

# MSC E-VISORY

Issue #26-11

September 7, 2011

State of New York Office for People With Developmental Disabilities  
Courtney Burke, Commissioner  
Distributed by: Division of Policy and Enterprise Solutions  
Suzanne Zafonte Sennett, Deputy Commissioner

The MSC E-Visory is an electronic advisory which provides pertinent and timely information about programs and services available to individuals receiving MSC. Announcements about MSC training, conferences and meetings appear regularly. **MSC Supervisors: Please share this issue with all MSC Service Coordinators and others as appropriate.** In order to receive an email notification when a new MSC E-Visory is posted, please sign up for our mailing list (listserv). Listserv information and past issues can be accessed via the following link: [http://www.opwdd.ny.gov/wt/publications/wt\\_publications\\_mscevisories\\_index.jsp](http://www.opwdd.ny.gov/wt/publications/wt_publications_mscevisories_index.jsp)

## In This Issue:

### Materials for MSC Supervisors Video Conference – September 15, 2011

The Fall MSC Supervisors Video Conference is being held on September 15, 2011

AM Session 9:30am – 12:00 pm  
PM Session 1:00 pm – 3:30 pm

Topics include:

- MSC Update
- National Core Indicators
- People First Waiver
- MSC Training Initiatives/New Education and Training Web Page
- Medicaid and SSA Information
- Employment First for MSC Supervisors
- Willowbrook Updates

NOTE: There will be no handouts. The PowerPoint that will be referenced during the video conference is attached.



Andrew M. Cuomo, Governor



Courtesy Burke, Commissioner

NYS Office For People With Developmental Disabilities

# Putting People First

## MSC Supervisors Fall Video Conference

September 15, 2011

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NYS Office For People With Developmental Disabilities

# Putting People First

## AGENDA

- MSC Update
- National Core Indicators
- People First Waiver
- MSC Training Initiatives/New Education and Training Web Page
- Medicaid and SSA Information
- Employment First for MSC Supervisors
- Willowbrook Update

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NYS Office For People With Developmental Disabilities

# Putting People First



## MSC Update

Presented by  
Eric Pasternak, MSC Statewide Coordinator  
Eric.Pasternak@opwdd.ny.gov

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 **Putting People First**

## National Core Indicators (NCI)

Presented by  
Ray Pierce



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## NCI Project

- Measure the performance of the NYS DD System.
- Trend outcomes year to year and compare NYS outcomes with other states.
- Consumer Satisfaction and Quality of Life
- 20-30 states participate annually

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## Current Status

- Finished 2010/2011 Data collection
- Approximately 2,300 Face-to-Face Interviews
- Data sent to the Human Services Research Institute, HSRI
- Reports for 2010/2011 available by December
- Gearing up for 2011/2012 data collection

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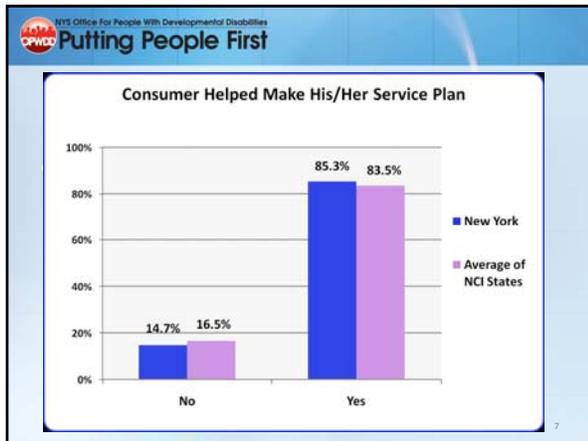
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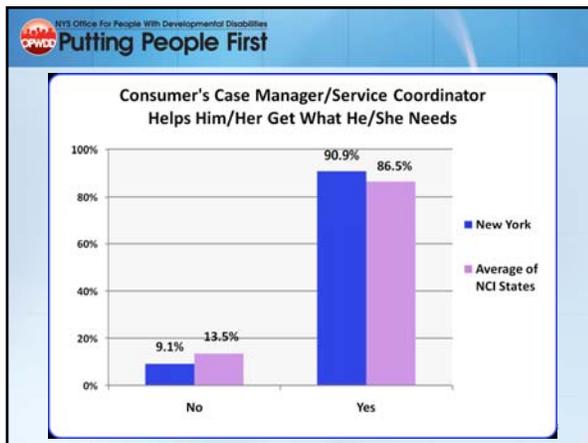
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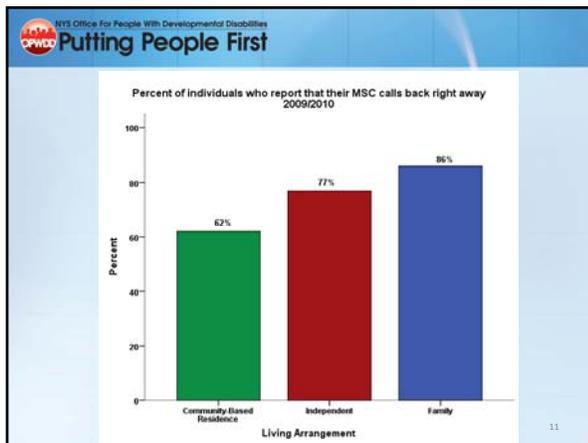
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**Older Adults with ID/DD 2009/2010**

