The Needs and Experiences of the Adult RI Medicaid Population

- Persons Age 65 and Older
- Persons Age 18-64 with Physical Disabilities
- Persons Age 21 and Older with Developmental Disabilities
- Persons Age 18 and Older with Severe Mental Illness

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Executive Summary

The purpose of this report is to present an overview of current knowledge about the needs and experiences of the diverse adult populations served by the RI Medicaid program, and to identify gaps in knowledge that may be helpful to program development and expansion. There is much information contained in this report, and much more in the sources from which the information was drawn. There are many caveats to keep in mind when reviewing these data, as is noted in the explanation of primary data sources contained in the introduction to each section. However, despite the differences in time frames, sample composition, and data collection methodologies that characterize these various data sources, a number of important findings can be gleaned from available data on current perceptions of the adult Medicaid population that are useful for program development, expansion and improvement.

The final section of this summary highlights information gaps that present limitations to program development and improvement efforts that are most likely to be successful in meeting the population's health and social service needs, as well as needs for respect, autonomy and quality of life.

The Elderly Population on Medicaid

- The highest levels of need for help with individual activities of daily living (ADLs) in the community-dwelling elderly population are for dressing and bathing. Levels of need for assistance with other ADLs such as getting in and out of bed, and getting around the house, are higher for people who are waiver eligible but not currently waiver participants. This may be partly attributable to higher levels of family support in the group that is not currently receiving waiver services.
- The highest levels of *unmet need* for assistance with ADLs are for getting out of bed (this is also true in national estimates of unmet need in a Medicaid population) and getting around the house, possibly because the amount of service required to meet these needs is difficult to obtain, from either family or formal sources.
- The highest levels of need for assistance with instrumental activities of daily living (IADLs) are for shopping and housework in the full population of community-dwelling elderly, and also for cooking among people with ADL impairment.

- Two thirds (66%) of the full community-based population on Medicaid live alone, and demographic trends suggest that this proportion is likely to increase in the future. This suggests that demands for community-based supportive services are likely to grow over time, even if rates of impairment among low income elderly decrease over the same time period.
- The highest level of perceived need for services in the community-dwelling elderly population are for eyeglasses, dental care, disposable medical equipment, home care, physical therapy, and for information about the Medicaid program.
- Regardless of whether perceived need for a given service is high or low, rates of unmet need for virtually all services are relatively high (15-48% of those who report service need), and are reported by all groups, even those who are not yet ADL or IADL impaired.
- The highest rates of unmet need are reported for dental care (48.2% of those with need) and information about the Medicaid program (45.3%).
- Elderly nursing home residents have more severe cognitive impairment, behavior problems and impairment in physical functioning that elderly people who receive Medicaid home care, although home care clients appear to have worse mood state. However, the extent of bias in the sample of Medicaid home care recipients with available assessment data is unknown, and this finding should be interpreted with caution.
- Both nursing home residents and their families report relatively high satisfaction with a variety of aspects of nursing homes and nursing home life. Lowest areas of satisfaction are with meals and dining and resident activities.
- Family members' ratings generally indicate lower levels of satisfaction than resident ratings on all aspects of nursing home life, although residents are less satisfied with "choice" in their lives than family members perceive them to be.

The Working Age Population with Physical Disabilities

- Estimates of need for assistance with all ADL and IADL activities are consistently higher for the working age population with physical disabilities than for the full elderly population on Medicaid, although much lower than for elderly waiver participants and waiver eligibles.

- Estimates of unmet need for assistance with ADLs among those with need for assistance in the working age population are higher than for elderly Medicaid recipients, despite lower proportions of working age people who live alone. This difference may reflect greater disability and thus more help required by working age people, which suggests that programs for people with higher levels of disability need to provide as many hours of care as is required to meet ADL needs. The working age population may also have less access to services designed to meet ADL needs.
- Estimates of unmet need for help with IADL activities are approximately the same in the two populations.
- Much higher levels of need for dental care, eyeglasses, mental health counseling, and nutritional counseling are reported by the working age population than the elderly population.
- Among people who report service needs, unmet need for specific services (defined as unable to access or unable to get enough to meet service needs) is considerably higher among the working age population, which may be attributable to elderly persons' greater access to services through the Department of Elderly Affairs and/or Medicare, since a larger proportion of elderly than working age populations are covered by both Medicaid and Medicare.
- Forty one percent (41%) of the working age population live alone.

Adults with Developmental Disabilities

- Nearly half of adults with developmental disabilities in Rhode Island live in group homes (46.5%) and 16.3% live independently, compared to national averages across states of 23.5% and 13%, respectively.
- Only 3.5% of adults with developmental disabilities live in institutions, relative to 16.5% nationally.
- Higher proportions of this population in Rhode Island are employed vs. national estimates, although none are enrolled in school, and a lower proportion receive service coordination or case management services relative to national estimates (87.5% vs. 95.4%).
- Estimates of satisfaction with choice and decision-making regarding various aspects of their personal lives are comparable to national estimates. Areas in which respondents are

least satisfied with their ability to choose are the place where they live and the people they live with.

- Respondents report high levels of satisfaction with system performance, with the exception of service availability, with 57.5% of respondents agreeing that needed services were not available.
- Relatively low proportions of respondents perceive infringement of their rights to autonomy and privacy.

The Adult Population with Severe Mental Illness

- Among residents of RI with serious mental illness (SMI) for whom a living situation is known, nearly 90% report living in a private residence. This compares favorably with other state averages.
- In addition, fewer adults with SMI are in jail than the state average, and slightly fewer are in institutional settings.
- About 4% of RI adults served in mental health programs are known to be homeless.
- Nearly one quarter of adults with serious mental illness is employed, which is comparable to national estimates. Rates of employment among people with schizophrenia (12%) are lower than for people with other diagnoses.
- Nearly 90% of consumers with serious mental illness are satisfied with the agency from which they receive services, and 90% are satisfied with perceived access to services.
- Access to psychiatrists appears to be the most difficult for this population, with 83% agreeing that they were able to see a psychiatrist when they want to.
- An average of 70% of consumers agreed that they experienced improvement associated with their treatment in various life domains. Levels of agreement ranged from 80% (dealing more effectively with daily problems) to 60% (doing better in school and work). Approximately 73% of consumers agreed they had improved in daily life functioning, and 72% agreed they improved in social connectedness.

Policy and Program Implications

- Levels of need for help with dressing and bathing in the community-dwelling elderly and working age populations with disabilities are high, and two thirds of the elderly population and 41% of the working age live alone. This suggests that expansion of home health aide services, mobility equipment and home accommodations, and expanded access to Assisted Living and other alternative residential arrangements that offer services targeted to a "low care" population may be effective strategies to enable these persons to remain in the community. It is likely that the majority of "low care" population currently in Rhode Island nursing homes is comprised of people who have need for help with one or two ADLs, but had no one at home to help them, and/or who may have lived in an environment that was not safe or did not contain the appropriate accommodations to assist them in performing ADLs by themselves. Persons in such situations may also suffer from isolation, loneliness and depression, all of which place them at risk for further functional decline and potentially, eventual nursing home placement.
- High levels of unmet need for getting out of bed and getting around the house, activities that require high levels of service, can best be addressed by expansion of the current Medicaid voucher-based waiver that originated with the Robert Wood Johnson Foundation's Cash and Counseling Program. The voucher program maximizes individual autonomy by allotting a cash benefit to persons to allow them, with "counseling", to decide on how to spend those funds to best meet their disability-related needs. While this type of program has been associated with younger persons with spinal cord injury and similar conditions, it is increasingly offered to people with other types of health conditions and impairments, and works well with older as well as younger persons.
- The highest level of unmet health-related service need in both the elderly and working age populations with disabilities is for dental care; therefore, to eliminate the current Medicaid dental benefit will greatly increase levels of unmet need, with people unnecessarily resorting to tooth extraction and other emergency procedures simply because the cost will be covered by Medicaid. This downstream approach to service

provision is in direct contrast to principles of prevention that underlie the intentions of the Medicaid Global Waiver. *In general, the principal of avoiding medical crises is essential to the development and implementation of programs designed to simultaneously reduce health care utilization, preserve functioning, and enhance the quality of life in populations with chronic illnesses and impairments.*

- Levels of health-related service need and unmet need are higher among the working age than among the elderly Medicaid populations, in part likely due to the greater access to services provided by the aging system, and nearly universal coverage of persons age 65 and older by Medicare. It is crucial to realize that services such as mental health services and nutritional counseling are vital aspects of chronic condition management. S*eparation of medical, ancillary and support services is ill advised when service need is complex. Unmet need in one area often has repercussions in other areas, often resulting in hospitalizations and nursing home placement that may have been avoidable.*
- *Focus upstream.* There are a number of risk factors for nursing home placement as well as functional decline identified in the literature that are subject to amelioration by intervention. The most important of these risk factors that are amenable to intervention are identification and treatment of *depression, polypharmacy, incontinence and malnutrition.* Also, falls prevention and exercise programs have been demonstrated to lower risk for functional decline, and chronic condition self-management programs are effective in stabilizing conditions through promoting behavior change in everyday life. Attention to principals of prevention and amelioration of risk factors will help people with impairment on Medicaid to remain in the community for as long as possible, thus achieving Medicaid program goals to reduce reliance on institutional care.
- The low levels of satisfaction with meals, resident activities and resident choice expressed by residents in RI nursing homes and their families suggest that the Medicaid program should endorse and encourage nursing home Culture Change in facilities that care for persons covered by Medicaid. The emphasis inherent in the Culture Change Movement on resident-centered care, resident autonomy, family involvement, staff empowerment and a home-like environment suggest that nursing homes need not be viewed as a last resort dreaded by elderly people and families alike.

Information Gaps and Recommendations

Despite the rich variety of useful information contained in this report, the many caveats described in the introductions to each section call attention to need for more systematic data collection to meet the Medicaid program's need for information upon which to base decisions regarding program development and quality improvement. This is particularly true for the adult populations with physical disabilities. As we have seen, most information on this population is derived from comprehensive surveys administered with grant funding on a one time basis. Thus, the only information available on the service needs of the working age population is outdated. Information on the community-dwelling elderly population will also be outdated soon, particularly as more and more elderly people with disabilities are triaged to community-based, rather than institutional care. A variety of new services are in development, and the capacity of existing services and alternative residences such as assisted living will be expanded to meet the needs of elderly people with disabilities who historically may have been placed in nursing home settings. *It is essential for the Medicaid program to monitor how well these services and living arrangements meet the needs of the populations triaged to them, in terms of health-related outcomes as well as quality of life.*

Although not included in this report, a Medicaid indicator system using available data bases (e.g., Medicaid Management Information System, RI Hospital Discharge data, RI Behavioral Risk Factor Survey) was developed and is updated regularly by MCH, Inc. to enable the Medicaid program to track health care utilization, receipt of preventive services, and health outcomes for various subgroups of the Rhode Island Medicaid population. Indicators relevant to the adult population with disabilities are now available and others are under development. In addition, CMS will soon be generating and disseminating information to states about rates of Ambulatory Care Sensitive (ACS) hospitalizations for persons on Medicaid. Thus, valuable information on utilization outcomes is now available and other information will be available soon.

As is clear from this report, we know little about persons on RI Medicaid who live in nursing homes, although all nursing home residents must be assessed at least annually using the Nursing Home Minimum Data Set. Information on all nursing homes in Rhode Island is

available on the CMS website Nursing Home Compare, although it is not possible to separate information on Medicaid from private pay residents. Soon, a new version of the MDS will be implemented that will include an assessment of quality of life as well as quality of care, to be reported by the residents themselves rather than by nursing home personnel.

Recommendation #1

The Medicaid program would benefit from annual monitoring of the quality of care and quality of life of nursing home residents covered by Medicaid through analyses of the extensive information collected via the Nursing Home Minimum Data Set. MDS data also allows for monitoring changes in the characteristics of nursing home residents, including information on acuity and prevalence of chronic conditions, to gain some idea of the impact of current initiatives to divert persons to community based care who may otherwise be placed in nursing homes. This recommendation is also contained in the evaluation plan of the ongoing Real Choice Systems Change Grant from CMS.

Currently, unlike the mandated assessments performed in nursing homes, there is no comparable assessment of elderly adults or working age adults who receive long term care services and who live in the community. The RI Medicaid Center for Adult Health initiated collection of an abbreviated version of MDS-Home Care for persons receiving Medicaid home health care in order to compare community based and nursing home populations on similar outcome measures, but that data collection was not systematic, thus we are not able to interpret findings with any certainty.

Recommendation #2

Computerization of the universal screening assessment to determine new applicants' level of care under the Medicaid Global Waiver would present an opportunity to monitor and better understand the characteristics of the community-based population on Medicaid and how these characteristics differ according to program type, e.g., recipients of Medicaid home care services vs. residents in Medicaid assisted living. Mandated annual repeat assessments of the same instrument would allow for the ability to track improvement and

decline in functional status and other health indicators in sub-groups determined by program type and population make-up.

Recommendation #3

Another valuable approach to assessing community based populations is to administer an annual survey such as the Personal Experiences Survey (Elderly/Disabled Version) used by other Real Choice System Change state grantees to better understand the unmet needs, experiences regarding choice and control over services, and treatment by service providers, of the adult populations who live in various service and residential arrangements in the community. A randomly selected sample of people from each type of service/residential program would allow an assessment of the fit between individuals' needs and preferences, and types of services received. Consultation with other states that have conducted this survey (and also with RI MHRH, see below) would provide insight on inexpensive ways to collect this information.

A similar approach is currently used for the adult populations with mental illness and mental retardation in Rhode Island. These surveys are administered annually to consumers by the RI Department of Mental Health, Retardation and Hospitals as part of national efforts (voluntary for the population with developmental disabilities, and mandatory for persons receiving community services for the seriously mentally ill) to monitor indicators of service satisfaction, unmet service needs and treatment outcomes. Thus, as we see in this report, regularly updated information with national benchmarks is available for use to track system performance over time and to identify problems as they arise. Although the information required for people with physical disabilities is somewhat different from that required for people with cognitive abilities, similar efforts for the elderly and working age populations with disabilities on Medicaid is advised as we go forward under the new Medicaid Global Waiver and the changes in service delivery incorporated within it.

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Introduction

An important part of the recently approved Rhode Island Medicaid Global Waiver is the mandate to expand home and community-based options for long term care, thus reducing reliance on institutional settings for persons with long term care needs. The service development, expansion and reorganization required by this mandate can best be accomplished by an understanding of the current situation of Medicaid recipients in both community-based and institutional settings, including their service needs, their unmet needs, and their experiences associated with the services they receive as consumers in the Medicaid system.

