Awareness of and Need for Home and Community Based Services for Rhode Island Adults on Medicaid

“Snapshot” Survey Results

Prepared by:
Jane Griffin, MPH
MCH Evaluation, Inc.
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Purpose

• To determine baseline awareness of HCBS for RI Adults on Medicaid who live in the community and are “nursing home eligible”

• To determine unmet need for HCBS for Adults on Medicaid who live in the community and are “nursing home eligible”

• To determine what respondents need to help them stay in their homes
Survey Measures

- Awareness of HCBS Services
- Unmet Need for HCBS
- Satisfaction
- Involvement with Care Plan
- Right to choose services
Method - Sample

Adults enrolled in Aged and Disabled Waiver (n=2,066 users or 1,601 average eligibles) who have a phone, speak English and were enrolled in waiver services >3 months from July 1, 2008 – June 30, 2009 (final n=1,400)
Method - Survey

• Designed one-page survey (five drafts)

• Linked selected sample to name and phone number

• Trained interviewers who conducted 201 telephone surveys from Nov-Dec 2009

• Systematic Random Sample (called every 10\textsuperscript{th} name on list, then repeated)

• Referred respondents to The Point for needed services
## Results - Sample

<table>
<thead>
<tr>
<th></th>
<th>Total Sample (n=1,400)</th>
<th>Respondent Sample (n=201)</th>
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<tbody>
<tr>
<td>% Female</td>
<td>82.4%</td>
<td>85.5%</td>
</tr>
<tr>
<td>% Dual (Medicaid and Medicare)</td>
<td>87.6%</td>
<td>86.6%</td>
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</tbody>
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Survey Respondent

- Medicaid Client: 1.6%
- Caretaker-Family: 14.4%
- Certified Nursing Assistant: 84.1%

(n=201)

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010
Satisfaction with the Medicaid Program

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010

- Very Satisfied: 50.8%
- Satisfied: 42.8%
- Not Very Satisfied: 6.5%

(n=201)
How Involved with Choosing Services from Medicaid

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010
Aware of Right to Choose Services Needed from Medicaid

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010

(n=201)
Types of Disabilities Represented in HCBS “Snapshot” Survey

Alzheimers, Bipolar, Blind, Cerebral Palsy, Chronic Obstructive Pulmonary Disease, Coma – Vegetative State, Diabetes, Fibromyalgia, Heart Failure, Lupus, Multiple Sclerosis, Paraplegic, Parkinsons, Quadriplegic, Schizophrenia, Seizures, Stroke
Care Provider Services

Who Provides Homemaker Services
93.6%  - CNA
  4.8 %  - Unpaid family

Who Provides Home Health Service
97.2%  - CNA
  1.4%  - Unpaid family

Who Provides Case Management Services
82.8%  - Social Worker/Case Manager
  8.0%  - CNA
  5.6%  - Unpaid family
  3.7%  - MD
HCBS Measured in Survey

**Care Providers**

- Someone to help with preparing meals, going shopping, or doing housework (like homemaker/CNA)

- Someone to help with bathing, dressing or using the toilet (like a CNA or home health aide)

- Someone to help get medical or social services (like a case manager or social worker)
HCBS Measured in Survey

Mobility Equipment

- A Cane or Walker
- A Wheelchair
HCBS Measured in Survey

Home Accommodations

• A Wheelchair Ramp

• Grab Bars in Bathroom

• A Raised Toilet Seat
HCBS Measured in Survey

**Medical Supplies**

- A Personal Electronic Device or “Help” Button that you can use in case of an emergency (“Lifeline”)

- Adult Pads like Depends
HCBS Measured in Survey

*Other Support Services*

- An Adult Day Program for recreation/activity
- Home Delivered Meals on Wheels
Survey Measures for each HCBS

• Is Recipient Aware if Medicaid Pays for HCBS?

• Does Recipient Need HCBS?

• Does Recipient Get HCBS?
Aware if Medicaid Pays for HCBS
Percent of Recipients Who Were **Aware**
That Medicaid Paid for Care Providers

- Health Aide: 89.4%
- Homemaker: 85.2%
- Case Manager: 76.4%

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010
* Of those who needed the service
Percent of Recipients Who Were **Aware*** That Medicaid Paid for Mobility Equipment

- **80.7%** for Wheelchair
- **79.3%** for Cane/Walker

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010

* Of those who needed the service
Percent of Recipients Who Were Aware* That Medicaid Paid for Home Accommodations

- Raised toilet seat: 40.0%
- Ramp: 38.1%
- Grab Bars: 29.5%

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010
* Of those who needed the service
Percent of Recipients Who Were **Aware**
That Medicaid Paid for Medical Supplies

