's Partnerships to Employment Conference.

Collaboratively develop, produce and fund a DD Network quarterly newsletter, featuring news and articles of interest to the developmental disabilities community from each of the 3 network agencies.

Continue to participate on each other's boards and committees to improve the goals, objectives, activities and plans of each agency.

### ***Current Resources & Projected Availability of Future Resources to Fund Services***

The Division of Developmental Disabilities (DDD) funds a statewide network of community supports for adults with developmental disabilities. These services are both privately operated and publicly operated. DDD is responsible for planning, providing, and administering supports for adults with developmental disabilities by ensuring equitable access to, and allocation of, available resources; enhancing the quality of supports so that people can move toward personal futures of inclusion and participation in community life, like any other citizen; and safeguarding them from abuse, neglect and mistreatment.

DDD's goals include: (a) providing more opportunities for individuals with developmental disabilities and their families to have more control over supports and services that they purchase within the funding available from DDD, (b) providing access to information that enables them to make informed decisions, (c) assisting providers in implementing innovative and flexible supports and services that address the individual needs of a person, (d) ensuring quality services that protect the rights of individuals with developmental disabilities, (e) providing the appropriate structure within DDD to respond to the changing needs of individuals and their families, (f)



providing a safe environment that assists individuals to meet their fullest potential and supports them in being meaningful participants in their community, and (g) providing a competent, caring stable workforce to provide needed supports and services for individuals within the developmental disabilities system.

While serving approximately 4000 individuals in addition to contracting with a statewide network of private community services, DDD provides community day and residential services through a publicly operated program, Rhode Island Community Living and Supports (RICLAS). RICLAS supports approximately 300 people in various settings throughout Rhode Island.<sup>22</sup>

In the five-year period between 2001 and 2005, DDD actual expenditures grew from \$187,932,503 to \$230,680,859 – an increase of 23%.

## E. Waiting Lists

*Provide the name of waiting lists in your state and the number of individuals with developmental disabilities on those waiting lists.*

*Waiting List Name*

*Public Housing(See below)*

*Section 8 Housing(See below)*

*Narrative: Provide a brief review of the waiting lists in your state*

In Rhode Island, lists are maintained at the local city/town level and some local housing authorities combine Public Housing and Section 8 waiting lists. Local Housing Authorities' waiting lists do not contain a breakdown of individuals with developmental disabilities. However, approximately 41% of the Local Housing Authorities do track the number of applicants with disabilities on their respective waiting lists; among these lists 26% of the applicants are classified as disabled. In June, 2006 the statewide waiting list for Section 8 housing was 3,882 and the waiting list for Public Housing was 5,526; with an additional 4,442 applicants on combined lists at the local housing authorities that do not segregate their list.

The Rhode Island Department of Mental Health, Retardation & Hospitals – Division of Developmental Disabilities reports that it does not have a waiting list for eligibility determination. RIDDC's feedback from individuals and families calling for referrals and advocacy, as well as with representatives from service provider agencies, is that some individuals determined eligible by DDD are being informed that provider agencies have insufficient funding available to provide requested services.

## F. Unserved and Underserved Groups:

**1.** *List and describe racial/ethnic groups that may be unserved/underserved and describe the barriers to their receipt of supports and services. You may identify barriers specific to a particular racial/ethnic group, identify general, overall barriers applicable to all racial/ethnic groups selected, or both.*

Barriers specific to a particular Group from US Census:

### **Asians**

Hmong, Lao, Vietnamese, and Cambodians each have different languages and cultural beliefs. Beliefs about disability and health care issues, distrust of government, and lack of familiarity with service delivery system are barriers, especially with older persons.

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22 Fiscal Year 2007 Budget Request. State of Rhode Island. Providence, RI: State Budget Office, 2006. 270. 31 Mar. 2006 <<http://www.budget.state.ri.us/PROGSUPP/1000.pdf>>.



### **African Americans**

While it is difficult to ascertain if African Americans remain underserved, due to the fact that many service records do not track race or ethnicity, it is clear that African Americans continue to be underrepresented in agency staffing, especially administratively and in policy making roles.

### **Hispanics/Latinos**

Dominicans, Puerto Ricans, Colombians, Guatemalans and Mexicans each have different cultural beliefs and dialects. Beliefs about disability and health care issues, as well as lack of access to health care and the service system on the part of undocumented persons are barriers.

### **Native American**

The Narragansett Tribe provides services to Tribe members. Barriers include their geographic location in the southwesternmost and most rural part of the state, which also has the least public transportation. Outreach from state and private agencies is minimal.

### **Overall barriers not specific to a particular racial or ethnic group:**

A lack of outreach in general, as well as into cultural communities, by state and private agencies results in a lack of awareness of and referrals for supports for individuals and families. Lack of translators and culturally appropriate materials is exacerbated by the diversity of ethnic cultures, languages and dialects. Minority populations are underrepresented in administrative staffing, and policy making boards.

*2. List and describe any other unserved/underserved groups and describe the barriers that impede full participation of these groups.*

### **Group 1: Persons dually diagnosed with mental illness and developmental disabilities.**

According to MHRH, people with developmental disabilities receive services from Rhode Island's network of Community Mental Health Centers (CSP services; GOP medication Services). Dually diagnosed persons involved with the courts and in need of inpatient psychiatric care or intensive supports provide a challenge for the mental health, developmental disabilities and corrections service delivery system, often requiring creative multi-disciplinary approaches.

### **Group 2: Individuals with developmental disabilities with elderly parents as their primary caretakers.**

In Rhode Island, approximately 40% of the approximately 2000 adults with developmental disabilities living with family members and receiving only non-residential supports from DDD are living with a parent over the age of sixty. In many cases, a lack of advance planning for the death or incapacity of these parents exposes these individuals to rely on a crisis response, which is often inadequate or results in less than optimal service delivery options.

### **Group 3: Individuals with developmental disabilities living in low income households.**

Barriers to service include the lack of public transportation, quality day care, and affordable health insurance. Often, low income parents are less able to take time out of work to access services and advocate for their child.

### **Group 4: Uninsured individuals with developmental disabilities.**

As Rhode Islanders continue to see annual double digit increases in the cost of health insurance, many families are left with few or no affordable options. The 2007 budget proposed additional cuts to Rite Care health insurance for low and moderate income families, which would reduce eligibility. Individuals without health insurance are less likely to receive support service information and referrals.



**Group 5: Households headed by an individual with cognitive disabilities.**

It is estimated that a parent with a cognitive disability heads approximately 500 households in Rhode Island. Service barriers include the lack of program materials and outreach information that can be understood by someone with cognitive deficits, and inability to integrate these families into traditional supports rather than develop a separate system for these families.

**Group 6: Individuals with disabilities who are homeless.**

Children with disabilities who are part of a homeless family are less likely to receive early intervention and special education services.

**Group 7: Individuals with disabilities residing in rural/suburban areas.**

Most rural areas of the state have little or no public transportation, few or no service provider agencies and usually less low or moderate income housing options.

*3.General Barriers for Unserved and Underserved:*

Lack of personal relationships that can lead to natural supports and fuller community inclusion.

Scarcity of meaningful employment opportunities needed to provide both the “feeling of self worth” and disposable income necessary to improve quality of life.

Scarcity of transportation, especially in rural areas and during off peak hours.

Lack of access to understandable, easy-to-read information.

Lack of community outreach to individuals and families not already “in the system.”

**G.Rationale for Goal Selection:**

**GOAL #1 Objective #1:**

To provide technical assistance to the Executive Committee of the Council (ExCom), including facilitating meetings for the ExCom, preparing analyses and/or summaries of information based upon the request of the ExCom, and providing organizational consultation as needed.

RATIONALE: This goal provides for the structure, support, planning and informational tools for Council members to act as fully contributing Council members and advocates.

**GOAL #1: Objective #2:**

To provide assistance, as needed, to Council Members to facilitate full participation and informed decision making in all business that comes before the Council and its committees.

RATIONALE: This goal provides for the structure, support, planning and informational tools for Council members to act as fully contributing Council members and advocates.

**GOAL #1: Objective #3:**

To develop and disseminate public education materials that will enhance the positive acceptance of persons with developmental disabilities with an emphasis on employment and job creation.

RATIONALE: This goal will continue the Council’s efforts to have Rhode Islanders accept persons with developmental disabilities in all aspects of community living and view these individuals as valued contributors to civic endeavors. The creation of additional opportunities for meaningful employment will provide both the “feeling of self worth” and disposable income necessary to improve quality of life.



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**GOAL #1: Objective #4:**

To assist the Rhode Island Developmental Disabilities Council and its staff in handling administrative details, and to perform important staff work as an assistant to the Council staff.

RATIONALE: This goal provides for the structure, support, planning and informational tools for Council members to act as fully contributing Council members and advocates.

**GOAL #1: Objective #5:**

To develop a comprehensive State Plan that satisfies Federal Guidelines and that will inform and guide Council activities through the years 2012-2016.

RATIONALE: This goal enables the Council to review and analyze state trends in the service system and community, and identify goals and strategies for increasing the independence, productivity, integration, inclusion and self-determination of Rhode Islanders with disabilities and their families. The process also provides for the Council to gather input from self-advocates and families, so that they might directly influence the priorities designated by the Council for commitment of resources and action.

**GOAL #1: Objective #6:**

To assist the Council's Executive Committee to carry out goals and objectives that includes leadership development and training for self-advocates, family and Council Members.

RATIONALE: This goal provides for the structure, support, planning and informational tools for Council members to act as fully contributing Council members and advocates.

**GOAL #2: Objective #1:**

To coordinate the development of an effective, cross disability, statewide self-advocacy organization. This organization would respond to currently identified and emerging issues on the local and state level. It would focus on:

- More comprehensive implementation of the "Olmstead Decision" and equal access to a wide variety of supports;

- Advocating for changes to Medicaid policies, which will remove or reduce disincentives to employment such as the earned income limit in the (PARI) aged and disabled waiver.

This organization would also maintain affiliation with a national advocacy organization providing similar efforts at the federal level.

RATIONALE: The Council believes that effective change must come directly from the influence of individuals with developmental disabilities. To that end, this goal seeks to empower individuals to effect systems change.

**GOAL #2: Objective #2:**

To annually identify three to five priority emerging issues for system advocacy and to educate key policy makers and legislators regarding the identified issues.

RATIONALE: The Council has been and will continue to be active in systems change advocacy and quality assurance. Objectives to further this goal will cut across several areas of emphasis including Quality Assurance, Employment, Transportation and Housing.



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**GOAL #2: Objective #3:**

To continue the collaborative working group comprised of the DD Network Sister Agencies, RI Developmental Disabilities Council (RIDDC), RI Disability Law Center (P&A) and Paul V. Sherlock Center at RI College (UCEDD) and other advocacy organizations.

RATIONALE: The Council, P&A and UCEDD have been working, and will continue their efforts to increase their mutual impact through collaboratively identifying statewide issues and conducting advocacy, policy analysis, and educational activities, to enable persons with developmental disabilities and their families to exercise greater self-determination.

**GOAL #3: Objective #1:**

To research and demonstrate a model(s) of adult continuing education programs and enhance the access to both specialized and mainstream adult education programs by individuals with disabilities, with an emphasis on courses that will promote better preparation for employment, including vocational and career-related information.

RATIONALE: The Council's research has identified a desire for adult education opportunities by individuals. It also has identified a lack of planning and expectations with regard to adult education for individuals with developmental disabilities. Additionally, in 2005 Rhode Island launched an effort to improve and reorganize adult education in general. The Council wants to take an active role in this improvement and reorganization to assure that individuals with disabilities will be included and well served by the resulting adult education system.

**GOAL #3: Objective #2:**

To support service learning opportunities for all learners, to influence attitudes and behaviors regarding integration and full inclusion of people with developmental disabilities in the community.

RATIONALE: This goal will provide increased opportunities for forming friendships, inclusion and building self-worth on the part of individuals with disabilities. It will also continue the Council's efforts to have Rhode Islanders accept persons with developmental disabilities in all aspects of community living and view these individuals as valued contributors to civic endeavors.

**GOAL #3: Objective #3:**

To promote effective access to the general education curriculum for students with developmental disabilities. To support families/students' advocacy efforts pertaining to universal design for learning<sup>23</sup> and the inclusion of students with developmental disabilities in general education classrooms, in their neighborhood schools. To analyze the outcomes and support the replication of successful practices throughout the state.

RATIONALE: The Council continues to be committed to provide individuals and families with the resources, knowledge and skills to become welcomed, included and contributing members of their community schools.

**GOAL #3: Objective #4:**

To provide leadership and self-determination training opportunities for people with developmental disabilities, parents, family members and service learning students so that they may become effective advocates in influencing public policy at the community, state and national level.

RATIONALE: This goal includes activities to promote self-advocacy training and opportunities as



required in the Development Disabilities Act. This goal seeks to provide individuals and families with the resources, knowledge and skills to become welcomed, included and contributing community members and effective community leaders and advocates. Activities to further this goal cut across many areas of emphasis, including quality assurance, health, education, and early intervention, formal and informal community supports.

## **Section IV – Goals & Objectives**

**GOAL #1:** The Rhode Island Developmental Disabilities Council promotes the development of an individual and family-centered service system. To this end, the Executive Committee (ExCom) will promote and develop information, activities and materials that will assist persons with developmental disabilities to achieve independence, productivity, integration, inclusion and self-determination.

**Objective 1:** To provide technical assistance to the Executive Committee of the Council, including facilitating meetings for the ExCom, preparing analyses and/or summaries of information based upon the request of the ExCom, and providing organizational consultation as needed. (Section 3G, Goal #1, Objective #1)

**Long-Range Planning** Area of Emphasis – Cross Cutting

**Activities:**

Provide orientation training.

- Orientation sessions would be held on four different occasions;
- Sessions would be offered in conjunction with Council staff and/or members.

Develop and implement a process to evaluate the Council’s activities using a methodology designed for evaluating outcomes of selected grantees and activities.

Provide facilitation for the Council’s Annual Meeting & Retreat.

- Planning for the Annual Meeting with the ExCom and staff;
- Facilitating the meeting and retreat.

**Type of Bid Requested: Competitive**

**Total Cost Per Fiscal Year: \$8,000**

**Objective 2:** Provide assistance, as needed, to Council Members to facilitate full participation and informed decision making in all business that comes before the Council and its committees. (Section 3G, Goal #1, Objective #2)

**Assistance for Council Meetings** Area of Emphasis – Community Support

**Activities:**

Make available to any Council Member who requests it a person to provide assistance in review of agendas, documents, materials, etc. prior to Council meetings, committee meetings, retreats and workshops to enable the Council member to more fully participate and make informed decisions.

**Type of Bid Requested: Competitive**

**Total Cost Per Fiscal Year: \$5,000**



**Objective 3:** Develop and disseminate public education materials that will enhance the positive acceptance of persons with developmental disabilities with an emphasis on employment and job creation. (Section 3G, Goal #1, Objective #3)

**Public Education** Area of Emphasis – Cross Cutting

**Activities:**

Research, develop and present a Public Information Plan identifying public information objectives and activities of the Council.

Research, write, take photographs for, produce and distribute four quarterly newsletters, 4,000 copies.

Revise and produce an annual report, black and 1 color, 1500 copies, including photographs.

Summer Recreation Guide - research, write, edit, print and distribute a program listing of inclusive and disability related summer recreation opportunities, 4,000 copies.

Update and maintain the Council's web site on a quarterly basis. Maintain standards for website accessibility according to state and national governmental guidelines.