- HSRI Data Brief
- Consumer Survey Data from 17 States
- 11,599 Adults
- 833 Adults age 65+
- Comparison between older adults and all other adults on key quality of life indicators

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### Characteristics of Older Adults

Overall, older adults have:

- Lower rates of ASD, Down syndrome, and CP
- Higher rates of a psychiatric diagnosis, Alzheimer’s or other dementia, vision or hearing problems, and physical disability
- A greater likelihood of living in provider-based settings (IRAs, ICFs, and NFs)

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### Older Adults Score Lower on Some Indicators

- Less likely to choose their homes, roommates, jobs, service coordinators, and staff
- Less likely to have friends or see family
- Less likely to shop, eat out, or go out for entertainment
- Less likely to have paid work

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### Older Adults Fare Better on Other Indicators

- More likely to report never feeling lonely
- More likely to have regular medical exams and vaccinations
- More likely to report that they received the services they need

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## Supporting Meaningful Outcomes

New York's People First Waiver will infuse the principles of quality, choice, and community into the heart of a redesigned service system and result in meaningful outcomes for the people we serve.

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## Address Complexities of the Current System

*Multiple state agencies with predefined services and structures and over 600 not-for-profit providers.*

*OPWDD's service system drives over 120 different billing categories, 5,318 rates, and over 13.5 million Medicaid transactions each year.*

*Existing service structures may not have the flexibility needed to meet individual needs with appropriate levels of care.*

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## Vision for the Future System

*To establish a person-centered service system that delivers coordinated care with funding that is transparent and targeted to needs.*

**Three Main Elements of Reform:**

- 1. Creating a Person-Centered, Supply-Oriented System**
  - Valid Needs Assessment
  - Equitable Resource Allocation
  - Choice of plans, providers and services
- 2. Enhanced Care Coordination and Person-Centered Planning**
  - "No Wrong Door"
  - Designed to meet the needs of people with developmental disabilities
- 3. Modernized financial platform**
  - Transparent funding streams that support individuals, not programs

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**OPWDD** NYS Office For People With Developmental Disabilities  
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## Vision for the Future System

*In addition, the waiver is an important opportunity to:*

1. Minimize reliance on institutional care
2. Improve our quality management system
3. Modernize reimbursement practices
4. Establish a "safety net" to provide preventive services

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## New York's People First Waiver

**WHAT?** A Section 1115 Research and Demonstration Waiver

**WHEN?**

- Application process launched in April 2011
- Approximately a 12-month process of working with all stakeholders to develop a complete application
- Transition from 1915 ( c ) to People First Waiver will occur at once, but system changes will roll out over several years

**WHY?** To suspend some Medicaid rules while redesigning the OPWDD service system for improved outcomes, increased efficiency and accountability within a larger State system of coordinated care

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The People First Waiver is an opportunity to:	The People First Waiver is <u>NOT</u> :
<ul style="list-style-type: none"> <li>• Redesign the system to support better outcomes for people</li> <li>• Focus on principles of person-centeredness, choice, quality, and community</li> <li>• Align the developmental disabilities service system with NY's healthcare reform &amp; achieve comprehensive care coordination across systems</li> <li>• Ensure future sustainability of the service system</li> </ul>	<ul style="list-style-type: none"> <li>• A Medicaid Block Grant to cap spending on individuals</li> <li>• A means to achieve budget reductions</li> <li>• A means to restrict or expand eligibility</li> </ul>

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## Scope of the People First Waiver

**Comprehensive services for Medicaid-enrolled individuals with developmental disabilities:**

- **All Medicaid health care services**
- **Long-term care services** within OPWDD system (DC, ICF, HCBS Waiver, CAH Waiver, MSC, clinic, day treatment) and also under the auspice of other state agencies (nursing homes, personal care, etc.)