The purpose of this report is to present an overview of current knowledge about the service needs and experiences of the diverse adult populations served by the RI Medicaid program, and to identify gaps in knowledge that may be helpful to program development and expansion. We draw our data from a variety of documents, most of them reports based on surveys commissioned or produced by the RI Departments of Human Services (DHS) and Mental Health, Retardation and Hospitals (MHRH). When possible, we compare RI data to data derived from national samples of comparable Medicaid populations.

Clearly, there is much more data contained in the data sources we accessed than is presented in this report, since our intention is to spotlight community-based long term care service needs and experiences of adults covered by Medicaid, as well as the scant data that exists from reports on elderly persons in the nursing home setting. Readers who are interested in further information on RI Medicaid population subgroups (e.g., demographic characteristic, acute care utilization), or who are interested in a more detailed explanation of the methodology used in data collection and/or data analysis, are encouraged to access the original reports via the web addresses or contacts listed in the "Summary of Sources" section of this report.

As the reader will see, the type of data currently available for persons with physical disabilities is weighted toward medical service needs while the data available for persons with cognitive disabilities focuses more on social needs, including community integration and consumer choice. However, paradigms of care are changing. A full picture of the medical, social, and quality of life needs and concerns of all persons addressed in this report is required if current efforts to expand options for community-based care and residence are to succeed, from both a programmatic and consumer point of view.

Summary of Sources Used in the Report

Section 1: The Elderly Population

- Allen, SM, Lima, J, Clark, M (February 2008) Health Status and Ethnic Diversity in the Community-Dwelling Elderly Medicaid Population: Needs Assessment Survey Results. Prepared for the Rhode Island Medicaid Program, Center for Adult Health.
    - The report was based on a 2006 telephone survey of a sample of the RI Medicaid population age 65 and older who lived in the community.
    - For full report, see http://www.ritecare.ri.gov/reports/
    - **Cited in this report as: Allen, Lima, and Clark (2008)**
    - In some instances, we used estimates based on analyses of these data that were not included in the official report. In these cases, we cite as: **Lima and Allen unpublished estimates, RI Needs Assessment Survey**

- Gozalo, P, and Allen, S, (February, 2008) The 2005 Medicaid Elderly Population in Nursing Homes vs. Community-based Waivers: Differences in Cognition, Mood, Behavior and Physical Functioning. Prepared for the RI Medicaid Program's Real Choice System Transformation Project.
    - The analysis of RI Medicaid waiver participants who received home care services in 2005 was based on data from an abbreviated version of the Minimum Data Set Home Care (MDS-HC) assessment. The analysis of the Medicaid nursing home population in RI was based on the Minimum Data Set (MDS-NH) assessments for 2005. The unit of analysis for these tables is the assessment rather than the individual person.
    - For full report, see http://www.ritecare.ri.gov/reports/
    - **Cited in this report as: Gozalo and Allen (2008)**

- Richards MS, Uman CG (2007) Resident and family satisfaction with nursing home care in Rhode Island: Prioritizing improvement. *Med Health RI*, Jul;90(7):223-224.
    - This paper is based on a survey of 3,057 face to face interviews with nursing home residents and 4,082 telephone interviews with family members, and was sponsored by the RI Department of Health.
    - **Cited in this report as: Richards and Uman (2007)**

- Lima J and Allen S, unpublished estimates using the Study on Aging II (SOA II), 1994
    - Used for making national comparisons of need and unmet need for assistance with daily living activities between the RI and national elderly Medicaid populations.
    - Information about the database can be found at http://www.cdc.gov/nchs/about/otheract/aging/soa2.htm
    - **Cited in this report as: Lima and Allen unpublished estimates using the SOA II**

Section 2: The Working-Aged Population with Physical Disabilities

- Payne, CA (February 2002) Needs Assessment Survey of Rhode Island Working-Age Adults with Physical Disabilities and Chronic Health Conditions on Fee-For-Service Medicaid. Prepared for the Division of Health Care Quality, Financing and Purchasing, Rhode Island DHS.
    - The report was based on a community-dwelling sample of fee-for-service RI Medicaid enrollees aged 21-64 who were enrolled during the October 1999-September 2000 period with physical disabilities and chronic health conditions. For full report, see http://www.ritecare.ri.gov/reports/
    - **Cited in this report as: Payne (2002)**

- Lima, J and Allen, S, unpublished estimates using the National Health Interview Survey – Disability; Adult Followback Survey (NHIS-D) 1994/1995
    - The NHIS-D is a unique national dataset containing detailed information on adults with a variety of disabilities, including data on need and unmet need for daily living activities. Data presented in this report were analyzed as part of the authors' prior work. These data are used in tables comparing the RI working aged population to a national population of working aged adults on Medicaid.
    - Information about the database can be found at http://www.cdc.gov/nchs/nhis.htm#NHIS%20on%20Disability
    - **Cited in this report as: Lima and Allen unpublished estimates using the NHIS-D**

Section 3: Comparison of Working-Aged and Elderly RI Medicaid Populations

- All information in this section taken from RI documents described above

Section 4: Persons with Developmental Disabilities

- Human Services Research Institute and National Association of State Directors of Developmental disabilities Services (February, 2009) National Core Indicators: Consumer Outcomes. Phase X Final Report, Fiscal Year 2007-2008 Data.
    - This report includes information from 24 States (including Rhode Island) on a sample of individuals who were receiving at least one service other than case management from a state developmental disabilities authority during fiscal year 2007-2008. There was a goal of 400 surveys per State -- Rhode Island successfully surveyed 312 persons.
    - For full report, see http://www.hsri.org/docs/CS%2007-08%20FINAL%20REPORT.pdf
    - **Cited in this report as: National Core Indicators (2009)**

Section 5: Persons with Severe and Persistent Mental Illness

- 2006 CMHS Uniform Reporting System (URS) (August 2007) Rhode Island Mental Health National Outcome Measures (NOMS). Accessed March 2008 from http://download.ncadi.samhsa.gov/ken/pdf/URS_Data06/RI.pdf.
    - The Uniform Reporting System was developed in response to the need for accountability for the expenditure of community mental health block grant funds received by States from the Federal Government. The intent of URS data is 1) to allow for tracking an individual state's performance over time and 2) the aggregation of state information to develop a national picture of the public mental health system of the States.
    - **Cited in this report as: 2006 CMHS Uniform Reporting System (URS) Tables, 2007**

- Unpublished estimates from the RI Mental Health Statistics Improvement Program (MHSIP) Consumer Survey, CY 2009 provided by Noelle Wood, PhD., of the RI Department of Mental Health, Retardation, and Hospitals (MHRH).
    - The survey is an ongoing initiative of the Substance Abuse and Mental Health Services Administration (SAMHSA) that supports states in developing and standardizing data/collection methodologies to improve information for decision making around mental health policy/programs.
    - The sample includes actively enrolled seriously mentally ill clients in the community support program of the Community Mental Health Organizations in RI.
    - For more information about these data, contact the RI Department of MHRH at http://www.mhrh.ri.gov/
    - **Cited in this report as: RI Dept. of MHRH (2009)**

Section 1: The Elderly Population

a. RI Elderly Medicaid Population who Live in the Community

b. RI Nursing Home and Home Care Comparisons

c. RI Family and Satisfaction Survey

Introduction: The Elderly Population on Medicaid

We begin our report with the elderly population, the primary focus of the state's "rebalancing" effort. Given how little is known, at either the state or national level, about elderly people who live in the community and are covered by Medicaid, we first describe the service needs of the community dwelling population on Medicaid as reported in a survey of this population (section 1.a). Since eligibility for Medicaid at age 65 and older is based on poverty status as well as disability, we present our results according to "waiver status", that is, by self-reported level of impairment in activities of daily living (ADLs) and instrumental activities of daily living (IADLs) since ADL/IADL impairment is a primary factor in determining waiver eligibility. Thus, readers of this report will have an idea of the level of service needs of those elderly people who are currently waiver participants, those who are waiver eligible, and those who do not qualify for waivers at the time of the survey but who may qualify at some point in the future. We compare the estimates of need and unmet need for ADL/IADL assistance for the total survey sample with national estimates of a comparable elderly population on Medicaid. However, the national data available to us were collected approximately ten years prior to the RI survey from which data are drawn, so comparisons should be viewed with this caveat in mind.

Section 1.b presents the results of analyses comparing information on the elderly RI population in nursing homes derived from 2005 MDS nursing home data, with comparable data collected by home health agencies on users of Medicaid home health services. While the MDS nursing home sample contains all residents on Medicaid with assessments in 2005, it is not known whether the comparable data from the community dwelling elderly who used Medicaid home health services is representative of all Medicaid home health users in 2005. In other words, this data may be biased in ways that are unknown. Also, it should be noted that unlike most of the information presented in this report, the data comparing nursing home residents and their community-based counterparts is largely descriptive of medical characteristics of the populations that have implications for service needs, rather than more direct self-reports of service need or service satisfaction.

The final section of data (Section 1.c) relevant to the elderly Medicaid population is the result of a satisfaction survey administered to both nursing home residents and their family members by the RI Department of Health.

Section 1.a
The Rhode Island Elderly Medicaid Population
Who Live in the Community

Results in this section are presented by "waiver categories" defined by need for assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) to better understand the implications of diversity in health status in the Rhode Island elderly population on Medicaid. The four categories are defined as follows:

- *Category 1: Waiver participant* - the respondent was enrolled in a Medicaid waiver program at the time of the survey.
- *Category 2: Waiver eligible* - the respondent was not enrolled in a waiver program, but needed assistance with at least one activity of daily living (ADL) including bathing, dressing, eating, getting around the house, getting out of bed, or toileting.
- *Category 3: High risk for waiver eligibility* – the respondent had no ADL needs at the time of the survey but did have at least one instrumental activity of daily living (IADL) need including the need for assistance with grocery shopping, managing medications, using the telephone, heavy housework or light housework..
- *Category 4: Low risk for waiver eligibility* – the respondent did not report needing assistance with any ADLs or IADLs.

Figure 1. The Elderly Community Dwelling Medicaid Population (N=612)

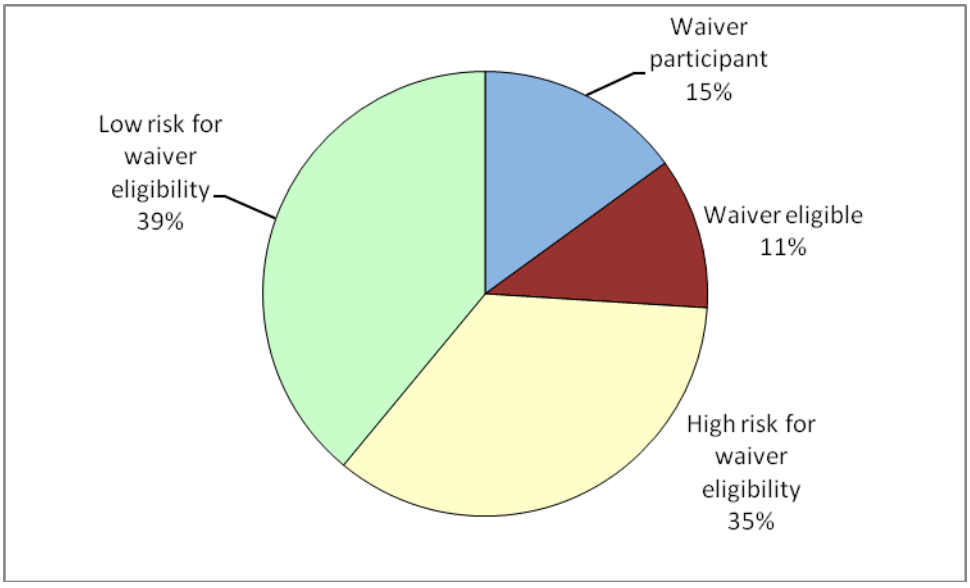


Table 1.a.1 Need and Unmet Need for ADL Assistance Resulting from a Health Problem or Disability Among the RI Medicaid Elderly Population by Waiver Status, 2006

	Waiver participant n=92	Waiver eligible n=69	High risk for eligibility n=217	Low risk for eligibility n=234	Total n=612
	%	%	%	%	%
Need for ADL Assistance					
Bathing	44.6	53.6	n/a	n/a	12.8
Dressing	28.3	34.8	n/a	n/a	8.2
Getting out of bed	16.3	33.8	n/a	n/a	6.2
Getting around the house	18.5	26.1	n/a	n/a	5.8
Eating	6.5	4.3	n/a	n/a	1.5
Toileting	4.3	5.8	n/a	n/a	1.3
Unmet Need for Assistance Among Those with Need					
Bathing	7.3	8.1	n/a	n/a	7.7
Dressing	23.1	0	n/a	n/a	12.0
Getting out of bed	26.7	23.8	n/a	n/a	25.0
Getting around the house	17.7	35.3	n/a	n/a	26.5
Eating	16.7	0	n/a	n/a	12.5
Toileting	0	25.0	n/a	n/a	12.5

Source: Allen, Lima, and Clark (2008); Lima and Allen unpublished estimates from the RI Needs Assessment Survey.

- Levels of need for assistance among waiver participants are highest for bathing and dressing. Bathing and dressing are termed "early loss" ADLs because persons tend to experience difficulty in performing these activities in the early stage of impairment, while other ADLs become problematic as disease progresses and impairment becomes more severe. An exception is the case of some conditions such as spinal cord injury or major stroke, in which impairment in all activities may be immediate.

- The prevalence of need for help with all ADLs, with the exception of need for help with eating, was higher among respondents eligible for waiver programs than it was for current waiver participants. This difference may be explained by higher rates of arthritis and musculoskeletal conditions in the waiver eligible group, and thus higher levels of disability (see original report). Another factor may be the greater availability of family help to waiver eligibles than to waiver participants, thus enabling elderly people to remain without formal services, and also to remain in the community, at higher levels of impairment.

- The prevalence of unmet need among those with need for assistance varies according to ADL activity, with the highest levels of unmet need reported for getting out of bed and getting around the house. However, unmet need data should be interpreted with caution due to sample size limitations.