Revise and produce Council's orientation manual, 10 copies, in 3 ring binders with designed cover (1 color); develop program on a CD or video.

Create a customer satisfaction survey of Council activities to be included in the newsletter.

**Type of Bid Requested: Competitive**

**Total Cost Per Fiscal Year: \$60,000**

**Objective 4:** To assist the Rhode Island Developmental Disabilities Council and its staff in handling administrative details, budgetary, clerical and office work, and to perform important staff work as an assistant to the Council staff. (Section 3G, Goal #1, Objective #4)

**Administrative/Support** Area of Emphasis – Cross Cutting

**Activities:**

Assist Council staff by performing a variety of routine administrative duties relating to planning, coordinating, directing and controlling the policies and functions of the Rhode Island Developmental Disabilities Council.

Assist in planning and organizing the daily operations of the Council, including fielding important information and referral phone calls and e-mails.

Conduct research and gather information for use as a basis for important decisions, as requested.

Assist with studies, analyses and recommendations for proposed changes in policies, programs, and procedures.

Assist in contacting officials and personnel for the purpose of obtaining information and recommendations relating to specific problems, activities or policies.

Handle important and routine verbal, electronic and written correspondence.

Process and maintain important Council documents and procedures.

Maintain Council's database.



Support the activities of the Council's grantees, as requested.

Participate in the processing and maintenance of financial, personnel or other important records.

To conduct, analyze and make recommendations that will improve Council's financial management system to comply with state and federal requirements.

Review, update and maintain financial information for all Council awards and contracts in order to implement accounting procedures that will effectively track and comply with federal and state fiscal years.

Keep Council members and staff apprised of current and future financial issues.

Review Council's database system and recommend improvements and modifications that will streamline the data and information.

Redesign and improve the quality of the data in order to improve the efficiency of the Council's overall and day-to-day operation/function.

Provide computer/tech support and troubleshooting in order to improve the efficiency of the Council's overall and day-to-day operation/function.

**Type of Bid Requested: Competitive**

**Total Cost Per Fiscal Year: \$50,000**

**Objective 5:** To develop a comprehensive State Plan that satisfies Federal Guidelines and that will inform and guide Council activities through the years 2012-2016. (Section 3G, Goal #1, Objective #5)

**Five-Year Plan** Area of Emphasis – Cross Cutting

**Activities:**

Provide Council with a review of research conducted for Council's previous 2007-2011 Five Year Plan and an update of projects completed by Council. Recommend a topical area for further research.

Provide Council with a review of one topical area in the current system, such as new strategies and models of service/support provision being used in other states and countries (as well as models underutilized here in RI).

Provide Council with detailed information on a particular topical area, gathered from three discussion groups and a survey with individuals and families.

Provide Council with a review and analysis of services to persons with developmental disabilities and their families, based upon the review of 16 State Agency Plans.

Provide Council with input from State and private service providers re: the Council's priorities, through the development and dissemination of an agency survey.

Incorporate information gathered from the above activities, together with Council's Five Year Goals and Objectives developed by the Council based upon this information, into the Five Year Plan for 2012-2016.

Solicit public input into the Council's proposed State Plan, through two public forums, and



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incorporate public comment into the Five Year Plan.

Provide technical assistance to the ExCom in writing the Plan and EDS data filing with the Administration on Developmental Disabilities.

**Type of Bid Requested: Competitive**

**Total Cost Per Fiscal Year: \$10,000**

**Objective 6:** To assist the Council's Executive Committee to carry out goals and objectives that includes leadership development and training for self-advocates, family and Council Members. (Section 3G, Goal #1, Objective #6)

**Leadership Development** Area of Emphasis – Quality Assurance

**Activities:** The Council will provide direction to the agency for the following activities:

To work with the Council staff to ensure that all arrangements are made and costs assumed for Council members, staff and relevant members of the DD community, to conduct or attend statewide and national workshops, meetings, conferences and training sessions (i.e., registration fees, lodging, food and transportation) as approved by the Council Executive Committee or its Executive Director;

To support Council members and staff to participate in leadership training opportunities. Leadership training opportunities should include, but not be limited to the following:

Identify, involve, support and advance leaders who are people with developmental disabilities, especially self-advocates and family members to become involved at a state and national level in federal policy development and implementation; and

Establish and sustain multiple strategies, including experiential learning, so that the participants gain a core of knowledge and skills to advance the goals of self-determination and choice through state and national level policymaking, program administration and oversight; and evaluate and publicize the results of the impact of activities from an individual, state and national perspective.

To make arrangements and manage fiscal resources for the Council's Annual meeting;

To purchase educational and other supportive materials as recommended by the Council, to increase Council members and staff knowledge of the state-of-the-art in the field of developmental disabilities.

**Type of Bid Requested: Competitive**

**Total Cost Per Fiscal Year: \$25,000**



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**GOAL #2:** It is the purpose of the System Advocacy Committee (SAC) to identify areas of need for systems change to encourage effective service delivery models, which foster:

- Increased levels of independence;
- Achievement of maximum potential;
- Improved quality of life;
- Meaningful employment opportunities for individuals with developmental disabilities and their families.

**Objective 1:** Coordinate the development of an effective, cross-disability, statewide, self-advocacy organization. This organization would respond to currently identified and emerging issues on the local and state level. (Section 3G, Goal #2, Objective #1)

**Statewide Self-Advocacy** Area of Emphasis – Quality Assurance

It would focus on:

- More comprehensive implementation of the “Olmstead Decision” and equal access to a wide variety of supports;
- Advocating for changes to Medicaid policies, which will remove or reduce disincentives to employment such as the earned income limit in the (PARI) aged and disabled waiver.

This organization would also maintain affiliation with a national advocacy organization providing similar efforts at the federal level.

**Activities:**

Recruit and coordinate a cross-disability coalition among existing Rhode Island self-advocacy organizations interested in jointly pursuing this objective.

Through a Request For Proposals (RFP), provide financial resources for the establishment of a statewide affiliate of a national self-advocacy organization.

**Objective 2:** Annually identify three to five priority emerging issues for system advocacy. Educate key policymakers and legislators regarding the identified issues. (Section 3G, Goal #2, Objective #2)

**Emerging Issues/Educate Policymakers** Area of Emphasis – Cross Cutting

**Activities:**

By November 30<sup>th</sup> annually, either independently or jointly with other agencies, conduct research or public meetings. These efforts will identify three to five priority emerging systems advocacy issues during the next legislative session.

The DDC shall provide dedicated staff support (i.e., consultant) to the SAC to develop, implement and coordinate a plan to educate key policy makers and legislators.

As needed, the SAC will draft legislative or policy recommendations, negotiate with policy makers and legislators, and provide testimony.

**Objective 3:** Continue the collaborative working group comprised of the DD Network Sister Agencies, RI Developmental Disabilities Council (RIDDC), RI Disability Law Center (P&A) and Paul V. Sherlock Center at RI College (UCEDD) and other advocacy organizations. (Section 3G, Goal #2, Objective #3)



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**DD Network Collaboration** Area of Emphasis – Community Support

**Activities:**

Develop and jointly fund a plan for RI's implementation of the US Supreme Court's Olmstead Decision enabling individuals with disabilities to choose to live in the most integrated setting appropriate to their needs. This plan may include:

- Policy analysis
- Legal initiative
- Information dissemination
- Training and public education

Continue to support the Sherlock Center's Project of National Significance Grant to develop a comprehensive support system for parents with disabilities that will enable them to keep their children at home. Activities may include:

- Providing funding for local and regional conferences and training;
- Collaborating on building system infrastructure, providing technical assistance, and information and referral for families;
- Continued participation in the New England Coalition for Supporting Parents with Cognitive Challenges.

Continue to collaborate on and support employment related activities such as the Sherlock Center's Partnerships to Employment Conference.

Collaboratively develop, produce and fund a DD Network quarterly newsletter featuring news and articles of interest to the developmental disabilities community from each of the 3 network agencies.

Continue to participate on each other's boards and committees to improve the goals, objectives, activities and plans of each agency.

Continue to collaboratively participate in committees of state agencies and community organizations that are developing and/or providing services to people with developmental disabilities and their families such as:

- Cash and Counseling
- Consumer Advisory Council for Real Choice System Change Grants
- Trends Analysis Quality Assurance Advisory Committee
- Governor's Cabinet on Chronic and Long Term Care

**Type of Bid Requested: Competitive for Objectives 1 & 2**

**Non-Competitive for Objective 3**

**Total Cost Per Fiscal Year: \$20,000**



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**GOAL #3:** It is the purpose of the Individual & Family Advocacy Committee (IFAC) to support activities designed to develop the capacity of individuals and families to participate fully in their community.

**Adult Continuing Education** Area of Emphasis - Education

**Objective 1:** To research and demonstrate a model(s) of adult continuing education programs and enhance access to both specialized and mainstream adult education programs by individuals with disabilities, with an emphasis on courses that will promote better preparation for employment, including vocational and career-related information. (Section 3G, Goal #3, Objective #1)

**Activities:**

Work jointly with RI Department of Education's (RIDE) consolidation effort to develop a comprehensive plan for adult education.

Research and demonstrate model program(s):

- Year 1 and 2 — Research current program model(s) available in state. Research model programs in other states and Canada. Publish findings.
- Year 3 — Develop RFP for demonstration or replication of model program(s) based on research findings, including financing options.
- Year 4 and 5 — Award grant for demonstration/replication of model program(s) and fully implement. Evaluate results.

Create and publish a statewide Accessible Adult Education Guide and make available in both print and on the internet.

**Objective 2:** To support service learning opportunities for all learners, to influence attitudes and behaviors regarding integration and full inclusion of people with developmental disabilities in the community. (Section 3G, Goal #3, Objective #2)

**Service Learning** Area of Emphasis - Education

**Activities:** Direct specific resources toward technical assistance for schools and youth programs that include programs of service learning on the part of youth with disabilities.

Participate on state and local planning and advisory bodies that plan and finance such programs.

**Objective 3:** Support Inclusive Education — To promote effective access to the general education curriculum for students with developmental disabilities. To support families/students' advocacy efforts pertaining to universal design for learning<sup>24</sup> and the inclusion of students with developmental disabilities in general education classrooms, in their neighborhood schools. Analyze the outcomes and support the replication of successful practices throughout the state. (Section 3G, Goal #3, Objective #3)

**Inclusive Education** Area of Emphasis - Education

**Activities:**

Use RIDE data to identify districts where access to the general curriculum is efficient, cost effective and producing desired outcomes. Identify key components of these districts and develop a presentation to encourage replication. Use RIDE data to identify districts that are less successful



and provide support and incentives to replicate practices of successful districts.

By the end of June of each year, either independently or jointly with other agencies/councils, conduct research, hold public meetings, etc. to identify and prioritize emerging issues related to access to the general education curriculum, universal design, and inclusive education in order to pursue policy changes with RIDE and/or local school district(s) during the following school year.

Provide dedicated staff support (i.e., consultant) to the IFAC to develop, implement and coordinate a plan for educating key policy makers with regard to the identified issues, including, if necessary, drafting of policy change proposals.

**Objective 4:** To provide leadership and self-determination training opportunities for people with developmental disabilities, parents, family members and service learning students so that they may become effective advocates in influencing public policy at the community, state and national level. (Section 3G, Goal #3, Objective #4)

**Self-Determination Training** Area of Emphasis – Quality Assurance

**Activities:** Coordinate and provide support to an advisory panel with diverse community leaders who will assist in recruiting trainees and provide technical assistance.

Recruit trainees and conduct training.

Create opportunities for self advocates to provide training and support to others interested in becoming self advocates.

Develop a pilot project to provide technical assistance to at least one school district to add Civil Rights Advocacy Issues Curriculum at the High School level for all students (including those with disabilities). This may include:

- Rhode Island for Community & Justice (RICJ)
- Martin Luther King, Jr. Nonviolence Training
- The use of members of Advocates in Action as paid trainers in the schools

Include self advocates in evaluation and planning of training activities.

Collaborate with Systems Advocacy Committee (SAC) on establishment of an effective, cross-disability, statewide, self-advocacy organization capable of responding to both currently identified and emerging issues on the local and state level, with affiliations to a national organization, which provides similar advocacy efforts at the federal level.

**Type of Bid Requested: Competitive**

**Total Cost Per Fiscal Year: \$20,000**



## Section V – Assurances

A. Written and signed assurances have been submitted to the ADD Office, Administration for Children and Families, United States Department of Health and Human Services, regarding compliance with all requirements specified in Section 122 (C) (5) (A) – (N) in the Developmental Disabilities Assurance and Bill of Rights Act. A form for assurances is included with the instructions.

B Signed Assurances have been submitted to DHHD. Yes  If no, date when Assurances were/will be mailed:\_\_\_\_\_.

C. Approving Officials for Assurances

1. For the Council (chairperson)
2. For DSA, not Council

## Section VI – Projected Council Budget [Section 125(c)(8)].

If you are only submitting budget year 1, State Plan Amendments will be expected to include subsequent year budgets.

### Budget Year: FY2007

Total Part B Budget Anticipated:.....	\$457,115
Estimated Part B Budget that is allocated to all Areas of Emphasis:.....	\$319,981
General Management (personnel, budget/finance/reporting):.....	\$137,134
Estimated Matching Funds for the Fiscal Year:.....	\$150,848

### Estimated Breakout of Part B Budget Allocated to Areas of Emphasis:

<u>Category</u>	<u>Part B \$:</u>
Employment .....	\$49,619
Housing .....	0
Health .....	0
Education & Early Intervention .....	\$64,619
Child Care .....	0
Recreation.....	\$49,619
Transportation .....	0
Quality Assurance.....	\$84,619
Formal & Informal Community Support.....	\$71,505



## Section VII – Public Review of Plan

Summarize the Council's process for public notice, input and review including how the Council revises the plan to take into account and respond to significant comments.

The Council involved the public in plan development through:

1. Telephone interviews with a randomly selected sample of 232 persons with developmental disabilities receiving services from DDD.
2. Telephone interviews with:
  - 6 heads of service provider agencies
  - 8 school district special education directors.
3. Focus Groups with 67 participants, including:
  - 2 Focus Groups with individuals
  - 2 Focus Groups with Special Education staff
  - 3 Focus Groups with day and residential support staff
  - 1 Focus Group with family members
4. 2001-2005 State Plan was posted on the internet with links requesting feedback.
5. Reports resulting from the telephone surveys and focus groups were also posted on the internet with feedback request links.

A draft state plan was developed using the above input as well as other research to guide the goal setting process. This draft was posted on the internet with feedback links and advertisements were placed for the July 12, 2006 public hearing to take comments on the proposed state plan. Below is a summary of the comments received and the Council's actions taken in response to the comments:

### Public Hearing Comments from Council members

#### Megan:

We are capable of telling others that we care about each other and that we care for other people just like us. In the Council's new orientation slideshow, we should have a voice-over with people on our committees stating what they think and what we should do as a team or a group.

I was at a RIPTA public hearing and they were talking about taking the bus systems out, and I told them my story of how I wouldn't be able to get to places like work, school, visit with family and friends. I use the bus everyday. Without the bus I wouldn't be able to go the places that I need. I told them that we need the buses, not just for me, but for people just like me. For me its my life, because I wouldn't be able to visit with my grandmother.

#### Charlie:

The DD Council is a role model for people with disabilities; we are a good role model for the program here; we should keep the same plan; the DD Council is number one in the state.