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## Care Coordination

For the purpose of the work of the People First Design Teams, comprehensive care coordination is defined as a person-centered, interdisciplinary approach to integrating health care and habilitation and support services in which:

- A comprehensive care plan is developed based upon a standardized needs assessment that incorporates the person’s strengths, needs, and preferences, and
- Services are managed and monitored by an identified care management organization.

Care coordination may be provided through the managed care organization or contracted to another provider through the managed care organization.

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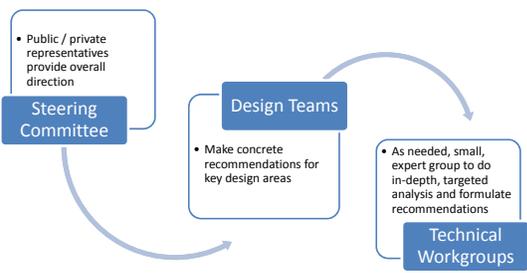
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## Development of the Waiver Application



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    graph TD
      A["Public / private representatives provide overall direction  
Steering Committee"] --> B["Design Teams  
Make concrete recommendations for key design areas"]
      B --> C["As needed, small, expert group to do in-depth, targeted analysis and formulate recommendations  
Technical Workgroups"]
      C --> A
  
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### Timeline

- May 2011
  - Listening Sessions and Public Forums
  - Establish Steering Committee
- Spring 2011
  - Steering Committee Reviews Design Team Charters
  - Establish Design Teams & Technical Workgroups
- Spring & Summer 2011
  - Design Team Research & Discussion
  - Formulate Recommendations
- Fall 2011
  - Hold Public Forums
  - Conceptualize pilot projects

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### Waiver Design Parameters

Providing a Baseline

**Fiscal Platform**  
 Extended transition to a Managed Care structure

**Provider Agencies and Service Delivery**  
 Some providers may become care management organizations  
 Others may deliver services through a contract with an MCO  
 Individuals will still exercise choice of MCO & service providers within MCOs.

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### Waiver Design Parameters

Providing a Baseline

**Eligibility**  
 Maintain current eligibility standards

**Needs Assessment**  
 Standardized needs assessment instrument will be used to assess need and allocate resources accordingly  
 Administered by independent entity  
 With flexibility that addresses changing needs – during emergencies and over a lifetime.

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## Waiver Design Parameters

Providing a Baseline

**Fiscal Neutrality & Service Sustainability**  
 Waiver must be cost neutral - i.e., federal costs must be the same with or without the waiver.

**Care Coordination**  
 Person centered approach integrating health care, habilitation and support services  
 Services managed and monitored by a care management organization

**Choice & Self Direction**  
 Opportunity to self-direct individualized budgets and staff

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## Maintaining Choice within Managed Care

People will exercise:

- Choice of Managed Care Plans
- Choice of Service Providers within Plans
- Choice of Services

Changes will be pilot tested.  
 Implementation will occur slowly, with care to avoid disruption

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## Transition from 1915 (c) to 1115

New York obtains CMS approval of the final 1115 application

A date will be established for ending the existing OPWDD 1915 (c) waivers and the new 1115 waiver will start

A transition plan will be developed for the orderly transition of care planning and services

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## Public Resources

People First Waiver Web page:  
[www.opwdd.ny.gov/2011\\_waiver](http://www.opwdd.ny.gov/2011_waiver)

People First e-mail address for comments and questions: [People.First@opwdd.ny.gov](mailto:People.First@opwdd.ny.gov)

People First comment line:  
 1-866-946-9733 or TTY: 1-866-933-4889

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## Important Next Steps

- Public Forums/online survey – public comment on design team recommendations
- Finalization of recommendations
- Ongoing dialogue with CMS
- Development of RFI/RFP for Pilot Projects