Table 1.a.2 Need and Unmet Need for IADL Assistance Resulting from a Health Problem or Disability Among the RI Medicaid Elderly Population by Waiver Status, 2006

	Waiver participant n=92	Waiver eligible n=69	High risk for eligibility n=217	Low risk for eligibility n=234	Total n=612
	%	%	%	%	%
Need for IADL Assistance					
Shopping	77.2	79.7	71.4	n/a	46.2
Housework	80.2	79.7	59.9	n/a	42.4
Preparing meals	40.0	50.7	17.1	n/a	18.1
Medications	19.8	11.8	13.8	n/a	9.2
Unmet Need for IADL Assistance Among Those with Need					
Shopping	12.9	16.4	9.9	n/a	12.0
Housework	13.9	13.7	33.1	n/a	23.5
Preparing meals	18.4	11.8	19.4	n/a	16.7
Medications	11.1	0	10.3	n/a	9.3

Source: Allen, Lima, and Clark (2008) and Lima and Allen unpublished estimates of the RI Needs Assessment Survey

- Levels of need for assistance are highest for shopping and housework across all three groups with IADL needs. Also, need for assistance with cooking is high among Medicaid elderly in the waiver participant and waiver eligible groups.

- The prevalence of unmet need for assistance is relatively high for housework and meal preparation among those who have need for IADL but not ADL assistance (the high risk for waiver group), suggesting that some members of this group who are still ineligible for Medicaid services may be in the early stages of impairment and have not yet found solutions to meeting these needs.

Table 1.a.3 A Comparison of the RI Elderly Medicaid Population and a Nationally Representative Sample of Community-Dwelling Adults Aged 70 and Over on Medicaid

Need for ADL and IADL Assistance	Need for help		Among Those with Need - % who do not get enough help	
	RI Estimates 2006[a]	National Estimates 1994[b]	RI Estimates 2006[c]	National Estimates 1994[b]
	%	%	%	%
ADL care				
Bathing	12.8	28.3	7.7	13.0
Dressing	8.2	19.2	12.0	15.1
Getting out of bed	6.2	14.2	25.0	20.4
Eating	1.5	7.8	12.5	14.0
Toileting	1.3	10.9	41.7	14.9
IADL care				
Shopping	46.2	42.2	12.0	7.9
Housework	42.4	47.9	23.5	16.8
Preparing Meals	18.1	28.6	18.2	18.0
Managing Medications	9.2	17.1	10.9	6.8

Note: Wording and sequence of questions differed substantially across the RI and national surveys
[a] Allen, Lima, and Clark (2008)
[b]Lima and Allen unpublished estimates using SOA II.
[c]Lima and Allen unpublished estimates using the RI Needs Assessment Survey

- Relative to the national population estimates of need for help with ADL care, elderly people on RI Medicaid have lower levels of need for help. However, there may be a number of differences in the national sample that account for this discrepancy, including the wording of questions ascertaining need for help. For example, the national sample includes people who need supervisory help and hands on help with ADLs, while Rhode Island estimates are for hands on help only. In addition, the national sample includes people age 70 and older, while the youngest respondents to the RI sample are age 65.

- In terms of need for IADL help, RI estimates are close to national estimates for shopping and housework, but lower for meal preparation and managing medication.

- Unlike estimates of need for help, estimates of unmet need for ADL and IADL help in the RI and national samples are quite comparable.

Table 1.a.4 Need and Unmet Need for Health Related Services in the Past Year Among the RI Elderly Medicaid Population by Waiver Status, 2006

Need for Service	Waiver participant	Waiver eligible	High risk for eligibility	Low risk for eligibility	Total
	%	%	%	%	%
Glasses/contact lenses	47.7	56.5	42.1	34.8	41.8
Dental care	38.9	44.9	40.7	40.7	40.9
Disposable medical equipment	44.9	49.3	33.5	17.7	30.9
Home health aides/personal care services	76.7	53.6	29.3	5.2	29.9
Physical Therapy	33.7	44.8	30.4	20.7	28.7
Nutrition counseling	12.2	17.4	11.2	5.6	9.9
Mental health counseling	12.2	11.6	8.9	5.6	8.4
Hearing aide	8.9	11.6	8.5	5.2	7.6
Speech therapy	2.2	4.4	0.5	0.4	1.2
Drug/alcohol therapy	2.2	1.5	0.9	0.9	1.2
Medicaid Information	26.1	31.9	28.4	17.2	24.2
Unmet Need for Services Among Those with Need					
Glasses/contact lenses	24.4	23.1	25.6	19.0	22.9
Dental care	51.4	51.6	56.3	38.3	48.2
Disposable medical equipment	12.5	8.8	23.6	9.8	15.5
Home health aides/personal care services	23.2	21.6	34.9	16.7	26.5
Physical Therapy	27.6	38.7	29.2	16.7	27.2
Nutrition counseling	45.5	33.3	37.5	30.8	36.7
Mental health counseling	36.4	37.5	31.6	23.1	31.4
Hearing aide	12.5	25.0	38.9	41.7	32.6
Speech therapy*	--	--	--	--	--
Drug/alcohol therapy*	--	--	--	--	--
Medicaid information	52.2	27.3	47.6	47.5	45.3

***Too few to include**

Source: Allen, Lima, and Clark (2008)

- Need for eyeglasses and dental care are relatively high across all subgroups of the elderly population, because loss of eyesight is a common phenomenon associated with aging, and aging teeth require considerable attention, regardless of disability status.

- Waiver participants and waiver eligibles have similarly high levels of service needs, although there is variation by specific services, which may be attributable to a higher prevalence of family caregivers available to people in the waiver eligible group, and different patterns of conditions between these two groups.

- The lower prevalence of service need among respondents at high risk for waiver eligibility reflects lower levels of impairment experienced by this population. Nevertheless, need for dental care, glasses, DME, home health aides and physical therapy is not trivial for this group.

- Not surprisingly, the lowest prevalence of service need is reported by the low risk group, defined as having no reported need for ADL or IADL assistance.

- Although the level of need reported for some services in the full sample are low, e.g., hearing aids, mental health services and nutritional counseling, approximately one third of persons who report a need for these services are unable to get the service, or to get enough to meet their need. Regardless of level of need, the prevalence of unmet need (defined as an insufficient amount of services, a problem with the service, or complete inability to access the service) among elderly respondents who report need for a given service is relatively high across all groups.

Table 1.a.5 Social Support of RI Elderly Medicaid Population by Waiver Status, 2006

	Waiver participant n=92	Waiver eligible n=69	High risk for eligibility n=217	Low risk for eligibility n=234	Total n=612
	%	%	%	%	%
Living Arrangement					
Alone	83.3	65.2	67.0	58.6	66.0
With Spouse	7.8	15.9	12.6	18.5	14.5
With Others (no spouse)	8.9	18.8	20.5	22.8	19.5
How many people can you count on to help you when you need help?					
0	7.6	4.4	6.0	6.8	6.4
1 to 2	35.9	30.4	36.4	27.8	32.4
3 to 6	44.6	52.2	37.3	42.3	42.0
7 or more	12.0	13.0	20.3	23.1	19.3
Do you have someone you can talk to about your personal feelings, worries or hopes?					
No	22.0	26.5	20.2	11.7	17.9
Yes	78.0	73.5	79.8	88.3	82.1

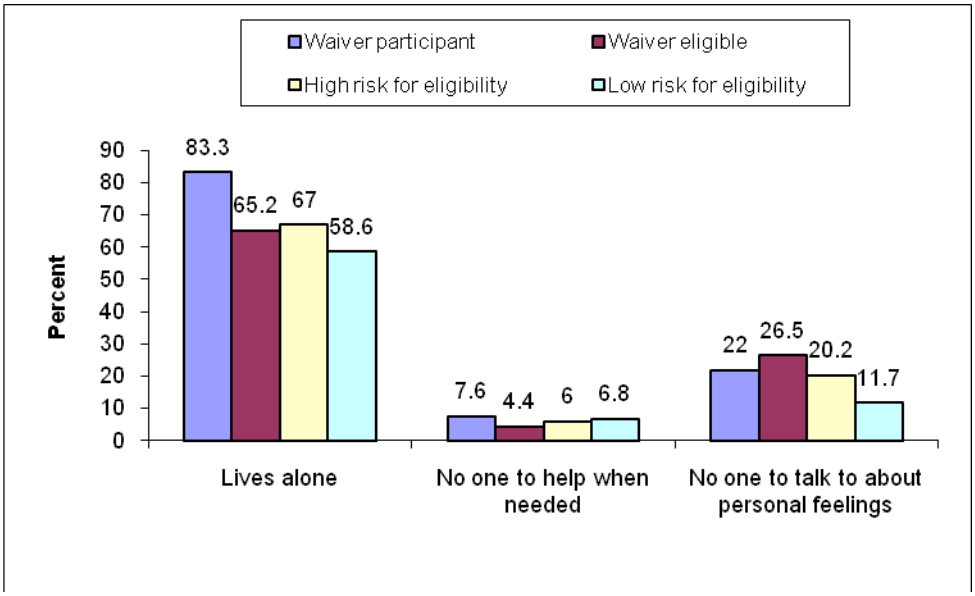
Source: Allen, Lima, and Clark (2008)

- Waiver participants are more likely than other groups to live alone, illustrating the emphasis placed on living arrangement in determining waiver eligibility. Those who do not yet have need for help with ADLs and IADLs (low risk for eligibility group) are most likely to report living with their spouse or other people.

- The vast majority of people in the sample report having at least one person to count on if they need help, and nearly one fifth report having many people. However, it is telling that the least impaired groups report the most helpers, perhaps because they have not yet had to actually request help from these hypothetical helpers.

- The least impaired group of elderly respondents is most likely to report having a confidant. Clearly "confidant" (emotional) support is perceived to be lacking to a greater extent than instrumental support in this sample.

Figure 1.a.1 Summary of Unmet Need for Social Support Among the RI Elderly Medicaid Population by Waiver Status, 2006



Source: Information adapted from above table.

- The figure above highlights variations in indicators of unmet need for social support in the subgroups of this sample of elderly persons on Medicaid.

Table 1.a.6 Health Care Screening Services/Preventive Health Care Among the RI Elderly Medicaid Population, 2006

	Total n=612
	%
In past year, have you had….	
Blood pressure checked	98.2
Cholesterol checked	89.7
Physical check-up or exam	88.8
Blood glucose (or sugar) checked	86.9
Eye exam	74.1
Flu or pneumonia shot	67.1
Any test for colorectal cancer	40.1
Gender-Specific Services	
Prostate screening (Men only)	64.2
Breast exam or mammogram (Women only)	62.7
Pap smear (Women only)	34.3

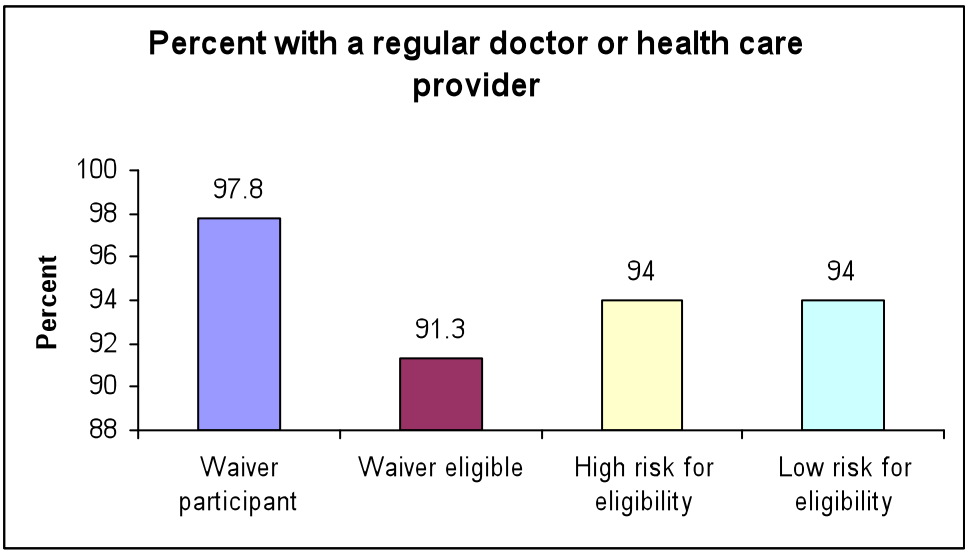
Note: Results not presented by waiver status as all groups appeared to have received nearly equal rates of preventive services.

Source: Allen, Lima, and Clark (2008)

- Rates of preventive service receipt reported by sample members look relatively high given that some of these tests are condition-specific (e.g., glucose, eye exam) and vary by age.

- However, there is substantial room for improvement in the receipt of both flu and pneumonia shots, and in tests for colorectal cancer, given the high risk of this disease at older ages.

Figure 1.a.2 Continuity of Care Among the RI Elderly Medicaid Population by Waiver Status, 2006



Source: Allen, Lima, and Clark (2008)

- The proportion of sample members who report having their own doctor is high, suggesting that continuity of care is not problematic in this population

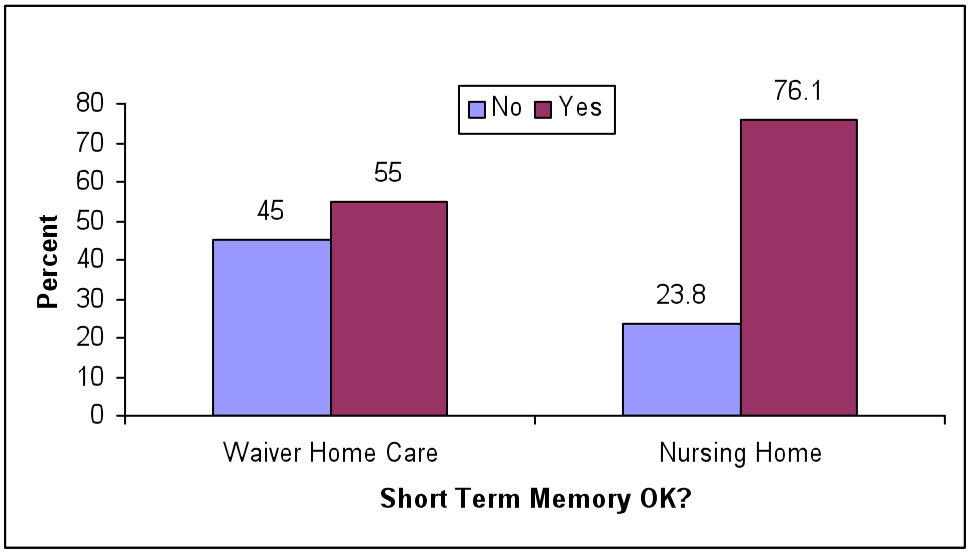
- It appears that waiver participation helps to ensure a regular health care provider, and thus the benefits of continuity of care.