#### Anne asked this question for point of clarification:

If you look at the DD act that created the DD Council, it defines a developmental disability as...., so cross disability is inherent in that, is it not? it says that a developmental disability is based on a physical and/or mental impairment of...the legal definition, so it is a cross disability and why would we say that in the plan instead of developmental disability? It was explained that the point of the use of the wording was that we are looking for other disability groups and organizations



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to join with us in a coalition. Anne's final comment was..let's make sure that in this coalition with other disability groups that voices of people with developmental disabilities are heard equally.

### **Section VIII – Evaluation Plan**

Summarize the Council's plan for monitoring, reviewing and evaluating this State Plan at least annually.

The Council has developed outcome indicators for its goals and objectives according to the requirements of the Administration on Developmental Disabilities (ADD). When grants are made, grantees will be required to include an evaluation component in their projects. Grantees and Council staff will evaluate and report annually on progress measured against the outcome indicators for each goal and objective. Annual program performance reports filed with ADD will detail progress on goals and objectives and outline any necessary amendments.

#### **ATTACHMENTS**

A survey of Rhode Island Residents With Developmental Disabilities

Focus Groups Concerning Quality of Life Issues of Rhode Islanders with Developmental Disabilities

Memorandum of Understanding MHRH & RIDDC

# Attachment 1

## Advantage Marketing Information

A survey of Rhode Island Residents  
With Developmental Disabilities Methodology

### Methodology

During the month of July 2003 a sample of individuals with developmental disabilities was interviewed by telephone. When it was not possible to speak with the respondent directly, their caregiver was interviewed.

The sample was provided by the State of Rhode Island, Department of Mental Health, Retardation and Hospitals, Division of Developmental Disabilities after appropriate guarantees were provided regarding the confidentiality of the sample. The completed sample was 232. Each potential respondent was provided with the opportunity in writing to opt out of the study prior to be called.

The instrument/questionnaire utilized in the study was developed in conjunction with Marshall & Associates and the Rhode Island Developmental Disabilities Council.

Section I, Findings, discusses the observations from the consumer/client study. Section II, demographics, describes the respondents and begins on page 11. The findings from a small sample study of agency and special education directors begins on page 14.

### Findings

Generally speaking, the organizations focused on assisting individuals with developmental disabilities have low unaided recall. When the respondents were asked if they had ever heard of the specific organizations listed below, this aided recall showed significantly greater awareness. In short, a substantial number of people with disabilities –but in most cases not a majority – can recall names of statewide organizations focused on people with disabilities – but only if prompted. This suggests that true understanding and awareness of these key organizations is quite low.

Awareness of State Organizations

ORGANIZATION	UNAIDED RECALL	AIDED RECALL
RIDDC or RI Developmental Disabilities Council	4.7%	48.3%
DDD	5.6%	54.7%
Local Special Education Office	5.2%	28.9%
RI Disability Law Center	1.7%	28.9%
RI ARC	15.9%	48.3%
Sherlock Center	3.0%	10.8%
Other	60.3%	Not asked

Note: a list of the ‘other’ organizations mentioned appears in the appendix.

## Advantage Marketing Information

The respondents' ability to offer an overall opinion as to how good the organizations are is also very low. The good news is that for those who were able to comment on each organization, their ratings were much more positive than they were negative.

Opinion of State Organizations

ORGANIZATION	EXCELLENT	GOOD	FAIR	POOR	UNSURE
RIDDC or RI Developmental Disabilities Council	9.1%	16.4%	5.2%	0.4%	69.0%
DDD	13.8%	19.0%	6.5%	1.7%	59.1%
Local Special Education Office	6.5%	9.5%	3.4%	1.7%	78.9%
RI Disability Law Center	6.0%	9.1%	1.3%	0.4%	83.2%
RI ARC	22.0%	20.7%	2.6%	1.7%	53.0%
Sherlock Center	3.0%	3.4%	0.9%	0.0%	92.7%

Given the low awareness of the organizations, it is not surprising to see that most do not know what these key organizations do.

RIDDC's Function

FUNCTION	1 <sup>ST</sup> FUNCTION MENTIONED	2 <sup>ND</sup> FUNCTION MENTIONED
Not sure/don't know	80.6%	95.7%
Other	1.3%	0.9%
Advocacy/lobbying/legislation	4.3%	0.0%
Funding/money	1.3%	0.9%
General assistance for disabled	5.6%	0.0%
Jobs for people with disabilities	0.9%	0.6%
Source of information	0.9%	0.0%
Provide support services (general)	5.2%	2.2%

DDD's Function

FUNCTION	1 <sup>ST</sup> FUNCTION MENTIONED	2 <sup>ND</sup> FUNCTION MENTIONED
Not sure/don't know	71.1%	90.9%
Other	1.7%	1.3%
Advocacy/lobbying/legislation	1.7%	0.0%
Knows social workers	8.6%	0.9%
Finds homes for disabled	3.4%	0.4%
Funding for disabled	2.6%	1.3%
General assistance for disabled	8.2%	3.4%
Manages/oversees group homes	2.6%	1.7%

## Advantage Marketing Information

### Local Special Education Department's Function

FUNCTION	1 <sup>ST</sup> FUNCTION MENTIONED	2 <sup>ND</sup> FUNCTION MENTIONED
Not sure/don't know	88.8%	94.8%
Other	0.4%	0.4%
Communication assistance, parents+ schools	0.9%	0.4%
Controls/manages special ed programs	3.9%	0.0%
Evaluates clients	1.3%	0.0%
General educational assistance	0.4%	0.9%
Place students in programs	3.0%	2.6%
Provide free education to disabled	1.3%	0.4%
Provide support services	0.0%	0.4%

Many have been helped by one or more of the primary organizations focused on helping people with developmental disabilities – with DDD showing the highest utilization.

### Organizations that have helped the respondents

ORGANIZATION	PERCENT HELPED
RIDDC or RI Developmental Disabilities Council	5.2%
DDD	24.1%
Local Special Education Office	9.5%
RI Disability Law Center	3.4%
RI ARC	19.4%
Sherlock Center	1.3%
Other	59.5%

Note: A complete list of 'other' organizations appears in the appendix.

The respondents were asked what services they have received and were encouraged to report up to four services used. The top services include:

- Finding /using social workers
- Help with jobs/work/employment
- Educational assistance
- General support are the most frequently mentioned services.

A more comprehensive list follows.

## Advantage Marketing Information

### Services used by the respondents

The first column represents the percentage of the respondents that mentioned the selected service first; the second column shows the percentage of respondents that mentioned the service second, and so on.

SERVICES	% - 1 <sup>ST</sup>	% - 2 <sup>ND</sup>	% - 3 <sup>RD</sup>	% - 4 <sup>TH</sup>
1 – None/Don't know	35.3	60.8	83.2	94.4
2 – Other	2.2	1.7	2.2	0.4
3 -Day programs	3.0	0.9	0.4	0.0
4 -Educational assistance – general	5.6	3.0	2.2	0.0
5 –Funding	1.7	1.7	0.4	0.0
6 -Group homes – living accommodations	4.3	3.0	0.0	0.0
7 – Health care/medicine	2.6	0.4	1.3	0.0
8 – Jobs/work/employment	8.6	4.7	0.9	0.9
9 – Problem solving – general	0.9	0.9	0.0	0.0
10 – Recreation	3.9	4.7	2.2	0.4
11 – Skills – independent living	1.3	0.4	0.9	0.9
12 – Skills – life training	0.9	0.9	1.7	0.0
13 – Skills – social	0.0	0.9	0.4	0.0
14 – Skills – crafts	0.4	0.0	0.0	0.0
15 – Social opportunities/personal interaction	5.2	4.7	1.7	0.4
16 – Social workers (provide with)	8.6	1.3	0.0	0.0
17 – Support – general	5.2	3.0	0.0	0.0
18 – Therapy – physical	0.9	1.3	0.4	0.9
19 – Therapy – speech	0.4	0.9	0.4	0.0
20 – Transportation	3.9	2.6	1.3	0.9
21 – Workshops	5.2	2.2	0.4	0.4

While some of the respondents are not using any services, a substantial number are using multiple services to improve the quality of their lives.

### Number of services used

NUMBER OF SERVICES USED	PERCENT OF RESPONDENTS
None	34.9%
One	25.9%
Two	23.7%
Three	10.3%
Four or more	5.2%

The respondents were asked to comment on a number of Developmental Disabilities Council publications and programs. Unfortunately, awareness of many of these are quite low.

## Advantage Marketing Information

People are most familiar with human rights training and least aware of the Council’s website. However, it should be noted that Internet use by this group is (unfortunately) very low.

### Developmental Disabilities Council Publications & Programs

PUBLICATION/ PROGRAM	AWARE OF	VERY SATISFIED	SOME- WHAT SATISFIED	UNSURE	SOMEWHAT DIS- SATISFIED	VERY DIS- SATISFIED
DD Council Newsletter	33.3%	32.9%	32.9%	31.5%	1.4%	1.4%
Summer Rec. Guide	32.9%	37.5%	20.8%	30.6%	8.3%	2.8%
Annual Report	22.9%	12.0%	26.0%	56.0%	4.0%	2.0%
Video & Lending Library	16.0%	38.9%	11.1%	47.2%	0.0%	2.8%
Partnerships to employment conference	14.3%	37.9%	20.7%	37.9%	0.0%	3.4%
5 year state plan	15.2%	11.8%	17.6%	64.7%	2.9%	2.9%
Human rights training	42.0%	46.7%	32.6%	19.6%	1.1%	0.0%
Self determination conferences	16.0%	13.5%	35.1%	48.6%	0.0%	2.7%
DD council web site	12.1%	28.0%	32.0%	32.0%	0.0%	8.0%

Note: Ratings are calculated only from the respondents who were aware of the Publication/program.

One function of the project was to assess the importance of a number of services and programs. The data clearly shows that people with developmental disabilities feel strongly about:

- Public education
- Advocacy
- Developing friendships
  - They are also extremely concerned about:
    - Safety
    - Transportation
    - Funding for healthcare

## Advantage Marketing Information

### Importance of alternative skills and services

	VERY IMPORTANT	SOMEWHAT IMPORTANT	NOT VERY IMPORTANT	UNSURE
Learning how to get a job	60.0	13.9	23.5	2.6
Learning how to do a job	66.1	17.0	15.7	1.3
Learning how to live on your own	62.0	13.5	23.1	1.3
Learning how to stay safe	79.0	13.5	7.4	0.0
Information and referral services	59.2	25.4	14.0	1.3
Talking with other people who want the same things as you do	61.4	23.7	12.7	2.2
Making a house accessible	70.0	8.4	19.8	1.8
Personal care services provided in the home or community	37.7	11.9	19.0	1.3
Being able to get a ride where you need to go	76.5	14.6	8.4	0.4
Getting an interpreter for English	53.3	6.7	36.4	3.6
Getting a signing interpreter	59.9	2.6	33.5	4.0
Pursuing educational goals	59.9	15.3	23.4	1.4
Importance of funding for special or adaptive equipment	70.5	6.3	21.0	2.2
Funding for Doctors or medicine	74.2	16.0	8.9	0.9
Public education about the needs of people with developmental disabilities	89.1	8.7	1.3	0.9
Importance of an advocate	89.1	6.6	3.5	0.9
Importance of opportunity to develop friendships and/or spend more time with friends	88.6	9.2	1.7	0.4

When the respondents were asked to rank these issues in priority order, not all peoples' priorities are the same. For example, when asked what is most important, the top responses were:

- Learning how to stay safe, mentioned first by 14.9%
- The opportunity to develop friendships and/or spend time with friends, mentioned first by 14.0%
- Learning how to get a job, mentioned first by 11.8%

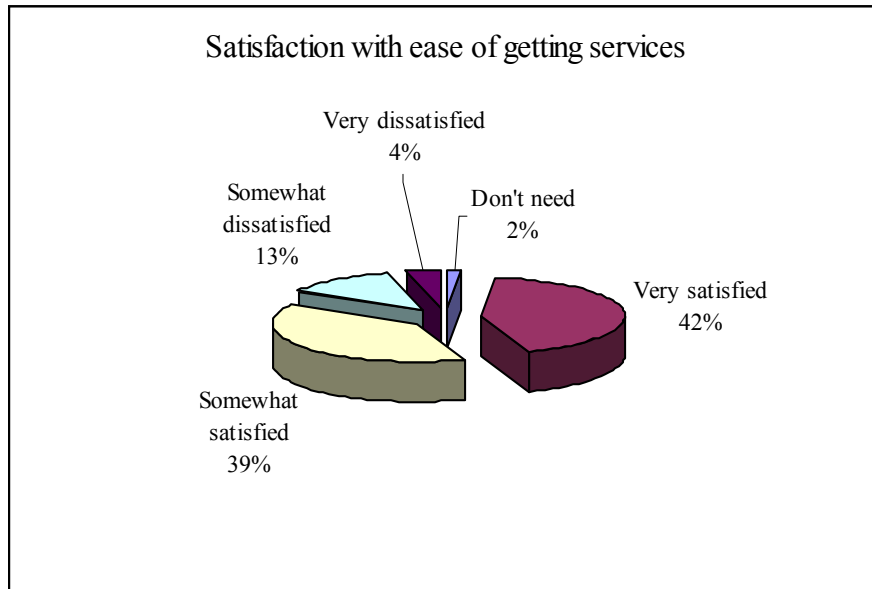
## Advantage Marketing Information

### Ranking importance of alternative skills and services

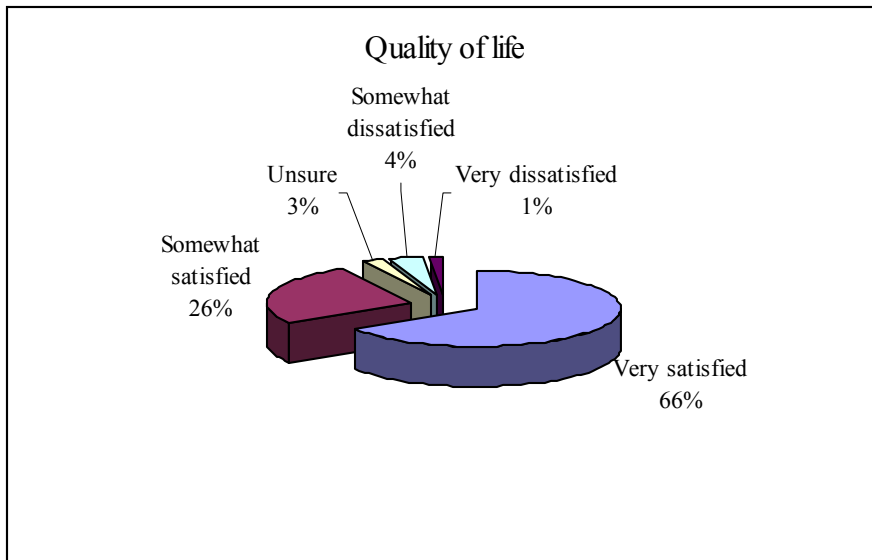
	PERCENT OF RESPONDENTS RANKING ISSUE #1	PERCENT OF RESPONDENTS RANKING ISSUE #2	PERCENT OF RESPONDENTS RANKING ISSUE #3
Don't know	10.9%	21.4%	35.8%
Other	0.0%	0.4%	0.9%
All equally important	2.6%	0.0%	0.9%
Advocacy	0.0%	0.0%	1.7%
Additional funding	0.0%	0.0%	0.9%
Independence	0.0%	0.0%	0.0%
More one-on-one teaching	0.9%	0.0%	0.4%
Public education and outreach	0.4%	0.0%	0.9%
Quality of life	0.0%	0.0%	0.0%
Respect	0.0%	0.0%	0.0%
Support groups	0.0%	0.4%	0.0%
Learning how to get a job	11.8%	9.6%	4.8%
Learning how to do a job	2.2%	6.1%	3.1%
Learning how to live on your own	6.1%	8.3%	7.4%
Learning how to stay safe	14.8%	8.3%	3.5%
Information and referral services	0.4%	3.9%	0.9%
Talking with other people who want the same things as you do	0.9%	2.2%	2.6%
Making a house accessible	7.0%	0.9%	1.3%
Personal care services provided in the home or community	3.1%	4.8%	2.6%
Being able to get a ride where you need to go	5.2%	5.2%	9.2%
Getting an interpreter for English	0.0%	0.9%	0.0%
Getting a signing interpreter	0.0%	1.3%	0.4%
Pursuing educational goals	1.7%	2.6%	0.4%
Importance of funding for special or adaptive equipment	3.9%	4.4%	4.8%
Funding for Doctors or medicine	6.6%	5.2%	3.9%
Public education about the needs of people with developmental disabilities	3.5%	3.9%	5.7%
Importance of an advocate	3.9%	3.1%	2.2%
Importance of opportunity to develop friendships and/or spend more time with friends	14.0%	7.0%	5.7%

## Advantage Marketing Information

For the most part, the respondents are satisfied with the ease of getting services.