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## MSC Training Initiatives/ New Education and Training Web Page

Presented by: Karen Galarneau and John Triller



<http://www.opwdd.ny.gov/>

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## Medicaid and SSA Information

Presented by:  
 Deirdre Dugan  
 Revenue Support Field Operations



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## Automated Renewals

- Automated Renewals for individuals receiving Social Security Benefits only
- Can't have a spenddown or DAC budgeting
  - DAC – Disabled Adult Child
- Eligibility for the Medicare Savings Program must remain the same

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## Automated Renewals

- Have to have resources less than 75% of the Medicaid Resource Level
- Current MA Resource Level is \$13800

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## Automated Renewals

- Individuals will get a notice advising that the Medicaid has been extended
- Local District must be advised of any changes which impact Medicaid eligibility

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## Medicaid Buy-In Program for Working People with Disabilities

- Increased Resource Level Effective 10/1/2011
  - \$20000 for an individual
  - \$30000 for a couple
- Retirement Accounts – Effective 10/1/2011  
Disregard of retirement accounts in determining resource eligibility for the program.

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## Social Security Administration

- All SSA offices now close to the public ½ hour earlier
- This change was effective 8/15
- If the office you deal with was open from 9 am- 4 pm, it is now open from 9 am - 3:30 pm

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## SSA Checks

- Beginning 5/1/2011, all applicants for SSI, Social Security and other federal benefits must get their benefits via direct deposit
- People who already get those benefits will have to set up a way to get their checks through direct deposit by March 1, 2013
- [www.usdirectexpress.com](http://www.usdirectexpress.com)

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## Employment First for MSC Supervisors

Presented by: Joanne Bushart  
The Center for Employment Excellence




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## OPWDD Vision Statement

- Enjoy meaningful relationships with friends, family and others in their lives,
- Experience personal health and growth,
- Live in the home of their choice, and
- **Fully participate in their communities.**




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## Employment First!

- Promoting employment for all people with disabilities
- Increasing the number of people with developmental disabilities who are working in their communities: 9633 people are working with OPWDD employment supports

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## Employment is for Everyone

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## Employment is Transformational!

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### Objectives of Employment First

- Assisting people to achieve their employment goals through person centered planning
- Assisting young people to transition from school to work
- Assisting interested individuals in day services to explore and choose employment




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### Employment First Resources

- Mythbusters
- Guide to Eligibility Assessment Resources
- Training for Medicaid Service Coordinators
- Local DDSO Employment Resource Information including: New York Makes Work Pay Website
- Enhanced Supported Employment Pilot
- Employment Training Program




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### Mythbusters

**facts for people with disabilities who want to work**

- Answers questions about employment and benefits for people with developmental disabilities
- Created in collaboration with the Self-Advocacy Association of NYS (SANYS) – Capital District Chapter
- Connects people with Independent Living Centers (ILCs) and other important resources
- Download the brochure by visiting:  
[http://www.opwdd.ny.gov/document/image/myths\\_about\\_DD\\_employment\\_layout.pdf](http://www.opwdd.ny.gov/document/image/myths_about_DD_employment_layout.pdf)




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## Guide to Eligibility Assessment Resources

- Developed to assist people in transitioning from ACCES-VR (formerly VESID) to OPWDD Supported Employment
- Provides information on testing and assessment services available in local communities across NYS
- To download the PDF document, visit:  
[www.opwdd.ny.gov/wt/forms/wt\\_guide\\_to\\_eligibility\\_assessment\\_resources\\_final.pdf](http://www.opwdd.ny.gov/wt/forms/wt_guide_to_eligibility_assessment_resources_final.pdf)




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### Guide to Eligibility Assessment Resources

**Finger Lakes**  
 Counties: Chemung, Livingston, Monroe, Ontario, Schoharie, Seneca, Steuben, Wayne, Wyoming, & Yates  
 DDOSO Eligibility Contact: Kathy Dillon, (585) 241-5741

**NOTE: All voluntary clinics are not funded for Adaptive Behavior Testing**  
**NOTE: Referrals for school age children are sent to school districts first.**