- A larger proportion of those who are waiver eligible report no regular doctor than is the case in other groups.

Section 1b

RI Nursing Home and Home Care Comparisons

Figure 1.b.1 Cognition Comparison of the RI Medicaid Population in Nursing Homes versus Community-Based Waivers, 2005

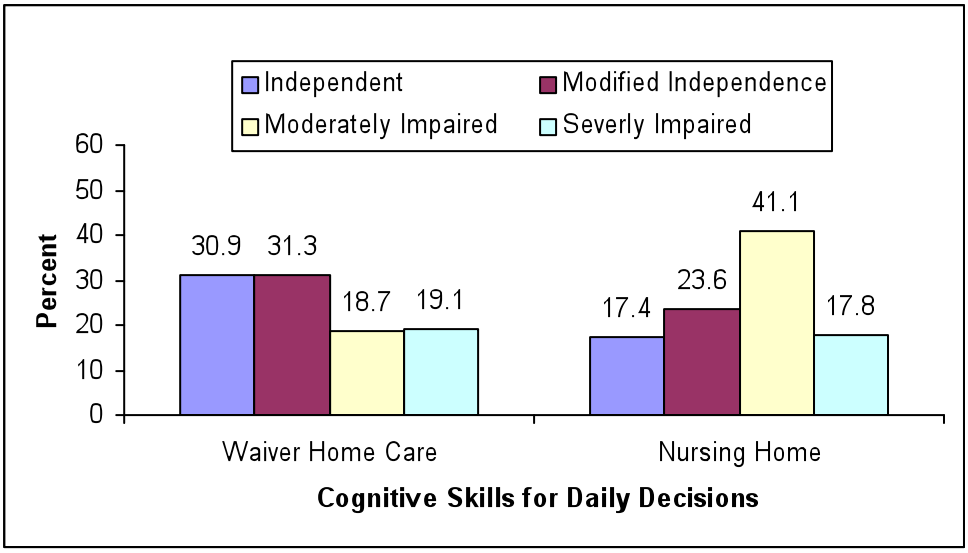


Source: Gozalo and Allen (2008).

- A higher proportion of Medicaid nursing home resident assessments than waiver participant assessments were rated to have "OK" short term memory.

- It is difficult to tell if this difference in short term memory is "real" or if the perceptions of raters in nursing homes may be based on different expectations from the perceptions of raters in home health settings.

Figure 1.b.2 Cognitive Skills Comparison of the RI Medicaid Population in Nursing Homes versus Community-Based Waivers, 2005

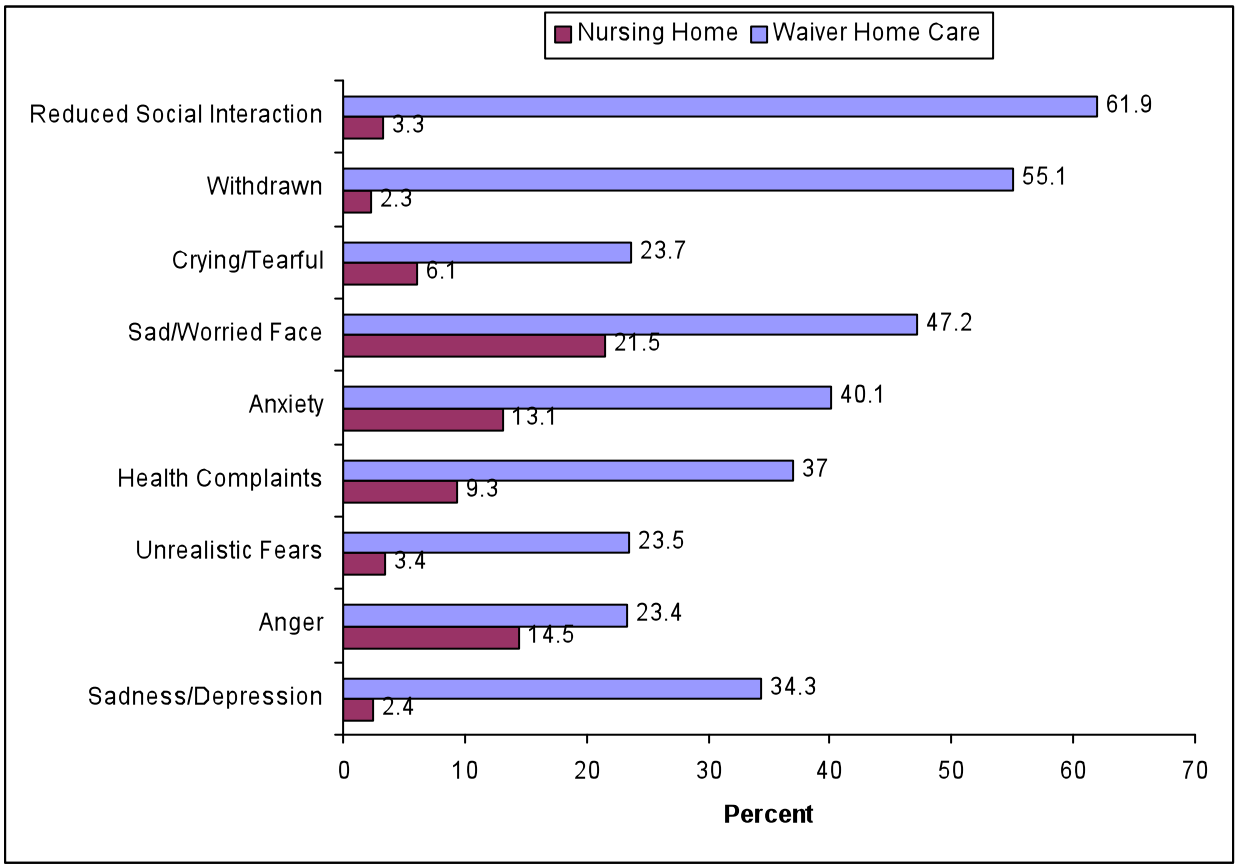


Source: Gozalo and Allen (2008)

- While about 60% of home care assessments indicated "independent" or "modified independent" ability to make daily decisions, nursing home resident assessments were much more likely to indicate "moderate impairment in cognition (41% vs. 19% of home care assessments).

- Interestingly, approximately the same proportion of home care and nursing home assessments (19% and 18% respectively) indicated "severe" cognitive impairment.

Figure 1.b.3 Mood Comparisons in the RI Medicaid Population in Nursing Homes versus Community-based Waivers, 2005

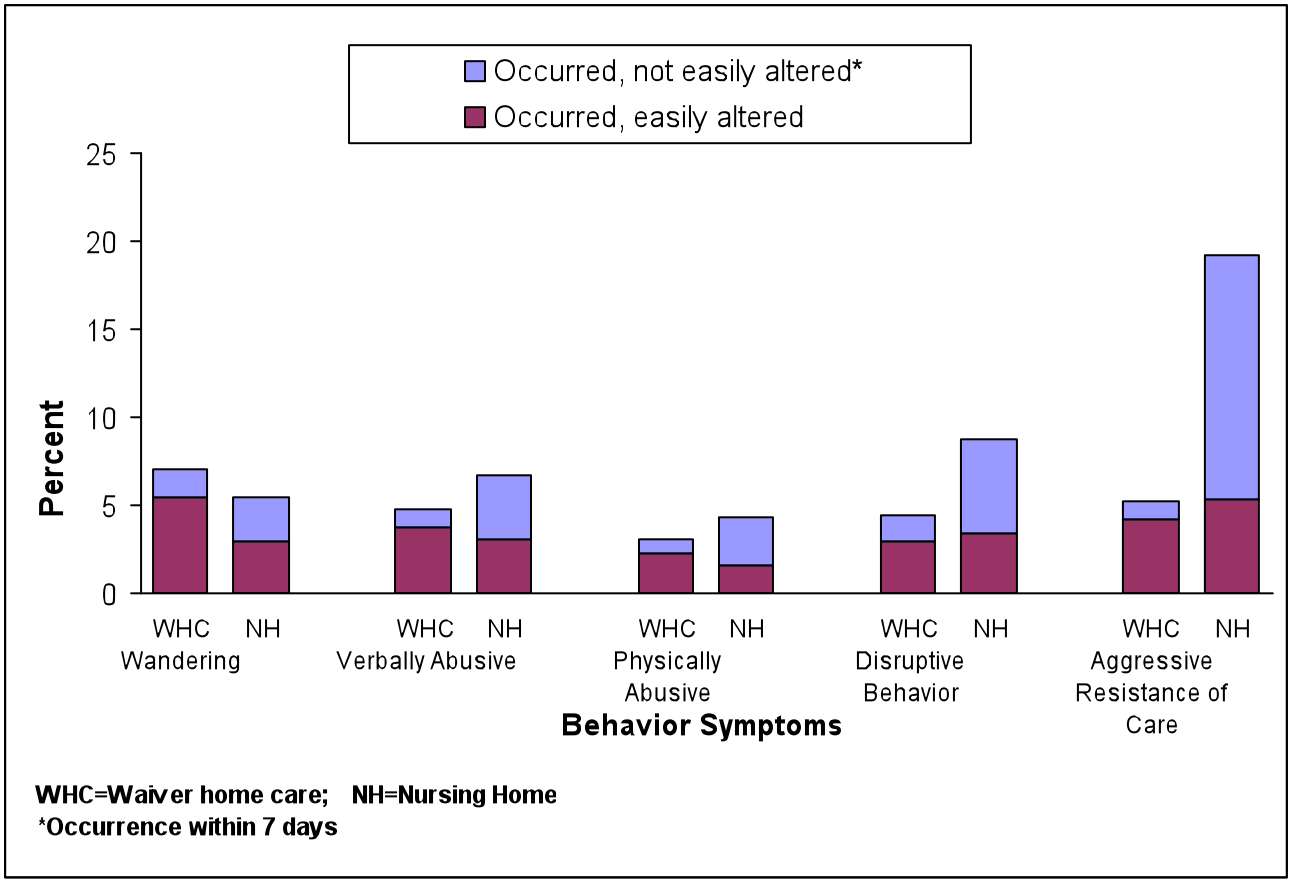


Source: Gozalo and Allen (2008)

- Findings regarding the substantial differences in ratings on nursing home resident assessments versus waiver home care assessments in indicators of mood state are surprising, with home care users rated as exhibiting higher levels of depression, anxiety, anger, etc.

- Again, this difference between nursing home and home health groups may be attributable to differences in raters' expectations in nursing home versus home health settings. Another possible explanation is that the nursing home population may be more likely to be on medications that have a positive effect on mood.

Figure 1.b.4 Behavior Symptom Comparisons of the RI Medicaid Population in Nursing Homes versus Community-Based Waivers, 2005

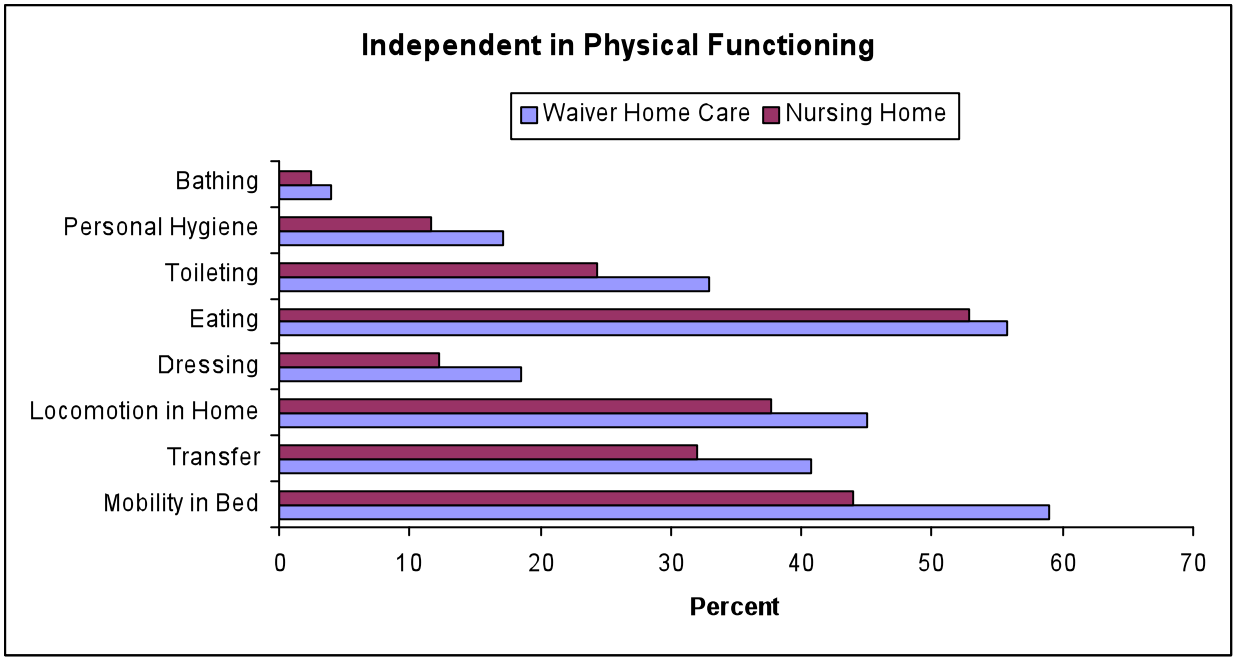


Source: Gozalo and Allen (2008)

- Nursing home assessments generally indicate higher levels of problem behaviors among residents than do waiver home care assessments, although the difference between the groups is modest, with one exception: while only 5% of home care assessments report aggressive resistance to care, resistance is reported in nearly 20% of nursing home assessments. However, nursing home residents are more likely to be rated "behavior occurred, not easily altered" while home care clients are more likely to be rated "behavior occurred, easily altered."

- Problem behaviors manifesting in home health clients may be associated with recent hospitalizations or acute illnesses.