It is also important to note that a majority of respondents are very satisfied with their quality of life.



The respondents offered a number of very specific suggestions for changing the way services are provided. While the detailed suggestions follow, the top issues appear to revolve around funding, communication, transportation, faster processes, more host

## Advantage Marketing Information

homes, and better trained and paid staff (note: there may be some bias here in that, in a number of cases, staff completed the questionnaire for the disabled respondent).

More specifically, comments included:

- More personal assistance and technical equipment needed for a home computer, need funding for it.
- Host homes, smaller settings for workshops (maybe 4 or 5 people), have organizations get together and have similar training so everything is uniform.
- To provide support for people who want to further their education; make adjustments to the RIDE program.
- Better transportation for those that need it.
- Legislation/ get the right people elected in office.
- Group homes should continue locally.
- More funding and being more informed to the finances that the handicapped receive.
- It is important to have communication between people with the developmental disability and an advocate.
- Some social workers could spend a little more time with their clients.
- Should have a raise in to parallel cost of living (like in nursing homes) and better funding.
- The field needs to be better paid w/ stricter training programs so it is more prestigious.
- Learn more about independent living in school and challenges in the outside world.
- Families should be paid to take in a person.
- Less red tape in supplying services
- Provide more transportation to various activities and events.
- Vocationally there are not enough opportunities; need more skill opportunities; teaching hands on skill to get a job.
- Provide more services and more attention to those who need it.
- More seminars and training needed.
- System needs more resources and funding. Job coaching is also very important.
- More funding is needed for the programs
- Getting people more aware to what services are available.
- Carpooling would be nice as well as having nurses that really care about their patients.
- It shouldn't take so long to get services to get approved of and established, people need them now.
- People need to be made more aware of what is out there so that they know where to go and what to do to get the help they need.
- The general public should be educated better on disabilities.
- More host homes; smaller settings for workshops; have organizations meet to create similar training programs so that everything is more uniform.

## Advantage Marketing Information

- Get materials out to the community and newsletters out to the parents. Also, help more people find services that they need.
- Better transportation services needed; allowance for working, financially penalized.
- People who work with handicapped people need to be paid more because right now they are not compensated enough.
- More one on one time with care providers, people need to spend more time with them so that they can learn more.
- Groups need to actually meet care provider or child and not just see paperwork to make decisions for care.
- Training of staff needs to be improved, must be sensitive to kids needs.
- Approval of services needed more.
- Needs to be more of an emphasis on speech for people who can't talk; better communication between group home and family.
- More places to get information and support, needs to be easier to acquire.
- Should advertise more.
- Need to listen to the doctors and the parents, public schools should have experience with developmental disabilities. North Providence has inadequate schools, their special education department is terrible.
- Hiring people that care more.
- Have better understanding between individuals.
- Takes WAY too long to process requests. Too many people seemed to be involved, and they don't get back to you right away.
- Better ability for accepting State Health Care Card, Rite Care.
- More "one-on-one" personal contact with disabled individuals, more family involvement.
- It is important for agencies to work together
- Put the person's quality of life first; just housing someone in a community is not enough, need extra help.
- Educating public is very important.
- Needs to be more services.
- Listen to what the client has to say.
- Would like to get out more.
- More people need to be alert to replace staff that cannot come in.
- Programs need to be more accessible.
- Need more medical help; need doctors, psychologists, prescriptions, etc.
- People need to be more aware of what services and opportunities are available.
- Funding takes too long to obtain.
- When a client is past a certain age, provide better information on where places are, what there is to do for their age group, etc. Also, more funding is needed.
- Need a service in Foster, for the northwestern section of RI.
- Dentists that don't cost too much should be offered for people with disabilities who can't work; daughter needs more training with speech in school.
- Make the system simpler to use.

## Advantage Marketing Information

- Providing exercise opportunities and physical therapy instead of watching movies all the time.
- More information on the Internet.
- Would like to see some more group homes for older persons who can get more specific care.
- More education should be offered more publicly.
- More information and referral services.
- Training new staff better (group homes) and more funding to keep good people longer.
- Deal more directly with the person (disabled individual) and not with other people.
- Empower parents and advocates to help people get the support they need. Increase taxes?

### Section II - Demographics

The respondents were fairly evenly spread throughout the age population.

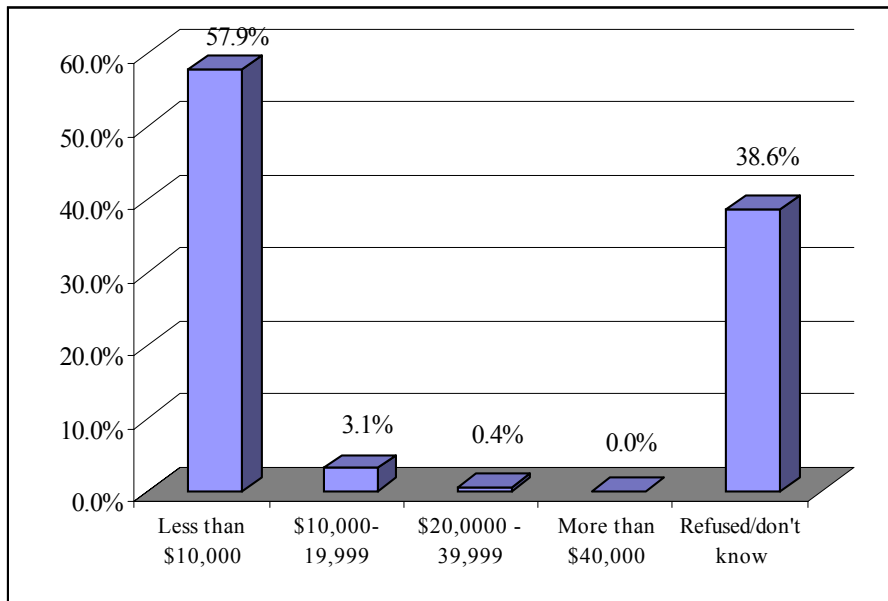
AGE	PERCENT OF RESPONDENTS
11 – 18	0.4%
19 – 21	7.5%
22 – 34	31.1%
35 – 44	21.1%
45 – 54	20.6%
55 – 64	11.0%
65 – 75	2.2%
75+	0.9%
Refused	5.3%

Most respondents live in relatively small ‘households.’

NUMBER IN HOUSEHOLD	PERCENT OF RESPONDENTS
One	10.1
Two	15.8
Three	26.3
Four	17.5
Five	10.5
6-10	16.2
11+	3.4

## Advantage Marketing Information

Individual income, as can be seen, is not high.



41.3% of respondents report that their income is sufficient; 47.1% state that it is not while 0.6% had some other comment to make and 11.0% were not really sure.

- 46.7% are female
- 53.3% were male

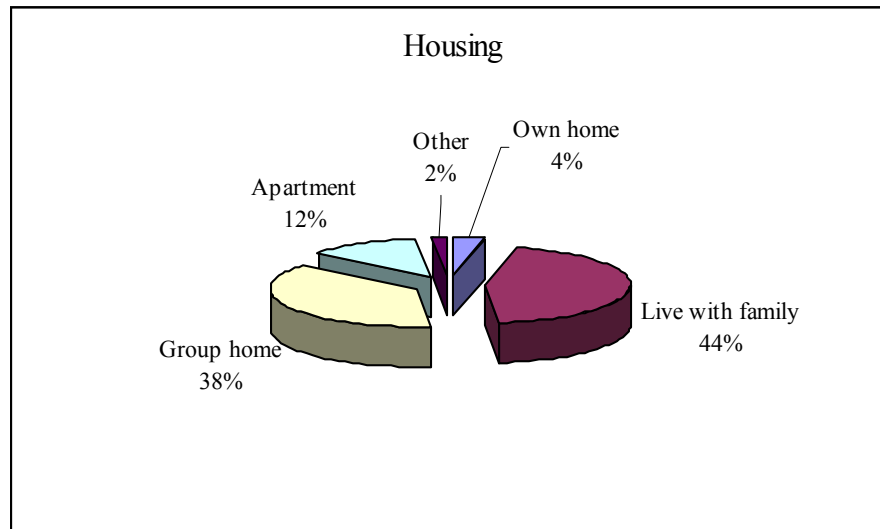
Not surprisingly, the majority speaks English at home (86.8%). No single language dominates among those not speaking English.

COUNTY OF RESIDENCE	PERCENT OF RESPONDENTS
Providence	50.7%
Kent	18.9%
Bristol	4.8%
Newport	8.8%
Washington	12.8%
Unsure	4.0%

- 64.9% are employed
  - 35.7% work full time
  - 64.3% work part time
    - 86.9% indicate part time status is by their choice
    - 4.1% prefer full time work
    - 9.0% don't know

## Advantage Marketing Information

- 0.9% are students
- 34.2% are not employed
  - Of those who are unemployed, 48% would like work



Most of the respondents are satisfied with their living accommodations.

- 89.8% like where they live
- 7.5% would prefer to be elsewhere
- 2.6% are unsure

Only 20.3% of this group reports Internet usage – making communication via the web less effective than with other populations

## Advantage Marketing Information

### *Section III – Findings Small Sample Survey Agency & Special Education Directors*

A small sample survey was conducted among two groups heavily involved in the area of developmental disabilities; Agency representatives and special education directors. Specifically, 6 agency heads and 8 special education directors were interviewed by telephone during the month of July 2003. The findings should be viewed as providing a ‘sense’ of the thinking of these groups. However, with the small sample size, caution should be used when evaluating the results.

Not surprisingly, awareness of the key players in developmental disabilities is high.

Unaided Awareness of State Organizations

ORGANIZATION	AGENCY	SPECIAL ED DIR.
RIDDC or RI Developmental Disabilities Council	100%	75%
DDD	100%	100%
Local Special Education Office	100%	0%*
RI Disability Law Center	100%	87.5%
RI ARC	83.3%	100%
Sherlock Center	0%	0%
Other	33.3%	0%

\* Note: The wording of the question was such that Special Education Directors might have interpreted the question as ‘other groups, not including themselves.’

There are some mixed reactions to RIDDC, especially as expressed by agency representatives. Specifically, 16.7% ranked RIDDC poor, 66.7% good and 16.7% excellent. IN the case of the education directors, the opinions were mixed between don’t know (33.3%) and good (66.7%).

In terms of RIDDC activities, both groups agreed at the same rate that the top job of RIDDC is to advocate. Agency heads then spoke of information sharing, protecting rights, and a negative ‘not too productive’ while Spec Ed respondents focused on helping disabled students, providing information and generally meeting needs of disabled.

Agency heads appear to be significantly more familiar with RIDDC products than are special education directors. However, even the agency head awareness estimates suggest relatively low awareness of the full range of RIDDC capabilities. Among special education directors, ‘ignorance’ is the norm. If these special education directors are important to achieving RIDDC’s goals, more attention may want to be directed in this area.

## Advantage Marketing Information

Agency head opinions regarding RIDDC Council publications & programs  
(In Percent)

PUBLICATION/ PROGRAM	AWARE OF	VERY SATISFIED	SOME- WHAT SATISFIED	UNSURE	SOMEWHAT DIS- SATISFIED	VERY DIS- SATISFIED
DD Council Newsletter	100	50.0	50.0	0.0	0.0	0.0
Summer Rec. Guide	66.7	33.3	16.7	50.0	0.0	0.0
Annual Report	66.7	16.7	33.3	50.0	0.0	0.0
Video & Lending Library	33.3	0.0	33.3	6.7	0.0	0.0
Partnerships to employment conference	33.3	16.7	16.7	66.7	0.0	0.0
5 year state plan	50.0	0.0	33.3	66.7	0.0	0.0
Human rights training	100	50.0	50.0	0.0	0.0	0.0
Self determination conferences	66.7	0.0	33.3	67.6	0.0	0.0
DD council web site	66.7	16.7	0.0	83.3	0.0	0.0

Special Education Directors opinions of RIDDC publications & programs  
(In Percent)

PUBLICATION/ PROGRAM	AWARE OF	VERY SATISFIED	SOME- WHAT SATISFIED	UNSURE	SOMEWHAT DIS- SATISFIED	VERY DIS- SATISFIED
DD Council Newsletter	62.5	12.5	25.0	62.5	0.0	0.0
Summer Rec. Guide	100	62.5	12.5	25.0	0.0	0.0
Annual Report	62.5	0.0	0.0	100.0	0.0	0.0
Video & Lending Library	12.5	0.0	0.0	100.0	0.0	0.0
Partnerships to employment conference	50.0	00.0	25.0	75.0	0.0	0.0
5 year state plan	50.0	0.0	12.5	87.5	0.0	0.0
Human rights training	37.5	0.0	25.0	75.0	0.0	0.0
Self determination conferences	50.0	0.0	25.0	75.0	0.0	0.0
DD council web site	12.5	0.0	0.0	100.0	0.0	0.0

## Advantage Marketing Information

Both the agency heads and special education directors were asked to evaluate the programs currently in place to help disabled citizens. Generally speaking, the programs were rated as being fair to good.