- **Helpline/PED**: 76.5%
- **Adult Pads**: 69.2%

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010

* Of those who needed the service
Percent of Recipients Who Were **Aware*** That Medicaid Paid for Other Support Services

- **Meals on Wheels**: 62.9%
- **Adult Day Program**: 25.0%

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010
* Of those who needed the service
Recipients Who Got HCBS They Needed
Percent of HCBS Recipients Who Got* Care Providers They Needed

- Homemaker: 96.4%
- Health Aide: 95.4%
- Case Manager: 91.5%

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010
* Of those who needed service
Percent of HCBS Recipients Who Got* Mobility Equipment They Needed

- Cane/Walker: 96.1%
- Wheelchair: 89.0%

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010
* Of those who needed service
Percent of HCBS Recipients Who Got* Home Accommodations They Needed

- Grab Bars: 87.1%
- Raised toilet seat: 77.3%
- Ramp: 68.3%

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010

* Of those who needed service
Percent of HCBS Recipients Who Got* Medical Supplies They Needed

- Adult Pads: 91.6%
- Helpline/PED: 86.8%

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010

* Of those who needed service
Percent of HCBS Recipients Who Got* Other Support Services They Needed

Data Source: HCBS “Snapshot” Survey, Real Choices Systems Transformation Grant, RI/DHS, 2010

* Of those who needed service
Two Major Unmet Needs Identified in Open Ended Question:

*What are some personal or medical services you might need in the next year to help you stay in your home?*
Two Unmet Needs

1) *Inability to fill allocated evening and overnight certified nursing assistant hours due to lack of staff resources*

2) *Inability to get repair and replacement of mobility equipment and needed home accommodations*
1) Inability to fill allocated evening and overnight certified nursing assistant hours due to lack of staff resources

Although percent of recipients who got care providers was very high there was still unmet need because many recipients did not get the full hours they were allocated. This was especially true for evening and overnight hours. Not having someone to help with overnight toileting ADL needs was a key predictor of nursing home admission.
Examples from Recipients

• Client is on oxygen 24/7, has diabetes and heart failure. She has a wheelchair that she paid for out of pocket, because she already had a scooter. If she doesn’t get more CNA hours (only has 3 hours a day now) she will have to go to a nursing home.

• Woman with Multiple Sclerosis who needs more CNA hours. Currently her CNA comes 9-2, but she needs early evening hours for dinner and bed.

• Sister responded to survey saying her sister had just been admitted to a nursing home due to severe mobility problems. She had a CNA for two hours in the morning to help her eat and get dressed. Meals on Wheels brought her lunch and then a CNA came to fix her dinner and put her to bed. She needed someone during the night to help her get up to go to the bathroom but that couldn’t be provided so she went to a nursing home.
2) **Inability to get repair and replacement of mobility equipment and needed home accommodations**

Although the percent of HCBS recipients who receive mobility equipment is high, there is need for wheelchair repair and replacement. Many recipients need a different type of wheelchair. A high percent of recipients who need home accommodations are not receiving them. In order for HCBS recipients to function at an optimal level individual assessments need to be made about the equipment and modifications they need.
Examples from Recipients

• Woman who had a stroke whose adult son (age 52 with Cerebral Palsy) is her caretaker. She is very worried about what will happen to him when she dies. She can’t find anyone to fix/repair her hand held shower. She got an electric wheelchair but it is too large for her apartment. She would like to exchange it for a smaller scooter.

• Two sisters, both disabled, live in their family home. One has a tracheotomy and a G-tube to eat. Caretaker sister has COPD and heart disease. They cannot afford to stay in family home and SSI payment was just cut. The equipment they have (gerry chair and bed lift) is old and breaking. Medicaid only pays for one trach mask a month and sister needs one a week. They have enough CNA hours but need equipment and supplies.

• Woman with several chronic conditions including osteoporosis, several surgeries, heart attack and diabetes. She has a wheelchair, but would also like a walker to exercise her legs. Her raised toilet seat is broken and would like to get out of the house. She was recently attacked in her apartment and fought off the intruder with a phone.
Major Recommendations - from five presentations of results

- Promote Self Directed Care (Personal Choice) for recipients who are not able to fill allocated CNA hours due to manpower shortage (priority – evening and overnight)

- Produce and disseminate brochure for long term care recipients explaining HCBS benefits

- Ensure that recipients attend “wheelchair clinic” to determine which mobility device best suits their long term needs (scooter vs. electric)

- Provide annual home assessment to determine if recipient needs replacement or repair of mobility equipment or home accommodations