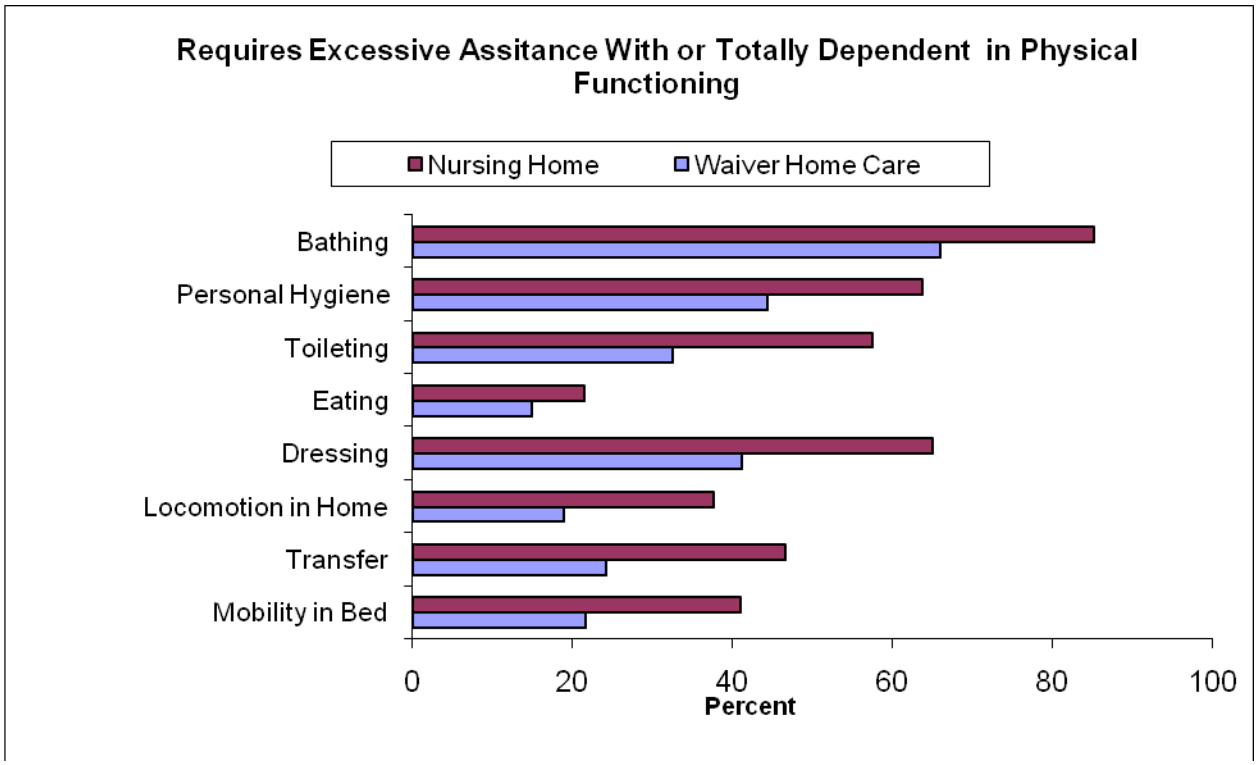
Figure 1.b.5 Physical Functioning Comparisons (1) of the RI Medicaid Population in Nursing Homes versus Community-based Waivers, 2005



Source: Gozalo and Allen (2008)

- As expected, a higher proportion of home care assessments rate waiver participants as "independent in activities of daily living" than is the case for nursing home residents' assessments. However, the differences between the groups do not appear to be large, with the possible exception of bed mobility.

Figure 1.b.6 Physical Functioning Comparisons (2) of the RI Medicaid Population in Nursing Homes versus Community-based Waivers, 2005



Source: Gozalo and Allen (2008)

- In contrast, the proportion of assessments rated as requiring excessive assistance with or totally dependent in the performance of an ADL is much higher among nursing home residents than waiver participants receiving home care. The magnitude of the difference is quite consistent across ADLs.

Section 1c

Rhode Island Nursing Home Resident and Family and Satisfaction Survey

Table 1.c.1 Rhode Island Nursing Home Resident and Family Satisfaction Survey

	Residents (n=3057)	Families (n=4082)
Overall Satisfaction	3.76	3.69
Facility Environment	3.85	3.56
Administration	3.77	3.78
Laundry	3.76	3.43
Resident Environment	3.73	3.58
Direct Care/Nurses Aides	3.68	3.65
Choice	3.63	3.69
Activities	3.61	3.49
Meals and Dining	3.56	3.41
Social Services	--	3.74
Professional Nurses	--	3.71
Admissions	--	3.66
Therapy	--	3.25

Source: Richards and Uman (2007)

- Nursing home resident and family respondents to this survey rated each of the nursing home characteristics listed above from 1 to 4, with 4 indicating the highest level of satisfaction. Clearly there is a high level of satisfaction expressed in all areas. However, the reader should be aware of a general tendency reported in the literature for people to say they are satisfied with health-related care, and even scores slightly lower than "very satisfied" (a score of 4) may be indicative of a problem.

- In general, family members' ratings tend to be lower than that of residents, although residents' rating of "choice" is lower than that of family members.

- Meals and dining, and also activities, received relatively low ratings by both families and residents, while the nursing home administration received high rankings by both groups.

Section 2: The Working Aged Population With Disability

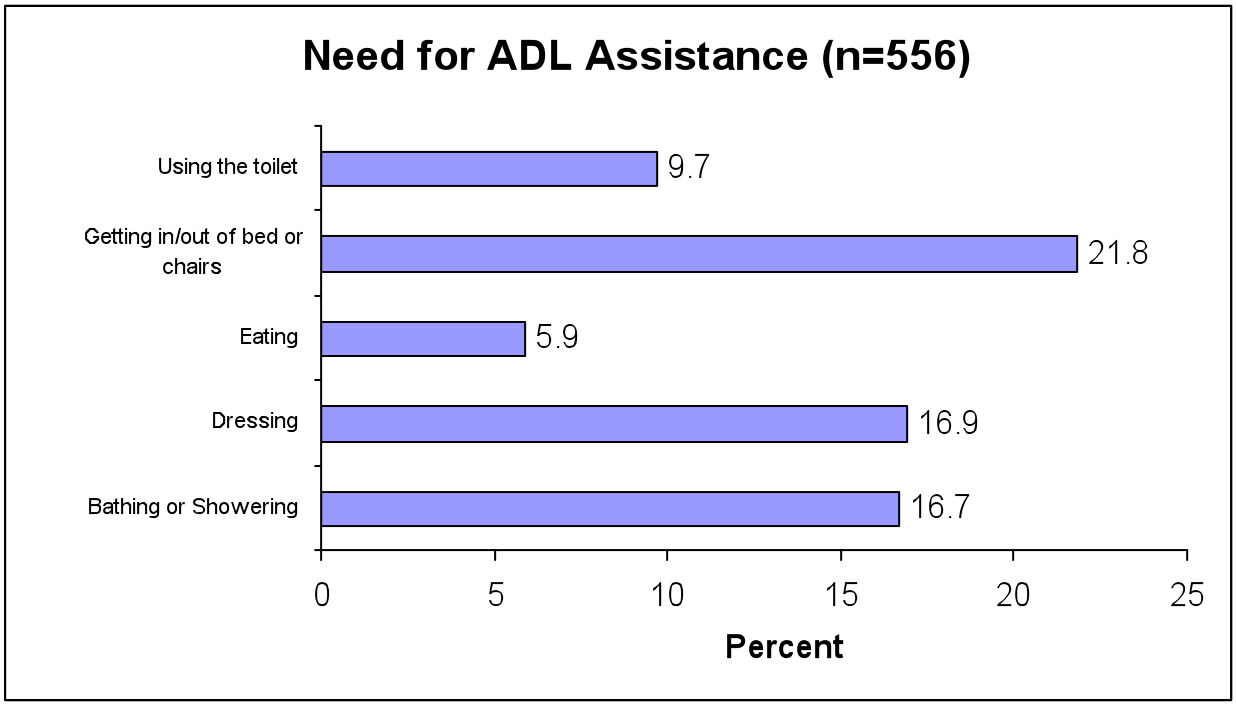
Introduction: The Working Aged Population with Physical Disabilities on Medicaid

The data presented in section 2 of this report describing the RI Medicaid working age population with physical disabilities is drawn from a report of the findings of a needs assessment survey conducted in 2000. Unlike the elderly population reviewed in the previous section of this report, all persons in the survey sample have health conditions and disabilities since disability is a necessary criterion for Medicaid eligibility in this age group.

It is important to remember that the survey was administered nine years ago, thus the estimates presented might be different with a current sample of this population, due to a different pattern of disabilities or programmatic changes in the Medicaid program or other programs accessed by this population since that time.

We also compare estimates of ADL and IADL need and unmet need in the RI population to a comparable national sample, working-age respondents to the National Health Interview Survey Disability Follow-back who reported Medicaid coverage. These data were collected in 1994/1995, so caution should be used when interpreting results.

Figure 2.1 Need for Assistance with Activities of Daily Living (ADLs) Resulting from a Health Problem or Disability Among the RI Medicaid Working Aged Population with Disability, 2000



Source: Payne (2002)

- There is a relatively high prevalence of need for assistance with ADL activities in this population, particularly with getting in and out of bed and chairs. This pattern of ADL need suggests a high level of disability among working age Medicaid recipients, which may partly reflect the high proportion of this population who reported some type of musculoskeletal condition (see full report).

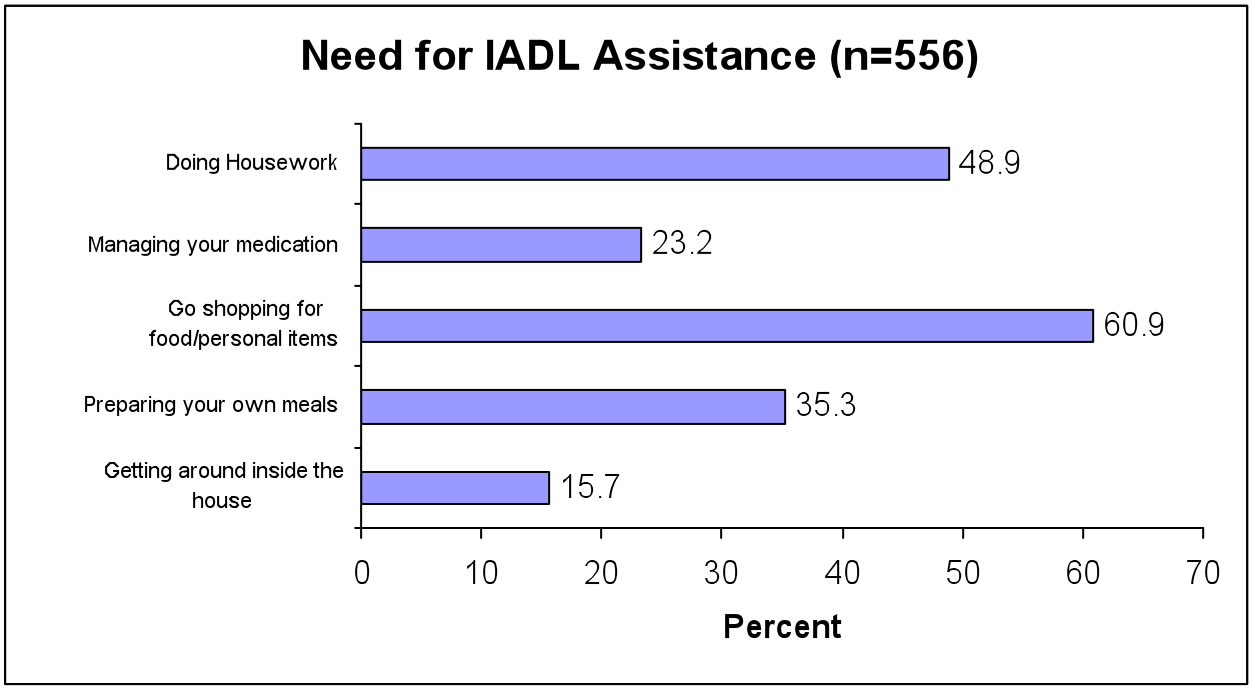
Table 2.1 Among Those Who Need Assistance, the Extent of Unmet Need for Assistance with ADLs Among the RI Medicaid Working Aged Population with Disability, 2000

ADL Need	% who do not get enough help
Bathing or Showering	22.8
Dressing	25.5
Eating	24.2
Getting in/out of bed or chairs	23.1
Using the toilet	32.1

Source: Payne (2002)

- Although the percent of respondents with need for assistance with ADLs varies according to individual activity, the proportion with need for help who report they do not get enough is fairly consistent, ranging from 22% who report inadequate help with bathing to 32% with unmet need for using the toilet.

Figure 2.2 Need for Assistance with Instrumental Activities of Daily Living (IADLs) Resulting from a Health Problem or Disability Among the RI Medicaid Working Aged Population with Disability, 2000



Source: Payne (2002)

- Need for assistance with instrumental activities is much higher than with basic activities of daily living, suggesting a high level of need for supportive services in this population.

Table 2.2 Among Those Who Need Assistance, the Extent of Unmet Need for Assistance with IADLs Among the RI Medicaid Working Aged Population with Disability, 2000

IADL Need	% who do not get enough help
Getting around inside the house	19.8
Preparing your own meals	15.8
Going shopping for food/personal items	11.2
Managing your medications	9.3
Doing housework	21.7

Source: Payne (2002)

- Despite a higher level of need for help with IADLs than with ADLs, the percentage of persons with IADL assistance need who do not have enough assistance is actually lower. It may be easier to meet IADL needs, since the need is not as constant as with ADL tasks. For example, need for help with housework and shopping can be met by a helper within the context of a weekly visit. Medications can be organized and food prepared in advance. In contrast, assistance with basic ADLS such as dressing and toileting requires assistance on an ongoing, daily basis.

Table 2.3 A Comparison of the RI Working-Aged Medicaid Population and a Nationally Representative Sample of Community-Dwelling Adults Aged 21 to 64 on Medicaid

Need for ADL and IADL Assistance	Need for help		Among Those with Need - % who do not get enough help	
	RI Estimates 2000[a]	National Estimates 1994/5[b]	RI Estimates 21-64, 2000[a]	National Estimates 1994/5[b]
	%	%	%	%
ADL care				
Bathing	16.7	14.4	22.8	16.4
Dressing	16.9	11.4	25.5	14.6
Getting out of bed	21.8	11.1	23.1	4.2
Eating	5.9	13.4	24.2	18.9
Toileting	9.7	11.0	32.1	8.5
IADL care				
Shopping	60.9	20.9	11.2	13.3
Housework	48.9	18.9	21.7	17.4
Preparing Meals	35.3	19.0	15.8	4.6
Managing Medications	23.2	18.4	9.3	4.8

Note: Wording and sequence of questions differ substantially across RI and national surveys.