### Agency heads (In percent)

RATING OF CURRENT PROGRAMS	EXCELLENT	GOOD	FAIR	POOR	DK/ NO ANSWER
Finding a meaningful job	0.0	33.3	0.0	16.7	50.0
Living more independently	0.0	66.7	16.7	0.0	16.7
Access to public places	0.0	50.0	16.7	0.0	33.3
Public transportation	0.0	16.7	66.7	0.0	16.7
Access to recreational opportunities	16.7	50.0	16.7	0.0	16.7
Voting	16.7	66.7	0.0	0.0	16.7
Access to English interpreters	0.0	16.7	0.0	0.0	83.3
Access to signing interpreters	0.0	50.0	16.7	0.0	33.3
Continuing ed. for those over 21	0.0	33.3	33.3	0.0	33.3
Obtaining adaptive equipment	0.0	33.3	33.3	0.0	33.3
Health care programs	0.0	66.7	0.0	16.7	16.7
Public education programs RE D. D.	16.7	0.0	66.7	0.0	16.7
Programs that help transition from work to school	0.0	0.0	33.3	16.7	50.0

### Special education directors (In percent)

RATING OF CURRENT PROGRAMS	EXCELLENT	GOOD	FAIR	POOR	DK/ NO ANSWER
Finding a meaningful job	0.0	37.5	62.5	0.0	0.0
Living more independently	12.5	37.5	50.0	0.0	0.0
Access to public places	0.0	75.0	25.0	0.0	0.0
Public transportation	12.5	50.0	37.5	0.0	0.0
Access to recreational opportunities	12.5	12.5	50.0	12.5	12.5
Voting	0.0	50.0	12.5	0.0	37.5
Access to English interpreters	12.5	12.5	25.0	25.0	25.0
Access to signing interpreters	12.5	50.0	0.0	25.0	12.5
Continuing ed. for those over 21	0.0	0.0	75.0	12.5	12.5
Obtaining adaptive equipment	0.0	50.0	37.5	0.0	12.5
Health care programs	37.5	37.5	12.5	0.0	12.5
Public education programs RE D. D.	0.0	50.0	50.0	0.0	0.0
Programs that help transition from work to school	0.0	62.5	37.5	0.0	0.0

## Advantage Marketing Information

According to special education directors:

- 62.5% have an adult education program for the general public
- 66.7% report that people with developmental disabilities participate in their adult education programs
- Only 16.7% have programs designed specifically for the developmentally disabled
- When asked what can be done to help school districts better prepare students for transition from school to work, each respondent commented differently. Their observations include:
  - Excite employers about people with DD
  - More public transportation
  - Currently satisfied
  - More links with others
  - Get involved earlier
  - More involvement from outsiders (to the system)

The agency director respondents stated that they are involved in the following activities:

- Independent living support
- Residential (3)
- Elderly day care
- Job placement/physical therapy

When asked what could be done to make it easier for their agencies to assist people with developmental disabilities in living more independently, the comments included:

- DDD stop being paternalistic
- Build more affordable housing
- Provide more clients
- Accessible transportation
- More funding

Suggestions for making it easier to assist people in finding meaningful employment include additional funding, economic incentives for employers, transportation, and encouraging employers to be more flexible.

For the most part, only about 1/3 agency heads believe that any of their clients are involved in continuing education.

**Advantage Marketing Information**

*Appendix 1*  
*Responses to Open Ended Comments*  
*Developmental Disabilities Survey 2003*

## Advantage Marketing Information

Question 1G – Other (note: 3-digit numbers are survey numbers)

- 001 – Forbes Street
- 002 – Greenville Rd.
- 003 – Grand Ave.
- 004 – Heritage Village
- 005 – Jamestown Village
- 007 – Refocus Inc.
- 008 – Oscar
- 009 – Fogarty Cty
- 019 – Community Care Nurses at RI
- 020 – Trudeau Center
- 021 + 022 – Trudeau Center, Meeting St. School
- 023 - MHRH
- 024 – Trudeau Center
- 025 – Maher Center
- 031 – Blackstone Valley
- 033 – Maher Center
- 034 – Bradley Hospital; Houghton St.
- 036 – Trudeau Center
- 037 – No. East; Cranston Center
- 038 – No. RI Arc
- 039 – Le Plant
- 041 – Park View School
- 042 – Trudeau
- 046 – Maher Center; Looking Upwards
- 047 – Blackstone Valley Center
- 048 – Pal; Self Advocacy Group
- 049 – UCP
- 050 – RIDE; Olean Center
- 052 – Fogarty Center
- 058 – Fogarty Center
- 061 – Citizens w/ Power Advocacy Group
- 062 – Trudeau
- 063 – America
- 064 – Meeting St. School; West Bay Group
- 065 – Fogarty Center
- 067 – Dep. Of Mental Health
- 068 – Refocus
- 069 – Trudeau
- 070 – Trudeau
- 071 – Gateways
- 072 – Trudeau
- 073 – PAL; Self Advocacy
- 074 – Fogarty Center
- 075 – Pal
- 076 – Cranston Center; West Bay Group; Blackstone Valley Center
- 077- Blackstone Valley
- 080 – Blackstone Valley
- 081 – Pals
- 082 + 083 – UCP; Shriners
- 085 + 086 – Trudeau
- 087 – Spectrum Center; Groden Center
- 088 – Groden Center; Trudeau
- 090 – Fogarty; Bucklin
- 091 – Advocates in Action
- 092 – Cranston Voices
- 095 – Fogarty
- 096 – Pal; Maher; Little Compton Community Center
- 097 – Maher Center
- 098 – Advocates in Action
- 099 – Advocates in Action
- 101- Special Olympics
- 102 – RI Clas
- 104 – Maher; Pals
- 105 – Oscar; Trudeau; RI Special Olympics
- 107 – Blackstone Valley
- 110 – Blackstone Valley
- 111, 112, + 113 – Maher Center; Pal
- 116 – Trudeau
- 118 – Maher Center
- 119 – La Plante Center
- 121 – Cove Center

## Advantage Marketing Information

- 122 – Maher Center; Looking Upwards
- 123 – New England RMS
- 124 – Riclas
- 125 – Blackstone Valley
- 126 – Olean Center
- 127 – Advocates in Action
- 128 – Le Plante Center
- 129 – Summit RI for handicapped; Cerebral Palsy of RI
- 130 – Arc of RI; Gateways
- 133 – Human Rights
- 134 – Special Olympics
- 136 – Church, Special Olympics
- 137 – Cove Center
- 138 – Moorefield Home
- 139 – TTP
- 142 – Advocates in Action
- 143 – ORS
- 149 – Project Friends; RIDE
- 151 – Gordon Center; Cove Center
- 153 – Northern Collaborative; SSI
- 155 – Sound and Sight Association of RI; Trudeau
- 159 – UCP; Blackstone Valley
- 162 – Looking Upwards
- 169 – Special Olympics
- 170 – Trudeau
- 171 – Mental Department of Health
- 172 – Visiting Nurses
- 174 – Pal
- 175 – Oscar
- 176 – Trudeau
- 179 – Perry Independent Living
- 180 – Self Advocacy
- 181 – Le Plante
- 182 – Behavior Review Bd.; Special Olympics; Pal
- 184 – Cranston Center
- 186 – RI Collaborative
- 191 – Pals
- 193 – Perspectives; South Shore
- 195 – Perspectives
- 196 – Advocates in Action; Freedom Friends
- 197 – Pal; Fogarty; Community Living of RI
- 199 – Blackstone Valley
- 200 – Life Inc.
- 201 – Looking Upwards
- 202 – PARI
- 203 – Maher Center
- 204 – Le Plante
- 207 – Tollman H.S.; Blackstone Valley; ARC
- 208 – Blackstone Valley
- 209 – Pal; Oscar
- 211 – Fogarty Center; Petillo Center
- 214 – Pal
- 215 – Arc of Northern RI
- 216 – Cove Center
- 218 – Trudeau
- 220 – Perspectives
- 222 – Fogarty Center
- 223, 224, 225, 226, + 227 – Services for the blind; OTBT
- 228, 229, 230, + 213 – Office of Quality Insurance; Fogarty Center; Human Rights Committee
- 232 – Life Inc.; Blackstone Valley
- 233 – ORS; Looking Upwards

## Advantage Marketing Information

### Question 3g – other

- 001 – Forbes Street, B. Valley
- 002 – Greenville Rd.
- 003 – Grand Ave.
- 004 – Heritage Village
- 005 – Jamestown Village
- 007 – Refocus Inc.
- 008 – Oscar
- 009 – Fogarty Cty.
- 021 + 022 – Trudeau Center, Meeting St. School
- 031 – Blackstone Valley
- 033 – Maher Center
- 034 – Bradley Hospital; Houghton St.
- 036 – Trudeau
- 037 – No. East; Cranston Center
- 038 – No. RI Arc
- 039 – Le Plant
- 041 – Park View School
- 042 – Trudeau
- 049 – UCP
- 052 – Fogarty Center
- 058 – Fogarty Center
- 061 – Citizens w/ Power Advocacy Group
- 062 – Trudeau
- 063 – America
- 064 – Meeting St. School; West Bay Group
- 065 – Fogarty Center
- 067 – Dep. Of Mental Health
- 068 – Refocus
- 069 – Trudeau
- 071 – Gateways
- 074 – Fogarty Center
- 076 – Cranston Center; West Bay Group; Blackstone Valley Center
- 077 – Blackstone Valley Center
- 080 – Blackstone Valley
- 081 – Pals
- 085 + 086 – Trudeau
- 087 – Spectrum Center; Groden Center
- 088 – Groden Center; Trudeau
- 090 – Fogarty; Bucklin
- 091 – Advocates in Action
- 092 – Cranston Voices
- 095 – Fogarty
- 096 – Pal; Maher; Little Compton Community Center
- 097 – Maher Center
- 098 – Advocates in Action
- 099 – Advocates in Action; Self Advocacy Groups
- 102 – RI Clas
- 104 – Maher; Pals
- 105 – Oscar; Trudeau; RI Special Olympics
- 107 – Blackstone Valley
- 109 – Blackstone Valley
- 111, 112, + 113 – Maher Center; Pal
- 116 – Trudeau
- 118 – Maher Center
- 119 – La Plante Center
- 121 – Cove Center
- 122 – Maher Center; Looking Upwards
- 123 – New England RMS
- 124 – Riclas
- 134 – Special Olympics
- 137 – Cove Center
- 138 – Moorefield Home
- 139 – TTP
- 142 – Advocates in Action
- 149 – Project Friends; RIDE
- 159 – UCP; Blackstone Valley
- 169 – Special Olympics
- 174 – Pal
- 176 – Trudeau
- 179 – Perry Independent Living
- 180 – Self Advocacy

## Advantage Marketing Information

- 181 – Le Plante
- 182 – Behavior Review Bd.; Special Olympics; Pal
- 184 – Cranston Center
- 186 – RI Collaborative
- 191 – Pals; Self Advocacy
- 193 – Perspectives; South Shore
- 199 – Blackstone Valley
- 200 – Life Inc.
- 201 – Looking Upwards
- 202 – PARI
- 203 – Maher Center
- 204 – Le Plante
- 207 – Tollman H. S.; Blackstone Valley; Arc
- 208 – Blackstone Valley
- 209 – Pal; Oscar
- 211 – Fogarty Center
- 214 – Pal
- 216 – Cove Center
- 220 – Perspectives
- 222 – Fogarty Center
- 232 – Life Inc.; Blackstone Valley

## Advantage Marketing Information

### Question 4a)

- 014 – Executive type branch?
- 023 – Provides funding, helps with the quality of life, works with people to help with developmental disabilities, and provides social workers.
- 026 – Help people out by talking to each other.
- 029 – Very little, support for people.
- 042 – Helps adults with disabilities
- 048 – Advocacy Group
- 049 – Help with work.
- 055 – Advocates
- 071 – Advocacy; Training Issues
- 075 – Puts out a magazine.
- 078 – Learning
- 082 + 083 – Provide services and fight for more funding to support their programs.
- 085 + 086 – Not much, don't know specifics.
- 093 – Program for independent living.
- 099 – Executive type branch; licensing
- 101 – Help get jobs; get people involved with groups
- 103 – Handles services for handicapped.
- 104 – Meetings with parents.
- 109 – Provides services on an individual basis and direct people to various resources.
- 110 – If you have needs you can go to them but she's not sure if they actually help.
- 117 – Help get legislature passed.
- 120 – Involved in advocacy and education efforts for public as well as transportation.
- 130 – Provides workshops and other such programs
- 140 – Funding and education? Not sure.
- 147 – Support for individuals.
- 152 – Help give funding for low-income families.
- 155 – Help with support and services; help with rights of people and make sure they are respected.
- 165 – Help people from different organizations; social worker
- 174 – Social workers come through; assist in giving information for services that are available.
- 214 – Hold meetings, update old information, and answer questions.
- 223, 224, 225, 226, + 227 – Support systems
- 228, 229, 230, + 213 – Quality of services plan.
- 233 - Advocates

## Advantage Marketing Information

### Question 5a)

- 013 – Is aware of social workers.
- 015 – Is aware of social workers.
- 018 – Is aware of social workers.
- 021 + 022 – Supplies funds for handicapped to do various things.
- 028 – Is aware of social workers.
- 029 – Is aware of social workers.
- 030 – Is aware of social workers.
- 032 – Investigation; social workers.
- 046 – Find people different centers.
- 048 – Is aware of social workers.
- 053 – Is aware of social workers.
- 055 – Is aware of social workers.
- 071 – Provides residential programs, coordinates services for people with developmental disabilities and quality control.
- 072 – Support people with developmental disabilities.
- 073 – Advocacy; investigate wrongs done and then asses them; placement
- 075 – Helps handicapped.
- 078 – Learning, also knows about social workers.
- 079 – Knows about social worker.
- 080 – Knows of the social workers, and that they help people with mental retardation.
- 082 + 083 – Is aware of social workers.
- 085 + 086 – Deals with placement of clients.
- 101 – Get clients into jobs; working with rides?
- 104 – Part of Pals
- 105 – Occupational and daily livings
- 107 – Has talked to a couple people from there to possibly get funding through them.
- 109 – Yes, has a social worker that is excellent.
- 110 – Is aware of social workers, Don Gardner is very good.
- 111, 112, + 113 – Oversees all group homes.
- 115 – Oversees that people's good quality of life standards are met.
- 117 – Funding; gives support; provides social workers.
- 131 – Represent and oversee care of clients.
- 143 – Gives resources within state.
- 144 – Provides residential funding and support staff.
- 172 – Place people in group homes.
- 174 – Offer other services and assist individuals with complaints.
- 175 – Given information on respite services and title 19.
- 191 – Is aware of social workers.
- 193 – Help people with ADD, ADHD, etc
- 194 – Advocates for developmentally disabled.

## **Advantage Marketing Information**

- 196 – Get information out to groups; inform people what rights and services they have.
- 197 – Manage money, find services for disabled within the community.
- 211 – Help with problems that may arise.
- 219 – Is aware of social workers.
- 228, 229, 230, + 213 – Referrals that people with developmental disabilities go to.

## Advantage Marketing Information

### Question 6a)

- 021 + 022 – Integrates handicapped people to various levels in the community.
- 026 – Look for jobs.
- 029 – In control of Special Ed.
- 042 – Help educate people and place people with disabilities in programs.
- 055 – Special Ed. Services for children, IEP
- 071 – Provides special and individualized education.
- 085 + 086 – Helps kids in school get summer jobs, etc.
- 101 – Assist social workers
- 109 – Yes, has a special ed. Direct
- 110 – Help out with education; give available programs.
- 120 – Provides free and appropriate education for all persons 21 and under.
- 131 – Help with education.
- 151 – Helps out people who have disabilities.
- 153 – Offer scholastic education referral to other places; explain services that are available.
- 172 – Place people in school programs, work with schools and parents, and offer other support services.
- 187 – Provides communication between parents and school department; gives information to parents about programs and services.
- 189 – Would like to see his daughter working on sign language and speech therapy.
- 192 – Evaluate clients; have an education program.
- 196 – Coordinate ISPs and integrate students.
- 214 – Teaching, placement, and guidance for residence.
- 219 – Kids are referred there for learning and physical services.

### Question 6b)

- 071 – Has the ability to transition to adult services network.

## Advantage Marketing Information

### Question 8a-d)

- 002 – Physical Therapy; Transportation; Daily Living Skills
- 003 – Volunteer Work; Transportation; Recreation; Physical Therapy; Living Speech Therapy
- 005 – Living; Transportation
- 007 – Transportation; Living; Recreation
- 008 – Transportation; Recreation; Social
- 009 – Transportation; Work
- 010 – Give funds; Pay for your life line
- 013 – Workshop; Social Worker
- 015 – Recreation; Workshop
- 016 – Social Worker; Workshops
- 018 – Social Worker; Therapist
- 020 – Activities
- 021 + 022 – Special Education Office; Gateway Center Activity
- 023 – They helped him to become more independent and improve the quality of his life, also used the rec center.
- 024 – Work; Interaction with group of peers
- 025 – Crafts; Socializes
- 028 – Social Worker
- 029 – Helped with schoolwork.
- 031 – Workshop; Group home
- 032 – Social Worker; Advocacy
- 033 – Transportation; Education; Recreation
- 034 – Test + Education; Work
- 036 – Social; Work; Transportation
- 037 – Respite Care
- 038 – Home Care; Employment; Social + Rec.; Formerly Educational
- 039 – Work; Recreational + Social; Transportation
- 040 – Transportation; Social + Rec
- 041 – Education; Transportation
- 042 – Recreational; Social
- 044 – Social
- 045 – Recreational (Special Olympics)
- 047 – Employment; Independence
- 048 – DDD; Self Advocacy
- 049 – Socialization
- 050 – Employment
- 051 – Social Worker
- 052 – Volunteering; Job Training; Skills
- 053 – Social Worker; Job Training; Workshop
- 054 – Transportation, Employment
- 055 – Social Worker; Recreation; Respite

## Advantage Marketing Information

- 056 – Social Worker; Employment
- 057 – Social
- 058 – Employment Opportunity
- 062 – Transportation; Social; Recreation
- 063 – Communications
- 064 – Social; Educational
- 066 – Employment; Transportation
- 067 – Provides Medicine; Education
- 068 – Transportation
- 069 – Employment; Social
- 070 – Projects
- 071 – Educational; Support
- 072 – Support
- 073 – Placement
- 074 – Sheltered workshop; Employment
- 075 – Day Programs, Speech, Residential Programs
- 076 – Day Programs; Physical Therapy
- 077 – Respite Care
- 078 – Support; Workshops
- 079 – Workshop
- 080 – Employment; Social Worker; Education
- 081 – Social Worker; Placement; Transportation; Support
- 082 + 083 – Workshop; PT provided; Speech Therapy
- 084 – Medical; Workshop; Recreation
- 085 + 086 – Workshops; Living Skills; Therapy
- 087 – Social Functions; Elementary Education
- 088 – Recreation; Social; some Education
- 091 – Social + Rec; Educational
- 092 – Recreational
- 094 – Employment; Recreational; Transportation
- 095 – Education
- 096 – Social + Recreational; SPREAD Program
- 098 – Attends meetings
- 101 – Placement; Support
- 102 – Educated on independent living
- 103 – Occupational Physical Therapy
- 104 – Assistance with problems
- 105 – Social; Physical Therapy
- 106 – Medical; Recreational
- 107 – Educational Assistance
- 109 – Social Worker; School Services (special ed.)
- 110 – Has a wonderful social worker and the state gave him a CAN while mother was at work.
- 111, 112, + 113 – Day program services.

## Advantage Marketing Information

- 115 – Attends day program
- 116 – Workshops; Employment; Education; Recreational
- 117 – Social Worker; Information on funding
- 118 – Employment; Transportation
- 119 – Recreational; Medical
- 120 – Employment; Recreational Activities
- 121 – Funding for adult services and day programs.
- 122 – Everything! Provides staff, money for bills, etc.
- 126 – Day programs; Workshops; Employment
- 128 – Employment
- 129 – Recreational
- 130 – Recreational
- 131 – Provides various services
- 144 – Funding
- 146 – Assistance; Support
- 149 – Recreational; Educational; Transportation
- 155 – Assistance; Support
- 158 – Workshops; Employment
- 159 – Education/Recreational; Funding; Medical
- 160 – Assistance
- 162 – Residential Assistance
- 165 – Placement; Social Worker
- 167 – Recreational – Special Olympics
- 171 – Educational; Psychologist
- 172 – Support
- 173 – Social Worker
- 174 – Assistance
- 175 – Case Worker; Residential Assistance
- 183 – Friendships
- 184 – Programs; Meetings
- 186 – Pilot program
- 189 – Tried to get speech therapy in to the Pleasant View School.
- 191 – Social Worker/ Advocate
- 192 – Workshops; Employment
- 193 – Employment; Educational Assistance
- 195 – Housing; Employment; Support
- 196 – Informational Assistance; Funding
- 197 – Support; Workshops; Education
- 199 – Receives Training
- 200 – Housing
- 201 – Employment; Social Activities
- 203 – Employment
- 204 – Employment
- 207 – Transportation

## Advantage Marketing Information

- 208 – Education
- 209 – Activities
- 211 – Medical Assistance
- 212 – Employment
- 213 – Future Planning Assistance; Financial Assistance
- 214 – Speech Therapy
- 215 – Employment
- 218 – Recreational Activities
- 219 – Education; Money for tuition
- 220 – Life Skills Training; Employment
- 232 – Residential Assistance
- 233 – Educational; Conferences

## Advantage Marketing Information

### Question 12a-c)

- 023 – Being independent, maintaining good qualities of life, and being productive.
- 049 – Interaction outside his home
- 054 – All equally important
- 079 – They are all important.
- 099 – Advocate for themselves; friends; job training
- 106 – Someone to be there for her.
- 108 – More one on one time for teaching
- 115 – Individually all are important, depends on the individual and their needs really.
- 121 – Public needs to be educated; making friends is really important; pursue community activities.
- 124 – Getting the public to understand.
- 126 – Having friendships and raising public awareness.
- 127 – Public should be more educated.
- 128 – Have human rights respected.
- 130 – General public should be more educated.
- 134 – Jobs, being safe, and transportation.
- 135 – Friendships!
- 146 – Counselors, friends, support groups
- 148 – Job; Safety; RIDE
- 172 – Having an advocate.
- 173 – Developing friendships
- 198 – Special Olympics
- 209 – Fire Safety
- 211 – Educating the public as well as advertising what help is out there for people with developmental disabilities.
- 221 – More funding.
- 228, 229, 230, + 213 – People to advocate for the developmentally disabled.

## Advantage Marketing Information

### QUESTION 13) (OPTIONS 4 or 5)

- 016 – He wanted to further his education and it was made impossible.
- 019 – Not easily accessible, lack of money
- 031 – Money is not there.
- 035 – Takes too much time and red tape, not enough money available either.
- 037 – Too much red tape, “too many chiefs, not enough Indians”
- 050 – Funds aren’t there in programs.
- 052 – Need to provide recreation for the weekends.
- 057 – Not as accessible as possible.
- 077 – Unsatisfied with getting transportation, speech therapy and physical therapy.
- 078 – Has to fight for services.
- 080 – Blackstone Valley never helped her like they should have; one of the nurses there was real mean to her.
- 103 – Too much of a project to get things done; need to make getting help easier!
- 105 – Too much of a hassle to uncover all the information needed to get the assistance he needs, and its not readily available.
- 119 – Have to fight for everything, so much of a hassle to get help.
- 121 – Special education departments not listening to the educators.
- 143 – Process is very difficult; social worker should explain services.
- 144 – Need more services and more supervision if developmentally disabled people live independently.
- 147 – Hard to find; have to find it yourself, too much red tape.
- 166 – Has to fight to get any kind of assistance or services.
- 188 – In Foster, there is nothing available.
- 220 – Must fight to get anything.
- 233 – There as been a struggle; takes a very long time. Not enough funding.

## Advantage Marketing Information

### Question 14)

- 010 – Would really like this: To see more personal assistance and technical equipment needed for a home computer, need funding for it.
- 014 – Host homes, smaller settings for workshops (maybe 4 or 5 people), have organizations set together and have similar training so everything is uniform.
- 016 – To provide support for people who want to further their education; make adjustments to the RIDE program.
- 017 – Better transportation for those that need it.
- 019 – Legislation/ get the right people elected in office.
- 020 – Group homes should continue locally.
- 021 + 022 – More funding and being more informed to the finances that the handicapped receive.
- 024 – It is important to have communication between people with the developmental disability and an advocate.
- 029 – Suggested that some social workers could spend a little more time with their clients.
- 031 – Should have a raise in polar cost of living (like in nursing homes) and better funding.
- 032 – The field needs to be better paid w/ stricter training programs so it is more prestigious.
- 045 – Learn more about independent living in school and challenges in the outside world.
- 046 – A family should be paid to take in a person.
- 048 – Less red tape in supplying services
- 052 – To provide more transportation to various activities and events.
- 055 – Vocationally there are not enough opportunities; need more skill opportunities; teaching hands on skill to get a job.
- 056 – Provide more services and more attention to those who need it.
- 057 - More seminars and training needed.
- 071 – System needs more resources and funding. Job coaching is also very important.
- 073 – More funding is needed for the programs
- 077 – Getting people more aware to what services are available.
- 080 – Carpooling would be nice as well as having nurses that really care about their patients.
- 081 – It shouldn't take so long to get services to get approved of and established, people need them now.
- 082 + 083 – People need to be made more aware of what is out there so that they know where to go and what to do to get the help they need.
- 085 + 086 – The general public should be educated better on disabilities.
- 099 – More host homes; smaller settings for workshops; have organizations meet to create similar training programs so that everything is more uniform.
- 101 – Get materials out to the community and newsletters out to the parents. Also, help more people find services that they need.

## Advantage Marketing Information

- 105 – Better transportation services needed; allowance for working, financially penalized.
- 107 – People who work with handicapped people need to be paid more because right now they are not compensated enough.
- 108 – More one on one time with care providers, people need to spend more time with them so that they can learn more.
- 109 – Groups need to actually meet care provider or child and not just see paperwork to make decisions for care.
- 110 – Training of staff needs to be improved, must be sensitive to kids needs.
- 111, 112, + 113 – Approval of services needed more.
- 114 – Needs to be more of an emphasis on speech for people who can't talk; better communication between group home and family.
- 117 – More places to get information and support, needs to be easier to acquire.
- 119 – Should advertise more.
- 121 – Need to listen to the doctors and the parents, public schools should have experience with developmental disabilities. North Providence has inadequate schools, their special education department is terrible.
- 122 – Hiring people that care more.
- 128 – Have better understanding between individuals.
- 135 – Takes WAY too long to process requests. Too many people seemed to be involved, and they don't get back to you right away.
- 136 – Better ability for accepting State Health Care Card, Rite Care.
- 138 – More “one-on-one” personal contact with disabled individuals, more family involvement.
- 143 – It is important for agencies to work together
- 144 – Put the person's quality of life first; just housing someone in a community is not enough, need extra help.
- 145 – Educating public is very important.
- 147 – Needs to be more services.
- 151 – Listen to what the client has to say.
- 160 – Would like to get out more.
- 166 – More people need to be alert to replace staff that cannot come in.
- 170 – Programs need to be more accessible.
- 171 – Need more medical help; need doctors, psychologists, prescriptions, etc.
- 175 – People need to be more aware of what services and opportunities are available.
- 178 – Funding takes too long to obtain.
- 181 – When a client is past a certain age, provide better information on where places are, what there is to do for their age group, etc. Also, more funding is needed.
- 188 – Need a service in Foster, for the northwestern section of RI.
- 189 – Dentists that don't cost too much should be offered for people with disabilities who can't work; daughter needs more training with speech in school.
- 191 – Make the system simpler to use.

## Advantage Marketing Information

- 192 – Providing exercise opportunities and physical therapy instead of watching movies all the time.
- 197 – More information on the Internet.
- 214 – Would like to see some more group homes for older persons who can get more specific care.
- 215 – More education should be offered more publicly.
- 219 – More information and referral services.
- 221 – Training new staff better (group homes) and more funding to keep good people longer.
- 223, 224, 225, 226, + 227 – More directly with the person and not with other people.
- 233 – Empower parents and advocates to help people get the support they need. Increase taxes?

## Advantage Marketing Information

### Question 20)

- 023 – Subsidized apartment building, but the rent is too high and he has little money.
- 044 – Pawtucket, it is where he was raised.
- 089 – Would like independence.
- 102 – Moving to a different group home.
- 110 – “Dying to get into Cove Center”
- 128 – Indian Run for elderly and handicapped
- 154 – She has been verbally abused by employees (they call her “black nigger”), would like to move into an apartment
- 160 – Would like to live in her own apartment.
- 173 – Would like to live on own, wants more independence.
- 198 – Would like to live with a friend, doesn’t like group home.
- 215 – Would like to get married and live in Newport.
- 220 – Live in a group home.
- 222 – Live in an apartment, doesn’t care for the group home.

## Advantage Marketing Information

### Question 31)

- 023 – Would like the RI Disability Law Center to send out a newsletter or pamphlet explaining what they do, maybe once or twice a year. He also has a preference for people with developmental disabilities to have better housing, Section 8, HUD, RI Housing and without long wait lists.
- 028 – Would like to see more funding and more help in general.
- 031 – There needs to be more group homes that are handicap accessible and capable of taking care of the elderly mentally handicapped.
- 047 – Getting rides to where you want to go is very important.
- 076 – It isn't right that people with disabilities get their funding cut.
- 078 – Should have a more open-ended kind of survey.
- 081 – Learning is very important to her.
- 094 – RIDE is not consistent with the pick up or drop off times, need to be on a schedule.
- 107 – The state should know about technical access for supplies and comprehensive medical services in Cranston for supplies. “ Quality help in groups should be getting quality pay as well” Be careful with the ratio of staff per client- important should really walk into programs to oversee how they are doing.
- 108 – She thinks that more care and information should be provided for people with DD who do not have a family or someone to advocate for them.
- 109 – More people should be educated about the kids needs so that they aren't afraid to work with them; more people should be involved in this because there aren't very many involved now.
- 115 – Things are gone about in a positive way; much progress has been made.
- 116 – Everything is run fairly well right now.
- 119 – Put the word out about people with developmental disabilities.
- 124 – Transportation is inadequate.
- 126 – Hygiene is very important for people with disabilities. Public awareness is low.
- 145 – Public awareness is so important!

## Advantage Marketing Information

- 153 – Transportation, Accessibilities, summer camp, and overall more activities are needed.
- 166 – More people should be aware of the individual’s illness and willing to help out; looking for where to go for hands on help need someone who takes their job to heart.
- 170 – Inform more people of available programs, need to keep active.
- 171 – DDD should hire more qualified individuals, especially psychologists; more physical therapy.
- 176 – Trudeau’s sports program needs much improvement, too much favoritism.
- 178 – Let people know what services and publications are available. Get service and publications to those who need it in a timely manner. FUNDING FUNDING FUNDING!
- 179 – More funding for group home staff.
- 189 – Issues should be really voiced to the Governor and the RIDDC should send a letter out explaining what is going on and the changes and efforts being made now.
- 190 – Driving is very very important, it’s good right now but important to her that it stays that way.
- 202 – Groups or organizations that can “relate” to a client’s problems.
- 208 – Transportation is too expensive to take a bus, \$90/month, cannot afford it, needs funding or some kind of compensation.
- 209 – Interested in knowing more about the summer recreation guide and the video lending library.
- 214 – We hope that whatever budget is needed we can get without budget cuts.
- 215 – Would like to learn about more people with DD.
- 233 – Might get out of state placement, need more information.