[a]Payne (2002)

[b]Lima and Allen unpublished estimates using the NHIS-D

- The national estimates reported in this table are from respondents to the Disability Follow-back survey conducted by the National Center for Health Statistics who report Medicaid coverage. Respondents to this national survey reported a wide variety of health problems and impairments, which may not be comparable to the conditions reported by the RI sample.
- Levels of both need and unmet need reported by working age people on Medicaid in RI are higher than levels reported by respondents to the NHIS-D on Medicaid, probably reflecting differences in the constellation of conditions and impairments reported by the two samples, as noted above.

Table 2.4 Health Care Service Needs Among the RI Medicaid Working Aged Population with Disability, 2000

In the PAST YEAR did you need…	Respondents Who Needed the Service	Of Those Who Needed the Service in Past Year		
	%	Not able to obtain %	Obtained but didn't satisfy need or there was a problem %	Satisfied %
Refills for Prescription Medication	90.5	1.4	12.0	86.7
A Doctor's Appointment	89.4	1.0	11.3	87.7
Over the Counter Drugs	68.7	3.9	35.5	60.5
Dental Care	64.9	31.1	20.3	48.6
New Prescription Medication	63.8	3.7	12.5	83.9
Eyeglasses	62.5	25.1	21.7	53.2
Transportation (to a doctor's office or pharmacy)	52.3	6.9	33.1	60.0
Specialty Medical Care	52.3	8.7	14.9	76.5
Information on your Specific Health Problem	42.0	18.1	20.7	61.2
Mental Health Counseling	36.8	20.6	18.6	60.8
Physical/Occupational Therapy	35.6	21.3	23.9	54.8
Durable Medical Equipment	30.7	10.6	16.5	72.9
Peer Support	30.0	46.1	5.5	48.5
Nutrition Counseling	25.9	28.5	13.2	58.3
Disposable Medical Supplies	24.1	7.5	17.9	74.6
Home Health Aid / Homemaker / Personal Care Services	20.2	32.1	19.6	48.2
Drug or Alcohol Counseling	5.8	6.3	9.4	84.4
Speech Therapy	3.4	47.4	10.5	42.1

Source: Payne (2002)

- The second column of this table reflects difficulty in access to needed services. In general, results suggest that it is easier to access medical services than supportive or ancillary services often required by persons with chronic conditions.
- The third column suggests that access alone may not be sufficient in meeting service needs. In order to be effective, the amount of service offered must match level of need. For example, if the physical therapy prescribed following a fall is not enough to enable the individual to regain functioning, that need is still unmet.

Table 2.5 Social Support Among the RI Medicaid Working Aged Population with Disability, 2000

	Total (N=556)	
	#	%
Help Getting Medical Care and Services:		
Self/No Help	226	40.6
Formal Only	96	17.3
Informal Only	234	42.1
Living Arrangements:		
Alone	231	41.5
Family	286	51.4
Roommates	39	7.0
Person to Count on:		
No one	30	5.4
One	91	16.5
Two or More	431	77.4
Someone to talk to:		
Yes	452	81.4
No	103	18.6

Source: Payne (2002)

- Fully 40% of the sample report having no one to help them get the care and services they need. Case management may be particularly helpful to such persons.
- 41% of the sample report living alone, suggesting that these people may be at particularly high risk of unmet need for any assistance that is required by their health conditions.
- On the other hand, over three quarters perceive that they have 2 or more people available to count on when they need help.
- Nearly one fifth of respondents report having no one to talk to, placing them at risk of loneliness, depression and social isolation.

Table 2.6 Health Care Screening Services/Preventive Health Care Among the RI Medicaid Working Aged Population with Disability, 2002

	Total n=556
	%
In the past year, have you had...	
Blood Pressure checked	95.7
Blood Sugar/Glucose test	78.9
Cholesterol checked	79.5
Flu/Pneumonia Vaccine	49.5
Physical Check-up	82.9
Eye Exam	59.3
Colorectal Screening	23.4
Gender-Specific Services	
Breast Exam (female only)	59.1
Cervical Pap Smear (female only)	55.4
Prostate Screening (male only)	32.0

Source: Payne (2002)

- Some of the preventive services listed are condition-specific and/or have age guidelines, thus it is difficult to determine if reported levels of receipt of services are adequate.

- However, everyone in this sample of persons with health problems and disabilities should have an annual check-up, and as members of a vulnerable population, should also have an annual flu vaccination.

- Additionally, annual pap smears are recommended for all working age women.

Tale 2.7 Health Services Utilization Among the RI Medicaid Working Aged Population with Disability, 2000

	Number	Percent
Have a Usual Place for Medical Care (% yes)	542	96.7
Private Doctor's Office	292	54.0
Hospital Clinic	130	24.0
Community Health Center	101	18.7
Hospital ER	5	0.9
Walk-in ER/Other	13	2.4
Have Own Doctor or Health Care Provider (% yes)	502	90.5

Source: Payne (2002)

- Connection with the health care system, also referred to as continuity of care, appears to be excellent in this population, with only approximately 3% naming an ER as their usual site of care. However, as indicated in Table 2.6, only 82% report receiving an annual check-up.

- Similarly, only approximately 10% of respondents report that they do not have a regular doctor or provider. However, other data in the source report suggests that these people without a regular provider are at risk for not receiving recommended services, suggesting that all effort should be made to ensure a medical home and regular provider for all members of the Medicaid population.

Section 3: Comparison of Working Aged and Elderly RI Medicaid Populations

Introduction: A Comparison of Working Aged and Elderly RI Medicaid Populations

The several tables included in this section were extracted from Sections 1 and 2 to present a comparison of the service needs of the two populations highlighted. There are several things to keep in mind when reviewing these comparisons:

- There are substantial differences in eligibility requirements between the two populations, such that a large proportion of elderly Medicaid recipients are poor but not disabled, while all of the working age population have some disability

- Among those who are disabled in the two populations, there are substantial differences in the constellation of conditions that result in need for assistance and other formal service use (e.g., higher levels of disability attributable to trauma in the working age population; higher levels of disability attributable to cognitive impairment in the elderly population).

- The survey of working age persons with physical disabilities was conducted six years prior to the survey of community-based elderly on Medicaid. It is possible that programmatic changes partly account for the differences between the two groups.

Despite these differences, it is instructive to the Medicaid program to be aware of the similarities and differences in these two populations, since the services they require overlap substantially.

Table 3.1 Need and Unmet Need for ADL and IADL Assistance Among the RI Medicaid Population

Need for ADL and IADL Assistance	Need for help		Among Those with Need - % who do not get enough help	
	Working-Aged[a], 2000	Elderly[b], 2006	Working-Aged[a], 2000	Elderly[c], 2006
ADL care				
Bathing	16.7	12.8	22.8	7.7
Dressing	16.9	8.2	25.5	12.0
Getting out of bed	21.8	6.2	23.1	25.0
Getting around the house	15.6	5.8	19.8	26.5
Eating	5.9	1.5	24.2	12.5
Toileting	9.7	1.3	32.1	12.5
IADL care				
Shopping	60.9	46.2	11.2	12.0
Housework	48.9	42.4	21.7	23.5
Preparing Meals	35.3	18.1	15.8	16.7
Managing Medications	23.2	9.2	9.3	9.3

[a]Payne (2002)
[b]Allen, Lima, and Clark (2008)
[c]Lima and Allen unpublished estimates of the RI Needs Assessment Survey

- Keeping in mind the differing Medicaid eligibility requirements for the elderly and working age populations on Medicaid, it is not surprising to see higher levels of need for both ADL and IADL assistance in the working age population than in the elderly population. As is clear from Section 1 of this report, a substantial proportion of the community-dwelling elderly Medicaid population do not have any need for assistance, but qualify for Medicaid on the basis of their impoverishment.

- Levels of unmet need for help vary according to ADL activity in elderly vs. working age populations with need for ADL help. While the elderly are more likely to report unmet need for help with getting around the house, working age persons are more likely to report unmet need for help with bathing, dressing, eating and toileting.

- There are a number of possible reasons for these differences, including elderly persons' access to services administered by the RI Department of Elderly Affairs and the difference in time frames (6 years apart) in which the respective surveys were administered.

- Levels of unmet need for help with IADL activities were similar between the two groups.

Table 3.2 Health Care Service Needs Among the RI Medicaid Population

Health Care Service Needs	Need for Service		Among Those with Need - Unable to Get Any or Enough Service	
	Working-Aged[a], 2000	Elderly[b], 2006	Working-Aged[a], 2000	Elderly[b], 2006
Dental Care	64.9	40.9	51.4	48.2
Eyeglasses/Contacts	62.5	41.8	46.8	22.9
Mental Health Counseling	36.8	8.4	39.2	31.4
Nutrition Counseling	25.9	9.9	41.7	36.7
Disposable Medical Supplies	24.1	30.9	25.4	15.5
Home Health Aid/Homemaker/Personal Care Services	20.2	29.9	51.7	26.5
Drug or Alcohol Counseling	5.8	1.2	15.7	--*
Speech Therapy	3.4	1.2	57.9	--*

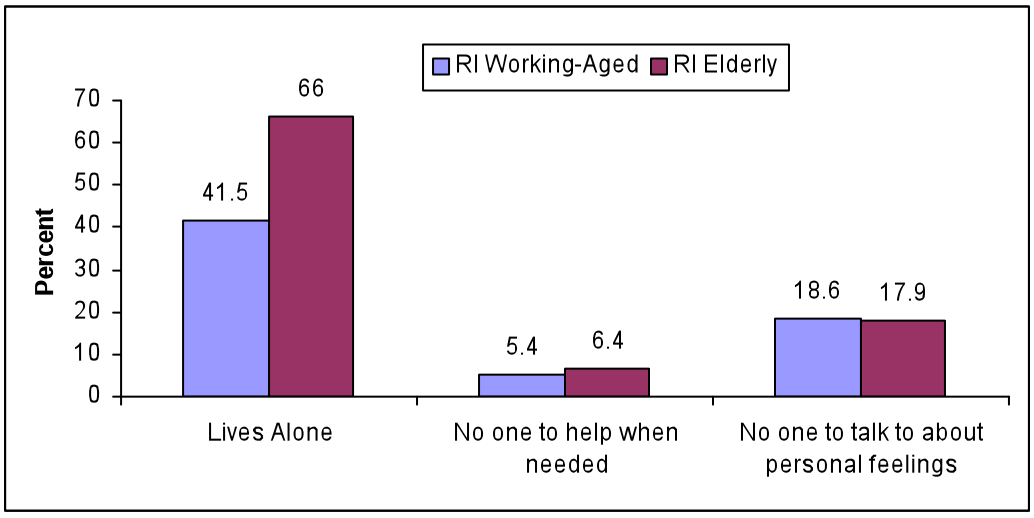
*too few to include
[a]Payne (2002)
[b]Allen, Lima, and Clark (2008)

- Need for dental care and eyeglasses are the most prevalent of health care service needs reported by both working age and elderly Medicaid survey respondents.

- Much higher levels of service need are reported by working age than by elderly respondents, with the exception of home care services and disposable medical supplies, which are reported more often by elderly than working age respondents.

- Among respondents who report service needs, levels of unmet need are relatively high, and are higher among the working age than the elderly population on Medicaid, which again may be partly due to services provided by the aging system as well as broader coverage by Medicare in the elderly vs. the working age population.

Figure 3.1. Lack of Social Support Among the RI Medicaid Population



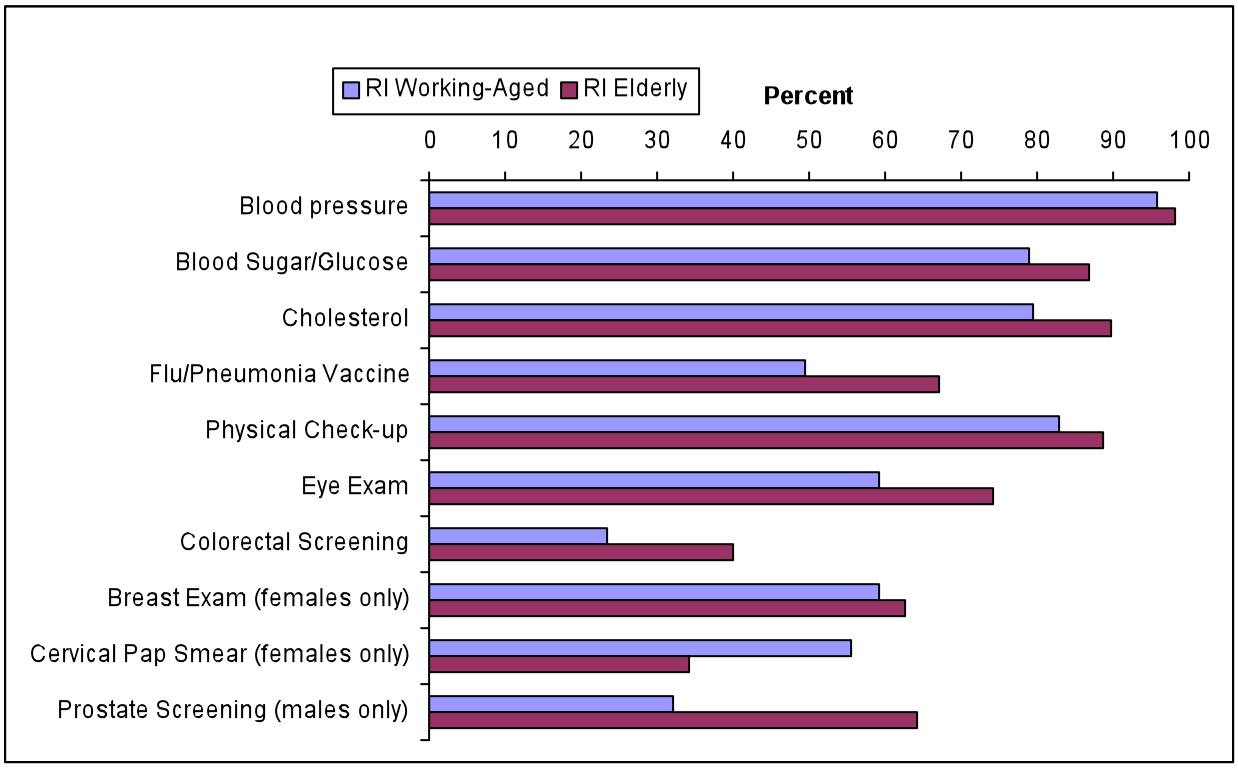
Sources: Payne (2002) and Allen, Lima, and Clark (2008)

- Higher proportions of elderly than working age populations live alone, thus putting them at risk for institutionalization due to lack of ongoing care and support.

- Few respondents in either population perceived themselves to have no one to help.