## Advantage Marketing Information

### *Appendix 2* *Consumer Questionnaire*

Survey Number \_\_\_\_\_ Developmental Disabilities Survey//Name \_\_\_\_\_

Telephone #: \_\_\_\_\_ - \_\_\_\_\_ Draft 9 April 4, 2003

Good \_\_\_\_, \_\_\_\_\_ from the Center for Opinion Research calling. I'm following up on a letter sent by the Rhode Island Developmental Disabilities Council in regards to \_\_\_\_\_ [READ NAME FROM LIST]. If Mr./Ms. is able to speak on the phone, may I speak with [him/her] please? [MANY RESPONDENTS MAY NOT BE ABLE TO SPEAK ON PHONE. IF YOU GET RESPONDENT, GO TO INTRO i. IF RESPONDENT CAN SPEAK BUT IS NOT THERE, GET CALL BACK TIME. IF RESPONDENT IS NOT PHONE CAPABLE, READ SCREENER 2].

[SCREENER 2] May I ask who I am speaking with? [RECORD NAME] \_\_\_\_\_. As I mentioned, I'm calling on behalf of the RI Developmental Disabilities Council. They are sponsoring a research study as part of the development of their 5 Year Plan and I have been asked to conduct the survey. Am I speaking with the person most familiar with Mr./Ms \_\_\_\_\_?

1 \_\_ yes → GO TO INTRO ii

2 \_\_ no → May I speak with [him/her] please? [IF REFUSED, NOTE REFUSAL AND DISCONNECT. IF YES, READ INTRO ii AND PROCEED. IF IS NOT AVAILABLE, GET CALLBACK TIME].

INTRO i. [WHEN SPEAKING WITH THE NAMED PERSON] As you may recall, as part of the development of their 5 Year Plan the RIDDC is sponsoring a survey that is very important because it will affect the types of services available to better assist Rhode Island residents. Your responses will be a very big help. May I start my questions by asking, [GO TO QUESTION 1]:

INTRO ii. [WHEN SPEAKING WITH A CARE GIVER] The RI DDC is sponsoring a survey that is very important because it will affect the types of services available to better assist Rhode Island residents with disabilities. I'd like to ask your help in completing the survey. Please give your best answer to each of the following questions. If you aren't sure or don't know, that's ok. Please just tell me that. Would you have a few minutes to help with this important project? [ASK QUESTIONS OR ASK FOR CALL BACK TIME]

1) What groups are you aware of that help people with developmental disabilities? [CHECK ALL THAT ARE MENTIONED IN UNAIDED RECALL COLUMN]

- a. RIDDC or RI Developmental Disabilities council
- b. DDD or The Division of Developmental Disabilities
- c. Local Special Education Office
- d. Rhode Island Disability Law Center
- e. Rhode Island ARC
- f. Sherlock Center
- g. Other → WRITE IN \_\_\_\_\_

1a) unaided recall    1b) aided recall

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

2) Are you familiar with any of the following groups? [READ NAMES ABOVE THAT WERE NOT CHECKED DURING UNAIDED RECALL QUESTION. CHECK ALL THAT APPLY. IF NONE, GO TO 10] 99 \_\_ NONE → GO TO 11

3) What is your overall opinion regarding: [READ NAMES OF EACH ORGANIZATION THEY ARE AWARE OF. CIRCLE ONE RESPONSE FOR EACH]

- |  | <i>Excellent</i> | <i>good</i> | <i>fair</i> | <i>poor</i> | <i>DK</i> |
|--|------------------|-------------|-------------|-------------|-----------|
| a. RIDDC or RI Developmental Disabilities council    | _____            | _____       | _____       | _____       | _____     |
| b. DDD or The Division of Developmental Disabilities | _____            | _____       | _____       | _____       | _____     |
| c. Local Special Education Office                    | _____            | _____       | _____       | _____       | _____     |
| d. Rhode Island Disability Law Center                | _____            | _____       | _____       | _____       | _____     |
| e. Rhode Island ARC                                  | _____            | _____       | _____       | _____       | _____     |
| f. Sherlock Center                                   | _____            | _____       | _____       | _____       | _____     |
| g. Other → WRITE IN _____                            | _____            | _____       | _____       | _____       | _____     |

4a) [ASK ONLY IF RESPONDENT AWARE *OF RIDDC*] **Do you know what the Rhode Island Developmental Disabilities Council, or RIDDC does?** [WRITE IN. BE SPECIFIC. WRITE IN AS MANY AS RESPONDENT CAN RECALL. PROBE FOR MORE.]

4B) **Can you think of anything else?**

5a) [ASK ONLY IF RESPONDENT AWARE OF **DDD or The Division of Developmental Disabilities**] **Do you know what DDD or The Division of Developmental Disabilities, does?** [WRITE IN. BE SPECIFIC. WRITE IN AS MANY AS RESPONDENT CAN RECALL. PROBE FOR MORE. – FOR EXAMPLE, DOES THE PERSON KNOW ABOUT HIS/HER DDD SOCIAL WORKER?]

5B) **Can you think of anything else?**

6a) [ASK ONLY IF RESPONDENT AWARE OF a *Local Special Education Office*] **Do you know what your local Special Education Office does?** [WRITE IN. BE SPECIFIC.PROBE. WRITE IN AS MANY AS RESPONDENT CAN RECALL]]

6B) **Can you think of anything else?**

7) **Which groups, if any, have helped you? [OR] Which organizations, if any, have provided Mr./Ms. \_\_\_\_\_ with services, information, or advice?** [CHECK ALL THAT APPLY. WRITE IN ALL OTHER RESPONSES THAT ARE MENTIONED. PROBE FOR MULTIPLE WRITE IN RESPONSES. ]

- a.  RIDDC or RI Developmental Disabilities council
- b.  DDD or The Division of Developmental Disabilities
- c.  Local Special Education Office
- d.  Rhode Island Disability Law Center
- e.  Rhode Island ARC
- f.  Sherlock Center
- g.  Other →WRITE IN \_\_\_\_\_

8a-d) **What did they do for you? [OR] What services, if any, has Mr./ Ms. \_\_\_\_\_ used?** [WRITE IN]

9) **Which of the following Developmental Disabilities Council publications or training programs are you familiar with, if any?** [READ LIST])

	Aware of	Not Aware of	Rating (1-5)
a) DD Council Newsletter	_____	_____	_____
b) Summer Recreation Guide	_____	_____	_____
c) Annual Report	_____	_____	_____
d) Video & Lending Library	_____	_____	_____
e) Partnerships to employment Conference	_____	_____	_____
f) 5 Year State Plan (2001-2005)	_____	_____	_____
g) Human Rights Training	_____	_____	_____
h) Self Determination Conferences	_____	_____	_____
i) DD Council Web Site ( <a href="http://www.RIDDC.org">www.RIDDC.org</a> )	_____	_____	_____

10) **Would you say that you are very satisfied, somewhat satisfied, unsure, somewhat dissatisfied or very dissatisfied with:** [READ ALL ITEMS IN QUESTION 9 CHECKED AS ‘AWARE OF’ AND RATE WITH 5=VERY SATISFIED, 4=SOMEWHAT SATISFIED, 3 = UNSURE, 2=SOMEWHAT UNSATISFIED, OR 1=VERY UNSATISFIED]

**11) I'm going to read you a list of skills and services. Please tell me if you think it is very important [PAUSE], somewhat important, [PAUSE] or not very important to provide people with developmental disabilities with each type of skills training or service. [REPEAT CATEGORIES FOR THE FIRST TWO SERVICES AND AGAIN AS NECESSARY FOR CLARITY. ROTATE]**

	Very Important	Somewhat Important	Not very important	Unsure
<b>How about:</b>				
a) Learning how to get a job	___	___	___	___
b) Learning how do a job	___	___	___	___
c) Learning how to live on your own	___	___	___	___
d) Learning how to keep yourself safe	___	___	___	___

<b>How about:</b>				
e) Information and referral services	___	___	___	___
f) Talking with other people who want the same things as you	___	___	___	___
g) Making a house accessible	___	___	___	___
h) Personal care services provided in the home or community	___	___	___	___
i) Being able to get a ride to where you want to go	___	___	___	___
j) Getting an interpreter if you don't speak English	___	___	___	___
k) Getting an interpreter if you are deaf or use signing	___	___	___	___
l) Pursuing educational goals	___	___	___	___

**In terms of funding, how important is it to have money for:**

m) special or adaptive equipment	___	___	___	___
n) doctors and medicine	___	___	___	___

o) How important is it for the general public to be educated about the needs of people with developmental disabilities?

[READ] 3 \_\_\_ very important    2 \_\_\_ somewhat important    1 \_\_\_ not very important    0 \_\_\_ don't need

**p) How important is to have someone who advocates for people with developmental disabilities? [READ]**

3 \_\_\_ very important    2 \_\_\_ somewhat important    1 \_\_\_ not very important    0 \_\_\_ don't need

q) How important is it to have the opportunity to develop friendships and spend time with friends? [READ]

3 \_\_\_ very important    2 \_\_\_ somewhat important    1 \_\_\_ not very important    0 \_\_\_ don't need

**12a-c) Of all the things that we've just been talking about, which do you think would be most important to people with developmental disabilities? [DO NOT READ LIST. INSERT LETTERS FROM ABOVE. PROBE FOR THREE]    \_\_\_\_\_**

[WRITE IN IF NECESSARY]

**13) How satisfied are you with the ease of getting the services that people with developmental disabilities need? [READ]**

- 1 \_\_\_ don't need any services → SKIP NEXT QUESTION  
 2 \_\_\_ very satisfied                      4 \_\_\_ somewhat dissatisfied → 15) Why? [WRITE IN]  
 3 \_\_\_ somewhat satisfied                5 \_\_\_ very dissatisfied → 15) Why? [WRITE IN]

14) Do you have any suggestions for changes in the way services are provided? [WRITE IN. BE SPECIFIC.]

15) The following questions are being asked for the purpose of statistical analysis. At no time are you personally identified.

15) How many people live in your home? [WRITE IN] \_\_\_\_\_

16) Do you work? [OR] Is Mr./Ms. \_\_\_\_\_ currently employed?

1 \_\_ yes, → What kind of work do you do? [OR] What type of job? [WRITE IN. IF SELF EMPLOYED, ASK AT WHAT]

2 \_\_ student → 16B) Do you want to work? [OR] Is a job of interest?

1 \_\_ no → [GO TO 18]      2 \_\_ yes → What type of job? [SPECIFY. GO TO 18]

3 \_\_ no → 16C) Do you want to work? [OR] Is a job of interest?

1 \_\_ no → [GO TO 18]      2 \_\_ yes → What type of job? [SPECIFY. GO TO 18]

17) Do you work full time or part time? [OR] Is this a full time or part time job? [CHECK ONE]

1 \_\_ Full time

2 \_\_ part time → Is the job part time by choice, or is full time work preferred?

1 \_\_ by choice      2 \_\_ want full time      3 \_\_ unsure

18) Do you own your own house, live with a family member, live in a group home, live in an apartment or somewhere else? [OR] Does Mr./Ms. \_\_\_\_\_ live in their own home, the home of a family member, live in a group home, live in an apartment or some other type of housing?

1 \_\_ own      2 \_\_ family      3 \_\_ group      4 \_\_ apartment      5 \_\_ other → [SPECIFY] \_\_\_\_\_ 6 \_\_ refused

19) Do you like where you live or would you prefer to live somewhere else? [OR] Would Mr./Ms \_\_\_\_\_ prefer to live somewhere else?

1 \_\_ like where you live → GO TO 21      2 \_\_ prefer to live somewhere else      3 \_\_ unsure → GO TO 21

20) Where would you like to live and why? [WRITE IN]

21) Do you use the Internet? [OR] Does Mr./Ms. \_\_\_\_\_ use the Internet?

1 \_\_ yes      2 \_\_ no      3 \_\_ unsure      4 \_\_ refused

22) How old are you? [OR] How old is Mr./Ms \_\_\_\_\_? [Do not read categories - check the category that applies]

1 \_\_ 11-18      3 \_\_ 22-34      5 \_\_ 45-54      7 \_\_ 65-74      9 \_\_ [DO NOT READ] refused  
2 \_\_ 19-22      4 \_\_ 35-44      6 \_\_ 55-64      8 \_\_ 75 or above

23) What is your annual income before taxes? [OR] What is Mr./Ms. \_\_\_\_\_ annual income before taxes? [Do not read categories - check the category that applies]

1 \_\_ less than 10,000      3 \_\_ 20,000 to 39,900      5 \_\_ 75,000+  
2 \_\_ 10,000 to 19,900      4 \_\_ 40,000 to 74,900      6 \_\_ [DON'T READ] refused/don't know [GO TO QUESTION 25]

**24) Is this amount of income enough to meet all financial needs, or is additional financial assistance, for example, SSI or food Stamps, required?**

- 1 \_\_ currently sufficient                      2 \_\_ currently not sufficient    3 \_\_ other [WRITE IN]  
4 \_\_ don't know

**25) WRITE IN (DO NOT ASK):** Gender of person with disability:    1 \_\_ female                      2 \_\_ male

**26) How satisfied are you with your quality of life? Would you say that you are:** [READ LIST] **[OR]**  
**Overall, how do you think Mr./Ms. \_\_\_\_ would rate their satisfaction with their quality of life? Do you think they are:** [READ LIST]

- 1 \_\_ very satisfied                                      4 \_\_ somewhat dissatisfied  
2 \_\_ somewhat satisfied                              5 \_\_ very dissatisfied  
3 \_\_ unsure

**27) What language do you speak every day? [OR] What language is used in daily conversation?** [WRITE IN] \_\_\_\_\_ [NOTE: SOME RESPONDENTS MAY USE SIGN LANGUAGE, GESTURES, OR NON-VERBAL COMMUNICATION.RECORD AS DESCRIBED.]

**28) What county do you live in? [OR] What county is this residence located in?** [READ ALL IF NECESSARY]

- 1 \_\_ Providence              2 \_\_ Kent              3 \_\_ Bristol              4 \_\_ Newport              5 \_\_ Washington              6 \_\_ Unsure

**29) If you would like someone from The Division of Developmental Disabilities to call you, I can give them this phone number? Do you want someone to call you?**

- 1 \_\_ yes, have someone call me              2 \_\_ no              3 \_\_ unsure

**30) Would you like to have someone from RIDDC call you?**

- 1 \_\_ yes, have someone call me              2 \_\_ no              3 \_\_ unsure

**31) And lastly, is there anything you want to tell me about the topics we've been discussing?**

Thank you very much for your time and your help. Good \_\_\_\_.

**Advantage Marketing Information**

*Appendix 3*  
*Special ED Director/Agency Questionnaire*

Ask for contact by Name.

Good \_\_\_\_, \_\_\_\_\_ from the Center for Opinion Research calling on behalf of the RI Developmental Disabilities Council. They are sponsoring a research study as part of the development of their 5 Year Plan and I have been asked to conduct the survey. I'd really appreciate your help because it will affect the types of services available to better assist Rhode Island residents. Is now a good time for you?

1) What groups are you aware of that help people with developmental disabilities? [CHECK ALL THAT ARE MENTIONED IN UNAIDED RECALL COLUMN]

- |  | 1a) unaided recall |
|--|--------------------|
| a. RIDDC or RI Developmental Disabilities council    | _____              |
| b. DDD or The Division of Developmental Disabilities | _____              |
| c. Local Special Education Office                    | _____              |
| d. Rhode Island Disability Law Center                | _____              |
| e. Rhode Island ARC                                  | _____              |
| f. Sherlock Center                                   | _____              |
| g. Other →WRITE IN _____                             | _____              |

2) What is your overall opinion regarding:

	<i>Excellent</i>	<i>good</i>	<i>fair</i>	<i>poor</i>	<i>DK</i>
a. RIDDC or RI Developmental Disabilities council	_____	_____	_____	_____	_____

3) [ASK ONLY IF RESPONDENT AWARE *OF RIDDC*] Do you know what the Rhode Island Developmental Disabilities Council, or RIDDC does? [WRITE IN. BE SPECIFIC. WRITE IN AS MANY AS RESPONDENT CAN RECALL. PROBE FOR MORE.]