- Very similar proportions appear to be lacking emotional support, despite the higher rate of co-residence with others among working age persons with disabilities. Clearly, living with others is no guarantee that need for emotional support will be met.

Figure 3.2 Health Care Screening Services/Preventive Health Care in the Past Year



Sources: Payne (2002) and Allen, Lima, and Clark (2008)

- Higher proportions of elderly than working age Medicaid recipients with physical disabilities received preventive services. A partial explanation for these differences is the enhanced access to care afforded by Medicare, given that a higher proportion of working age than elderly persons on Medicaid are covered by Medicaid alone.

- In addition, providers may be more likely to perceive elderly than working age people as vulnerable or at risk for certain illnesses, thus accounting for the higher proportion of elderly who receive flue and/or pneumonia shots, for example.

- Again, the reader should keep in mind the six year difference between the two surveys.

Section 4: Persons with Developmental Disabilities

Introduction: Persons with Developmental Disabilities on Medicaid

The information presented in this section was taken from the 2009 report on consumer outcomes submitted to the National Association of State Directors of Developmental Disabilities Services as part of the National Core Indicators Project. Initiated in 1997, the aim of NCI was to help states develop and implement outcome indicators that would enable them to measure service delivery system performance. Following a development and testing phase, 12 states, including Rhode Island, participated in the initial collection of the selected and tested indicators in 2000, considered the NCI baseline. Today, there are 30 states participating in this voluntary data collection effort. Most indicators presented here compare Rhode Island's results with the average score of 23 other participating states.

The reader will notice that the information contained here and also in the following section on adults with serious mental illness is quite different in nature from the information presented on the elderly and working age adults with physical disabilities. While people with developmental disabilities are also known to be at elevated risk for physical health problems, the emphasis of state authorities has historically been placed on issues such as housing and inclusion in society, measured by rates of employment, of meaningful relationships and of participation in community activities. Satisfaction with services received by this population has also been a particular focus, while medical utilization is less prominent. As we have seen in the previous sections of this report, the reverse is true for populations characterized by high levels of physical illness and/or impairments. While Rhode Island has long been in the forefront of deinstitutionalizing persons with cognitive disabilities, it is only recently that this emphasis has shifted to the physically disabled population as well.

The report from which the data presented here is drawn is rich and highly informative to the state as a means of tracking problems in service delivery as well as improvements over time. In addition, these data allow for benchmarking progress to the performance of other states. Readers interested in this population are encouraged to view the full report, as it was not feasible to include all data in this overview.

Table 4.1 Type of Residence Among Persons Receiving at Least One Service Other than Case Management from a State Developmental Disability Authority During Fiscal Year 2007-2008

Type of Residence	RI	Average across all other States
	%	%
Specialized Institutional Facility	3.5	16.5
Group Home	46.5	23.5
Apartment Program	5.4	5.4
Independent Home/Apartment	16.3	13.0
Parent/Relative's Home	24.0	28.7
Foster Care/Host Home	2.9	8.8
Nursing Facility	0	0.9
Other	1.0	2.9
Don't Know	0.3	0.4

*State average includes AL, AR, AZ, CT, DE, GA, HI, IN, KY, LA, ME, MO, NC, NJ, NM, NY, OK, PA, SC, TX, VT, WV, WY.
Source: National Core Indicators (2009)

- Relative to the other states included in this report to CMHS, twice as many adults with developmental disabilities reside in group homes in RI, and far fewer live in institutions, than in other states participating in the NCI project.

- In addition, RI is above the state average in the proportion of its population living independently.

Table 4.2 Services and Supports Received Among Persons Receiving at Least One Service Other than Case Management from a State Developmental Disability Authority During Fiscal Year 2007-2008

	RI	24-State Average
	%	%
Service Coordination/Case Management	87.5	95.4
Voc - Supported Employment	23.1	12.6
Voc - Group Employment	18.6	6.3
Voc - Facility Based	46.2	24.5
Non-Voc Day Services	34.0	40.3
Community Participation	59.0	41.0
Enrolled in School	0	3.6

*State average includes AL, AR, AZ, CT, DE, GA, HI, IN, KY, LA, ME, MO, NC, NJ, NM, NY, OK, PA, RI, SC, TX, VT, WV, WY.
Source: National Core Indicators (2009)

- Twice as many persons with developmental disabilities in Rhode Island are in supported employment than is the average of other states, three times as many are in group employment, and nearly twice as many in facility-based employment. Clearly, RI is far ahead of the curve in employment rates for this population.

- Additionally, approximately 60% of consumers with developmental disabilities are participating in the community in RI, compared to an approximate 40% average across other states.

- In contrast, no adults in RI were enrolled in school at the time of this report.

Table 4.3. Consumer Outcomes -- Choice and Decision Making Among Persons Receiving at Least One Service Other than Case Management from a State Developmental Disability Authority During Fiscal Year 2007-2008

Proportion of respondents who reported that they chose…	RI	Average across all other States
	%	%
The place where they live	48.8	46.4
The staff who help them at home	60.1	60.6
Place of work or day activity	59.1	56.9
The staff who help them at work/day activity	64.9	65.9
Case manager/service coordinator	53.6	56.0
The people they live with	41.6	40.1
Their daily schedule	79.6	78.8
How to spend free time	90.6	89.4
What to buy with their spending money	88.8	87.4

*State average includes AL, AR, AZ, CT, DE, GA, HI, IN, KY, LA, ME, MO, NC, NJ, NM, NY, OK, PA, SC, TX, VT, WV, WY.
Source: National Core Indicators (2009)

- Rates of consumer choice and decision-making are parallel to the average of other states contributing data to this report. It is important to note that this information was based on a consumer survey of the population with developmental disabilities in RI.

Table 4.4. Consumer Outcomes: Relationships Among Persons Receiving at Least One Service Other than Case Management from a State Developmental Disability Authority During Fiscal Year 2007-2008

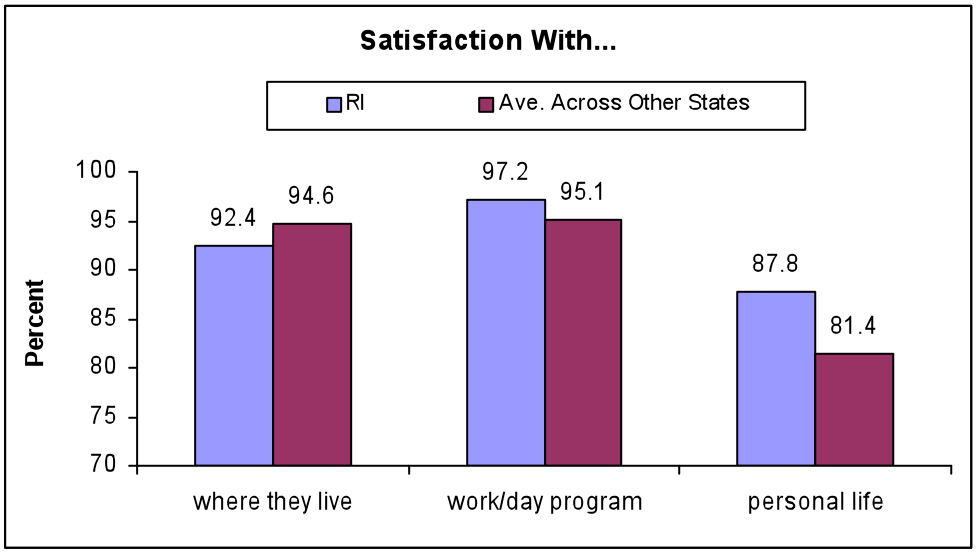
Proportion of respondents who reported …	RI	Average across all other States
	%	%
Having friends and caring relationships with people other than support staff and family members	85.1	69.3
Having a close friend	96.2	83.4
They are able to see their family when they want to	92.4	77.6
They are able to see their friends when they want to	96.0	80.8
Feeling lonely (often/sometimes)	41.7	45.5

*State average includes AL, AR, AZ, CT, DE, GA, HI, IN, KY, LA, ME, MO, NC, NJ, NM, NY, OK, PA, SC, TX, VT, WV, WY.
Source: National Core Indicators (2009)

- Higher proportions of RI adults with developmental disabilities report social relationships with family and friends than the participating state average.

- Perhaps as a result, RI respondents are slightly less likely to report feeling lonely. However, loneliness appears to be a particular problem for this population.

Figure 4.1 Consumer Outcomes: Satisfaction Among Persons Receiving at Least One Service Other than Case Management from a State Developmental Disability Authority During Fiscal Year 2007-2008



*State average includes AL, AR, AZ, CT, DE, GA, HI, IN, KY, LA, ME, MO, NC, NJ, NM, NY, OK, PA, SC, TX, VT, WV, WY.
Source: National Core Indicators (2009)

- Ironically, despite the fact that many more consumers live in group homes and far fewer live in institutions than in other states participating in the NCI project, RI consumers are slightly less likely than the other states' average to report being satisfied with where they live. Overall, however, rates of satisfaction are high.

- RI consumers with developmental disabilities are slightly more likely to report satisfaction with their work/day programs than in other states, and considerably more likely to report satisfaction with their personal lives.

- However, it should be noted that rates of satisfaction with personal life are lower than on other measures, both in RI and other states.

Table 4.5 System Performance Reported by Persons Receiving at Least One Service Other than Case Management from a State Developmental Disability Authority During Fiscal Year 2007-2008

Proportion of respondents who reported …	RI	Average across all other States
	%	%
Service Coordination		
Their service coordinators help them get what they need	89.6	76.7
They know their case manager	98.2	90.0
Their case manager asks them what's important	84.1	74.4
Access		
That needed services were not available	57.5	12.4
They received help to do or learn new things	80.5	81.4
They have adequate transportation when they want to go somewhere	89.5	79.2

*State average includes AL, AR, AZ, CT, DE, GA, HI, IN, KY, LA, ME, MO, NC, NJ, NM, NY, OK, PA, SC, TX, VT, WV, WY.
Source: National Core Indicators (2009)

- Rates of satisfaction with service coordination in the RI sample are substantially higher than the average of other participating states, suggesting an effective case management component to the service system.

- Satisfaction with availability of transportation when needed is also high relative to other participating states average.

- In contrast, Rhode Island scored lowest of all participating states in rates of satisfaction with available needed services. Reasons for this discrepancy are not clear.

Table 4.6 Health and Welfare Among Persons Receiving at Least One Service Other than Case Management from a State Developmental Disability Authority During Fiscal Year 2007-2008

Proportion of respondents who reported…	RI	Average across all other States
	%	%
Safety		
They feel safe in their home	82.8	83.0
They feel safe in their neighborhood	86.2	83.2
Health		
Having a physical exam in the past year	85.1	87.2
Having a gynecological exam in the past year (women)	55.1	49.6
Having a dental visit in the past six months	66.3	52.4
Medication		
Receiving psychotropic drugs	50.8	47.2

*State average includes AL, AR, AZ, CT, DE, GA, HI, IN, KY, LA, ME, MO, NC, NJ, NM, NY, OK, PA, SC, TX, VT, WV, WY.

Source: National Core Indicators (2009)

- Rates of receipt of a physical exam, a gynecological exam and dental care are comparable to those of working age adults with physical disabilities.
- Approximately half of adults with developmental disabilities receive psychotropic drugs, which is slightly above the 23 state average.

Table 4.7 Respect/Rights Among Persons Receiving at Least One Service Other than Case Management from a State Developmental Disability Authority During Fiscal Year 2007-2008

Proportion of respondents who reported that…	RI	Average across all other States
	%	%
They have an advocate or someone who speaks on their behalf	100	86.4
Their mail is opened without permission	12.2	11.9
They have some restrictions on being alone with guests	10.3	12.3
There are restrictions on their use of phone	8.1	8.9
Other people enter their home without permission	15.1	14.4
Other people enter their bedroom without permission	19.2	19.6
They have attended activities of self-advocacy groups	32.8	32.0
They can be alone (have privacy)	91.8	91.4
Most day support staff treat them with respect	94.2	93.8
Most residential support staff treat them with respect	97.5	89.7

*State average includes AL, AR, AZ, CT, DE, GA, HI, IN, KY, LA, ME, MO, NC, NJ, NM, NY, OK, PA, SC, TX, VT, WV, WY.
Source: National Core Indicators (2009)

- All Rhode Island respondents to the NCI survey question report having an advocate (although only 60 of 312 respondents answered the question -- the reason for this is unknown).

- Rates of indicators of infringement of the rights to autonomy and privacy are relatively low and are very comparable to the average of other participating states.

- In addition, the vast majority of Rhode Island and other states' respondents report they are treated with respect by support staff.

Section 5: Persons with Severe and Persistent Mental Illness

a. Results of the U.S. CMHS Uniform Reporting System, 2006

b. Results of the RI Mental Health Statistics Improvement Program (MHSIP), 2008

Introduction: Persons with Severe and Persistent Illness on Medicaid

The information presented in the first part of this section is from the U.S. CMHS Uniform Reporting System, which was designed to provide accountability for state mental health block funding from the federal government. Since all states are mandated to submit data on an annual basis to CMHS, the URS allows individual states to monitor system improvement over time, as well as to identify problems that arise from year to year. In addition, aggregate data from all states presents a national picture of the state of the service system for people with severe and mental illness. As part of the URS, states are required to administer a survey regarding service satisfaction to consumers, and domain scores from this survey are included from this survey.

The second part of this section presents data from the entire consumer survey, both individual items and domain scores. This survey is administered to all consumers at the time of their annual review and revision of their treatment plan, and allows consumers to reflect on their progress over the previous year and to voice areas of satisfaction and dissatisfaction with the service system. In addition, RI MHRH uses the information to provide feedback to the provider network. It is an important part of the agency's ongoing quality assurance dashboard/performance measure reviews. Thus, the consumer survey is an important tool at the individual, provider, state and federal level.

An important caveat to remember in reviewing these data is that only consumers who are active in the community treatment system are surveyed. People with serious mental illness who drop out of the system are not tracked and therefore not represented in these data.