3B) Can you think of anything else?

4) Which of the following Developmental Disabilities Council publications or training programs are you familiar with, if any? [READ LIST])

	Aware of	Not Aware of	Rating (1-5)
a) DD Council Newsletter	_____	_____	_____
b) Summer Recreation Guide	_____	_____	_____
c) Annual Report	_____	_____	_____
d) Video & Lending Library	_____	_____	_____
e) Partnerships to employment Conference	_____	_____	_____
f) 5 Year State Plan (2001-2005)	_____	_____	_____
g) Human Rights Training	_____	_____	_____
h) Self Determination Conferences	_____	_____	_____
i) DD Council Web Site ( <a href="http://www.RIDDC.org">www.RIDDC.org</a> )	_____	_____	_____

5) Would you say that you are very satisfied, somewhat satisfied, unsure, somewhat dissatisfied or very dissatisfied with: [READ ALL ITEMS IN QUESTION 4 CHECKED AS 'AWARE OF' AND RATE WITH 5=VERY SATISFIED, 4=SOMEWHAT SATISFIED, 3 = UNSURE, 2=SOMEWHAT UNSATISFIED, OR 1=VERY UNSATISFIED]



**The Rhode Island Developmental Disabilities Council  
State Plan 2007-2011**

## **Attachment 2**

**Focus Groups Concerning Quality of Life  
Issues of Rhode Islanders with  
Developmental Disabilities**

**Conducted and Reported on by Marshall & Associates  
for the RI Developmental Disabilities Council  
December, 2002 through March, 2003**

# **Focus Groups Concerning Quality of Life Issues of Rhode Islanders with Developmental Disabilities**

## **Methodology**

During the months of December, 2002 and February through March, 2003, a series of eight (8) focus groups were held at locations throughout the state of Rhode Island.

- The participants in two of these groups were consumers (including both adults and older students).
- Residential and day support staff participated in three of the groups.
- Certified and non-certified special education staff participated in two groups.
- One group was held for family members living with individuals with developmental disabilities.

Sixty-seven participants were recruited through advocacy organizations, service provider agencies, local special education offices and word-of-mouth. Size of the groups ranged from four to twelve participants with the average group having eight participants.

The actual group sessions consisted of a facilitated two-hour discussion of quality of life issues using a prepared script incorporating several large and small group exercises.

While the facilitator had been briefed on the subject matter, she did not have a background in service delivery for individuals with disabilities. She did however have a background in elementary and secondary education. The same facilitator was used for all of the groups. The script was essentially the same for each group

with some minor modifications to language to accommodate the different point of view of each respective constituency.

The structure of the session laid the ground work for development of a list of system advocacy issues that would improve the quality of life for Rhode Islanders with developmental disabilities.

### **Findings**

Generally speaking, all of the participants were eager to contribute, fully accepted the structure of the exercises and expressed that they felt the session was very worthwhile both to RIDDC's planning process and to each of them personally. All expressed gratitude for having been included in RIDDC's planning process.

No clear common advocacy issues emerged across all four of the constituencies participating; however, several issues resonated across multiple constituencies:

- A wider and more meaningful variety of employment options for individuals with disabilities emerged as an issue to be addressed in all of the consumer, support staff and family member groups; however, it was not mentioned in either of the special educational staff groups.
- Educating the community on the acceptance and value of inclusion of individuals with disabilities especially with regard to employment was identified by two of the three support staff groups, family members and both of special education staff groups; however, it was not mentioned by either of the consumer groups.

- The need for opportunities for continued skill development and maintenance of skills through adult education, GED classes and continuing education was identified by both of the consumer groups, one of the residential support staff groups and family members; however, it was not mentioned by either of the special education groups.
- A wider variety of choices and opportunities with regard to living situations was identified by one of the consumer groups, two of the three residential support staff groups and family members.
- More opportunities for increased independence was identified by both consumer groups, family members and one of the support staff groups.
- More and better transportation options was raised as a concern by both consumer groups and one of the support staff groups.
- A wider and more accessible variety of recreational opportunities was raised as an issue by one of the consumer groups and the family members.
- Two of the three support staff groups raised increased privacy for consumers through smaller homes (2, 3 or 4 consumers per home) and single rather than multi-person bedrooms as an area that needed to be addressed.

As you can see from the above findings, there was ample common ground between the consumers, family members and residential/day support staff on advocacy issues. However, with the exception of the community education issue, the special education staff's focus was on an entirely separate set of issues mostly relating to:

- Increased resources in the schools for students with disabilities.
- Increased involvement and understanding of the issues by principals and administrators.
- Greater availability of specialized disciplines in the schools, especially behavioral specialist.
- More inclusion in the schools.

In general when referring to the school systems, family members expressed similar concerns as the special education staff.

A subset of two of the constituencies, residential support staff and non-certified special education staff, expressed an interest in a more formalized training and certification program for themselves. Suggesting that this could possibly be set up through one or more of the colleges.

Family members expressed the need for additional support for families that were living with adult family members with disabilities, in the form of:

- additional respite care, with shorter waiting lists
- in-home skills training
- emergency services for families in crisis
- financial support through tax exemptions or vouchers for homes with individuals with disabilities
- assistance with long-term planning

## **Conclusion**

It is recommended that the above items be given consideration in developing advocacy plans for the RIDDC. It was clear that the constituencies participating in this study would expect these issues to be taken into consideration when developing a new-five year plan for the Council.

It is noteworthy that many of the issues identified were common across two or more constituencies, as well as the consistency of issues between the consumers, support staff and family members.

The lack of consistency in focus on the part of special education staff with that of the other three constituencies is also an issue that should be looked at as a possible area for the RIDDC to work on. It is also curious that the educators were the only constituency not to identify adult education as a need area.

## Appendix — Focus Groups' Quality of Life Advocacy Wish Lists

### Consumers

- More quiet time
- Having phone line and cell phone of my own
- To speak slowly and clearly on the phone
- To have a cell phone
- Being able to trust other people
- Stop being paranoid
- To calm down
- I have everything I need
- To have more transportation to social outings
- More transportation to places
- More money for recreation
- More recreation time
- Get my license to drive
- To have more meetings to make decisions
- Learn to make decisions
- A better home
- To have a place of my own
- Choice of who I live with
- To be able to live with my parents
- More independence
- To live on my own
- To become more independent
- To go anywhere I want
- To take a bus alone with a friend
- To make my own choices
- To do things on my own
- Reading and cooking by myself
- GED classes/Adult Education

- To be able to work at the General Store
- To have a job I can do
- To be able to do my own shopping
- To teach children
- To become a policeman
- To be able to take care of myself
- Being able to read
- Know how to get in touch with property manager for repairs/safety problems
- Classes to learn things

#### Residential and Day Support Staff

- Keep Groups Small (4-5 to house)
- More attention to group compatibility in housing assignments
- More individualistic/holistic/humanistic non-bureaucratic approach to meeting people's needs
- More one-on-one time to explore new things
- Staff advocate for consumers relative to new staff assignment
- Small housing arrangements
- Need for more privacy (no shared bedrooms)
- Higher staff ratio during hours 3-6 pm
- Larger budget for house expenses
- More adaptive equipment available
- Better quality furniture
- Psychiatric consults for dual diagnosis
- Music/Art/Pet therapy would benefit a lot of individuals
- Group therapy for consumers
- Group therapy for staff
- Nutrition education for staff/consumers
- More nursing hours for staff training

- More staff training
- Having staff be appreciated by management/administrators
- Executives should be in better contact with front-line staff
- Educate management/staff on true positive reinforcement approach to behavior
- Bottom-up management style
- Staff with good skills
- Dedicated/motivated staff
- Staff should be prepared and professional when in community with clients
- Correct differential between state and provider staff pay
- Better pay/perks
- Staff ability to select work site
- Better matching of staff skills with client needs
- A better informed staff to better serve clients
- Staff retention incentives
- Staff incentives
- Employee incentives for superior employment
- Reduce turnover/change of staff
- Better staff transition during turnover
- Job placement specialists
- More exposure in schools
- Adult education opportunities for consumers
- More vocational opportunities for consumers
- Need more working options for lower functioning, non-verbal individuals
- Educate community that work options are not a liability due to disability
- The disabled can do the jobs
- Family education programs
- Public service announcements
- Degree program at CCRI for this profession
- Accepting reality of clients' abilities

- Accept that many individuals are not going to be independent in living skills
- Let consumers try things, but be willing to stop
- Educate the community on acceptance and value
- More vehicles that are geared to individuals' needs for transportation to work options
- Vehicles that fit in the community

### Family Members Living with Individuals with Developmental Disabilities

- Less barriers to services
- More therapeutic respite
- Less paperwork
- More recreation opportunities (dances, music)
- Early intervention (more, sooner for life skills)
- ADL skills training in home
- Social skills training
- Support adults socially
- Make it easier to get services in schools
- Shorter waiting list for home-based therapy and respite
- Longer hospital stays for crisis (2-2 days not enough)
- Emergency services for families in crisis
- More flexible managed care
- More support for independent living
- More options for independent living/assisted living
- Long-term planning for residential services
- Job finding skills
- Public education to hire disabled
- More opportunities for job coaching
- College opportunities (more college acceptance, finding out how)
- Professional development/specialization of CEDARS

- CEDARS not working as planned – is an obstacle not a gatekeeper
- Easier transition from school to adult services
- More community involvement with transition
- Start transition training earlier
- Better integration for individuals with disabilities
- Consultants for parents going through transition
- Easier access to adaptive equipment
- Keyboards at school for kids with fine motor problems
- Accessible bathrooms
- Accessible buildings
- Accessible software for computers
- Knowing what you are eligible for
- RI-TAP
- Sharing knowledge with younger mothers
- Replication of what's working in other states
- Greater awareness of teachers in dealing with individuals with developmental disabilities – need knowledge, time and support for teachers
- Legislative advocacy for adequate monies for schools
- Tax exemptions/vouchers for families with developmental disabilities
- After-school programs
- Programs for siblings
- Help/support/keep families strong
- Peer support for caretakers
- Better involvement by spouse

#### Certified and Non-certified Special Education Staff

- Acceptance by regular education teachers/better teacher training
- Regular education teachers to be more sensitive to needs of students for inclusion

- A cooperative teaching model
- Self-contained students should have more opportunity for integration into regular education classrooms
- Enforce mainstreaming
- More mainstreaming with adequate supports
- Reduce class size to facilitate inclusion models
- Do away with special education/regular education distinction. Have full inclusion.
- More interactive learning model
- Educate parents on children's rights (i.e. IDEA, least restrictive environment, smaller MDT meetings so to not intimidate parents, enforce non-compliance corrections)
- Education for parents regarding IE
- Parents teach nutrition at home
- More parental involvement
- More education for parents
- Parental accountability – teacher meetings, provide needs, attendance of students, hygiene
- Nutritious lunch/snacks from home
- Thorough knowledge of student history
- Everyone should have an IEP
- IEP arrive before student
- Shorter time span between IEPs
- More monies to hire more professionals/case-load caps enforced for ST/OT/PT
- All classrooms should have one or two paraeducators
- Better pay/training/benefits for paraeducators
- Psychologist for each school
- Bring back guidance counselors
- Mental health services available in each school
- OT professional development for all staff

- On-site, all day nurse
- Behavior specialist in each school
- Behavior room in each school
- Self-contained class in each school
- Better training relations between teachers and teacher assistants
- More/continuing/better training for assistants and specialists (on discipline, developmental expectations, confidentiality)
- Have available what kids need
- Physical environment improvements
- Schools should be fully accessible
- Appropriate desks for size of students
- Access to adaptive technology
- Up to code bathrooms
- Administrators “spread too thin” among multiple buildings
- Administrators to be more in touch with classrooms
- Administrators should be in school all day
- More active role by principals
- More support of teacher recommendations for special services
- Culturally diverse administration
- More modifications for state testing
- Culturally diverse testing
- Stop teaching to the test
- Teach usable skills
- Looser criteria for alternative assessment
- Less red tape for special needs ordering
- Zero tolerance for drugs/violence
- More out-of-district placements
- All-day kindergarten throughout state
- All children to be age 5 by start of school
- Special/separate class for Spanish speaking children, not special education

- ESL for multiple languages
- Individualized decisions
- More time with resource kids out of classroom
- More/better supplies for classrooms
- More male teachers

The Rhode Island Developmental Disabilities Council  
State Plan 2007-2011

## Attachment 3

**Memorandum Of Understanding  
Between The Department Of Mental Health, Retardation And Hospitals  
And The Rhode Island Developmental Disabilities Council**

### I. Purpose

The purpose of this agreement is to outline the functions and responsibilities of the Department of Mental Health, Retardation, Hospitals and the Rhode Island Developmental Disabilities Council and to formalize working relationships between the Department and the Council in implementing the Developmental Disabilities Act, P.L. 100-146.

### II. Background

The Developmental Disabilities Act (P.L. 100-146) as amended provides for payment to States to assist in the development of a comprehensive system and a coordinated array of services and other assistance for persons with developmental disabilities through the conduct of, and appropriate planning and coordination of, administrative activities, Federal priority activities, and a State priority activity, in order to support persons with developmental disabilities to achieve their maximum potential through increased independence, productivity, and integration into the community.

The Council's major role is to advocate and plan for improved services for individuals with developmental disabilities and their families. A primary responsibility of the Council is the preparation of a two-year plan that addresses the needs of persons with developmental disabilities. The plan identifies specific goals, objectives and strategies that will:

- bridge identified gaps in the present service system
- analyze existing policies and develop new ones addressing identified needs of persons with developmental disabilities
- collaborate with other policy analysis and advocacy groups to develop and disseminate information about the legal and human rights of persons with developmental disabilities
- work within the legislative and budgetary processes in order to promote policies and identify resources that will increase opportunities and alternatives for persons with developmental disabilities.

In that the Department and the Council are both committed to improving the quality of life of persons with developmental disabilities, the Council and the Department of Mental Health, Retardations and Hospitals have agreed to jointly develop goals that will improve services for persons with developmental disabilities.

The purpose of this agreement is to formally establish a basis for a close working relationship between the Council and the Department. The agreement includes specific responsibilities and activities that would best represent the interests of individuals with developmental disabilities and their families and also assist the Council in carrying out the mandates of the federal Developmental Disabilities Act.

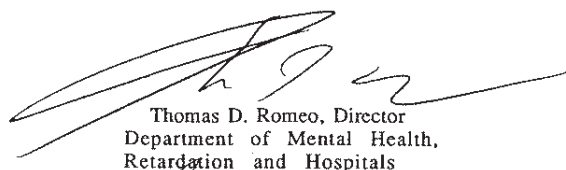
The Council will provide the Department, specifically, the Division of Retardation and Developmental Disabilities, with long range planning through the development of a State plan, topical research and development, data collection and policy analysis, and activities that would increase public awareness/education.

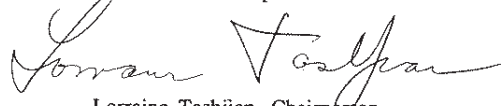
DATE

8-22-89

DATE

8-22-89

  
Thomas D. Romeo, Director  
Department of Mental Health,  
Retardation and Hospitals

  
Lorraine Tashjian, Chairperson  
Rhode Island Developmental  
Disabilities Council