Section 5a

Results of the U.S. Center for Mental Health Services Uniform Reporting System

Table 5.a.1 Living Situation of Consumers Served by State Mental Health Agency Systems, FY 2006

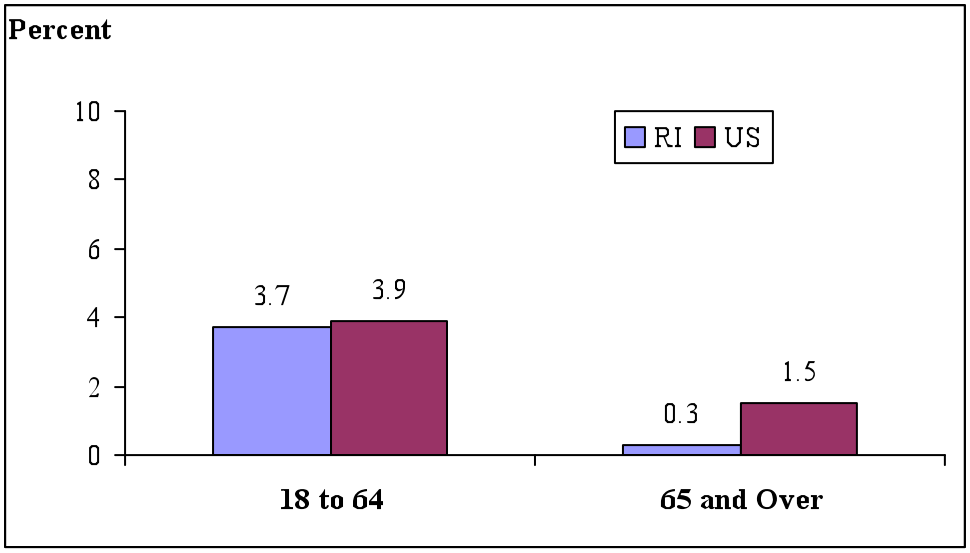
Adults over age 18	Percent with Known Living Situation* RI (n=13,308)	US (n=3,124,448)
Private Residence	89.1	78.2
Foster Home	0.1	0.8
Residential Care	4.4	5.3
Crisis Residence	-	1.4
Children's Residential Tx	-	0.0
Institutional Setting	2.8	3.9
Jail/Correctional Facility	0.2	2.4
Homeless or Shelter	3.5	3.7
Other Living Situation	-	4.2

*5387 persons had unknown living situation in RI, and 649,746 in the US.
Source: 2006 CMHS Uniform Reporting System (URS) Tables 8/20/2007

- Among residents of RI with serious mental illness for whom a living situation is known, nearly 90% report living in a private residence. This compares favorably with other state averages.

- In addition, fewer adults with SMI are in jail than the state average, and slightly fewer are in institutional settings.

Figure 5.a.1 Percent of Persons Served in MH Programs who were Homeless, by age (data from Appropriateness Domain: Table 5): URS Year 5)



Source: 2006 CMHS Uniform Reporting System (URS) Tables 8/20/2007

- While the proportion of RI adults with serious mental illness who are homeless is comparable to the national average, fewer elderly adults with serious elderly adults are without homes than is the case nationally.

Table 5.a.2 Evidence-Based Practices Provided to Adults with Serious Mental Illness Reported by State Mental Health Agency Systems, FY 2006

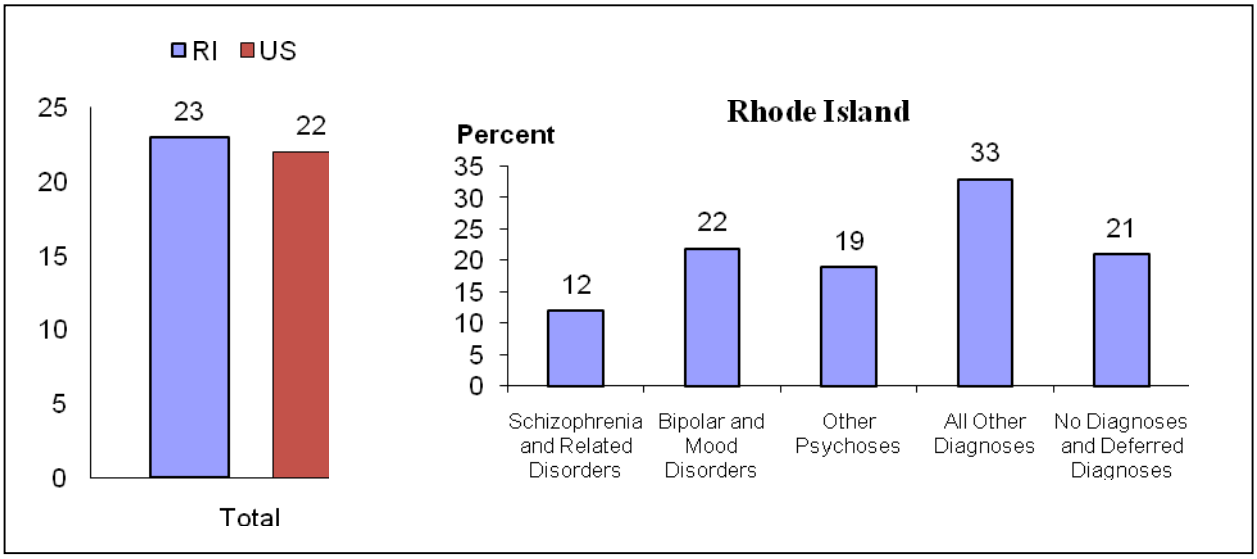
Adult EBP Services	RI		US	
	n	Penetration Rate	n*	Penetration Rate
Supported Housing	-		1,428,669	5.5%
Supported Employment	12,235	4.4%	1,600,312	2.7%
Assertive Community Treatment	12,235	10.5%	1,744,901	2.8%
Family PsychoEducation	-		742,981	1.3%
Dual Diagnosis Treatment	-		682,047	4.1%
Illness Self Management	-		674,626	17.3%
Medications Management	-		440,381	38.8%

*n's differ due to the number of states included in each measure
Source: 2006 CMHS Uniform Reporting System (URS) Tables 8/20/2007

- The proportion of RI adults with serious mental illness who are in assertive community treatment is approximately three times the national average, and rates of supportive employment are higher.

- Rhode Island did not submit information regarding consumers' participation in other types of evidence-based (i.e., scientifically demonstrated to be effective) treatment programs; thus it is not know how participation compares to other states nationally.

Figure 5.a.2 Employment Rates of Adult State Mental Health Consumers Served in the Community, for the Total Population and by Diagnosis, FY 2006



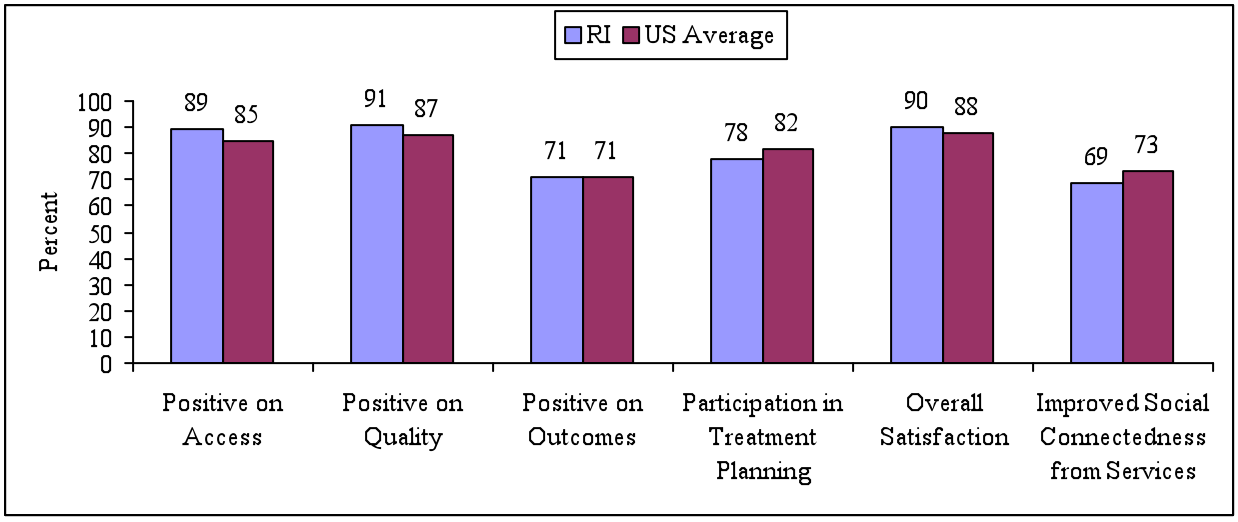
Source: Total percentages from p.1 of 2006 CMHS Uniform Reporting System (URS) Tables 8/20/2007. RI by diagnoses from Outcomes Domain: Table 1a of 2006 CMHS Uniform Reporting System (URS) Tables 8/20/2007;

- Nearly one quarter of adults with serious mental illness were employed at the time of this survey, which is comparable to employment rates in this population nationally.

- Rates of employment for people with schizophrenia are lowest among seriously mental ill adults in Rhode Island, and highest among people with "other" diagnoses.

- While the national rate for adult mental health service consumers is based on reports from all states, employment rates by diagnosis were reported by 35 states only; thus, national comparisons are not presented to avoid confusion caused by discrepancies with the overall national average.

Figure 5.a.3 URS Year 5 Adults Consumer Survey Results



Note: US Average based on varying number of states per item.
Source: Data from Outcomes Domain: Tables 2 and 4 of 2006 CMHS Uniform Reporting System (URS) Tables 8/20/2007

- Levels of consumer satisfaction on outcome domains (e.g., scores averaged across questions within domain) are relatively high with only minor differences between Rhode Island and national averages.

- Rates are lowest regarding satisfaction with social connectedness and treatment "outcomes", and highest on service quality, access, and over satisfaction with the service system.

Section 5b

Results of the RI Mental Health Statistics Improvement Program (MHSIP), 2008

Table 5.b.1 Consumer Satisfaction with and Access to Services

MHSIP CONSUMER SURVEY ITEMS	n*	Agree/Strongly Agree %
Summary: Consumer Satisfaction with Services	**3,190**	**89.3**
If I had other choices, I would still get services from this agency.	3,167	87.2
I would recommend this agency to a friend or a family member.	3,115	88.7
Summary: Consumer Perception of Access to Services	**3,192**	**89.9**
The location of services was convenient (parking, public transportation, distance, etc.).	3,094	87.9
Staff were willing to see me as often as I felt it was necessary.	3,197	91.4
Staff returned my call within 24 hours.	3,002	90.3
Services were available at times that were good for me.	3,176	92.9
I was able to get all the services I thought I needed.	3,197	88.7
I was able to see a psychiatrist when I wanted to.	3,162	83.2

*Total N=3237; n for each item excludes responses of Not applicable/ unknown/missing

Source: RI Dept. of MHRH (2009)

- In general, satisfaction with access to services was rated highly by consumers with SMI; with an overall satisfaction with access score of 90%.

- Access to psychiatrists appears to be the most problematic for this population.

- Slightly more than 10% of the sample of respondents appears less than satisfied with the agency from which services were received.

Table 5.b.2 Consumer Perceptions of Service Appropriateness

MHSIP CONSUMER SURVEY ITEMS	n*	Agree/Strongly Agree %
Summary: Consumer Perception of Service Appropriateness	**3,201**	**91.8**
Staff here believe that I can grow, change, and recover.	3,191	89.1
I felt free to complain.	3,162	86.7
I was given information about my rights.	3,193	91.4
Staff encouraged me to take responsibility for how I live my life.	3,179	90.6
Staff told me what side effects to watch for.	3,162	86.0
Staff respected my wishes about who is, and is not, to be given information about my treatment.	3,196	92.9
Staff were sensitive to my cultural background (race, religion, language, etc.).	2,951	89.0
Staff helped me obtain the information I needed so that I could take charge of managing my illness.	3,153	88.7
I was encouraged to use consumer-run programs (support groups, drop-in centers, crisis phone line, etc.).	3,058	82.5

*Total N=3237; n for each item excludes responses of Not applicable/unknown/missing

Source: RI Dept. of MHRH (2009)

- Indicators of satisfaction with service staff were also high, although lower levels of satisfaction are observed for encouragement to use programs run by other consumers.

Table 5.b.3 Consumer Perceptions of Participation in Treatment Planning and Treatment Outcomes

MHSIP CONSUMER SURVEY ITEMS	n*	Agree/Strongly Agree %
Summary: Consumer Perception of Participation in Treatment Planning	**3,130**	**79.4**
I felt comfortable asking questions about my treatment and medication.	3,205	92.1
I, not staff, decided my treatment goals.	3,154	77.5
Summary: Consumer Perception of Treatment Outcomes	**3,119**	**71.8**
ADRS I deal more effectively with daily problems.	3,187	80.2
ADRS I am better able to control my life.	3,187	78.1
ADRS I am better able to deal with crisis.	3,166	74.0
ADRS I am getting along better with my family.	3,024	72.8
ADRS I do better in social situations.	3,132	68.7
ADRS I do better in school and/or work.	1,760	59.7
ADRS My housing situation has improved.	2,860	69.8
ADRS My symptoms are not bothering me as much.**	3,159	68.5

*Total N=3237; n for each item excludes responses of Not applicable/ unknown/missing

**This item is used to calculate both the Treatment Outcomes and Perception of Improved Functioning Domain Scores

Source: RI Dept. of MHRH (2009)

- While consumers appear comfortable asking questions about their treatment, approximately one quarter agree that goals for treatment were decided by staff rather than themselves.
- Although the majority of consumers feel that they have improved in various aspects of their daily lives, clearly many still struggle. School and work appear to pose particular problems.

Table 5.b.4 Consumer Perceptions of Improved Functioning and Social Connectedness

MHSIP CONSUMER SURVEY ITEMS	n*	Agree/Strongly Agree %
Summary: Consumer Perception of Improved Functioning	**3,156**	**73.3**
I do things that are more meaningful to me.	3,157	77.1
I am better able to take care of my needs.	3,166	81.0
I am better able to handle things when they go wrong.	3,163	71.2
I am better able to do things that I want to do.	3,149	74.0
ADRS My symptoms are not bothering me as much.**	3,159	68.5
Summary: Consumer Perception of Social Connectedness	**3,150**	**71.6**
I am happy with the friendships I have.	3,130	76.8
I have people with whom I can do enjoyable things.	3,147	78.0
I feel I belong in my community.	3,142	69.9
In a crisis, I would have the support I need from my family or friends.	3,150	78.3

*Total N=3237; n for each item excludes responses of Not applicable/ unknown/missing

**This item is used to calculate both the Treatment Outcomes and Perception of Improved Functioning Domain Scores

Source: RI Dept. of MHRH (2009)

- Clearly, the majority —nearly three quarters-- of Rhode Island consumers who participate in CSP services feel they have improved in functioning over time.

- In addition the majority of consumers perceive themselves to be socially connected, a major challenge for adults with serious mental illness. However, nearly 30% of survey respondents do not feel connected to friends, family members or their community.