Agency	Contact Information	Resource Type	Program Description	Reimbursement Information
Ar. of Monroe-AC Health Services 1000 Elmwood Avarham, Suite 500 Rochester, NY 14620	(585) 271-0601 x1574 Tricia Williams <a href="http://www.armoniac.com">www.armoniac.com</a>	OPWDD Article 16 Clinic	Psychological Testing including IQ scoring and Adaptive Behavioral Assessment, Psychiatric Assessment and Social Work Assessment.  The clinic also provides the following services to individuals with Developmental Disabilities: Physical Therapy, Hearing Services, Speech and Language Services, Vocational Rehabilitation, Social Skills Counseling, Psychiatric Medication Monitoring, Capacity Evaluations, Genetic/Comprehensive Medical Assessments.	Medicaid, Private Pay  Client needs a complete list of all insurance benefits to ensure proper billing.  The clinic will need a formal letter from the DDOSO requesting testing for eligibility purposes or a copy of a letter of Determination (DOD) from the Department of Health.
Ar. of Yates 210 North Ave Perry Yan, NY 14827	(315) 536-7447 Doree O'Neil <a href="http://www.arofyates.org">www.arofyates.org</a>	Provider Agency	Psychological and Adaptive testing for OPWDD Eligibility, Psychological evaluations for VESID, Psychiatric, medication, and nursing evaluations.	Medicaid, Managed Care Medicaid, Private Pay, VESID contract
Chemung ARC 711 Bushnell Street Elmira, NY 14885	(607) 734-6151 X155 Patricia Overholt, LMSW <a href="http://www.chemungarc.org">www.chemungarc.org</a>	OPWDD Article 16 Clinic	Psychological evaluations, including assessments for IQ, adaptive skills, Autism Spectrum Disorders, Neuro-cognitive functioning.	Medicaid, Private Pay, Third Party Health Insurance, Medicare, DDOSO payments for assessments requested by Access Team
Easter Seals Comp Primary D&T Center 103 White Square Blvd Rochester, NY 14623	(800) 421-3440	DOH Article 28 Clinic	Approximately 3 to 4 months for an appointment.	
Finger Lakes DDOSO State Clinic 620 Westfall Road Rochester, NY 14620	(585) 481-6877	OPWDD Article 16 Clinic	Evaluation process generally completed within 5 weeks.	

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## Employment First Training for Medicaid Service Coordinators

- Parent to Parent partnered with OPWDD for the Spring 2011 trainings and told their family's story
- Service Coordinators are a key resource in helping people to achieve their employment goals
- MSC trainings provide information and discussion with colleagues on employment support and local resources




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## Local Employment Resource Info

Provides local contact information for:

- DDSO program coordinators for SEMP, ESEMP and ETP
- SANYS, Parent to Parent and ILCs
- Website links for ACCES-VR, Department of Labor, Social Security, Medicaid and Work Incentives

Available online at: [www.opwdd.ny.gov/cee/index.jsp](http://www.opwdd.ny.gov/cee/index.jsp)




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## New York Makes Work Pay

- Employment resources for people with disabilities and their families, service providers and businesses
- Tools that can help New Yorkers with disabilities develop a path to employment
- Developed through the Medicaid Infrastructure Grant in collaboration with Cornell University

[www.ilr.cornell.edu/edi/nymakesworkpay/index.cfm](http://www.ilr.cornell.edu/edi/nymakesworkpay/index.cfm)




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## Work Incentives Information Network (WIIN)

Creating solutions to employment barriers by:

- Providing free training to develop a cadre of certified benefits counselors in NYS
- Increasing understanding of how the work incentives programs can be used by people with disabilities
- Certified benefits counselors can be found by visiting: <http://www.ilr.cornell.edu/edi/nymakesworkpay/rny-benefits.cfm> (this is a **FREE** service)




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### Enhanced Supported Employment Pilot Project (ESEMP)

Objective: to demonstrate that people with significant disabilities who are motivated to work can achieve and sustain employment in their communities




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### Enhanced Supported Employment Pilot Project (ESEMP)

- Launched statewide in 2009, serving 464 people
- Project expands October 2011
- Provides comprehensive individualized supports that assist people to obtain and maintain employment
- See the OPWDD web site for ESEMP projects in your DDSO!




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### Employment Training Program (ETP)

Objective: to assist motivated individuals with developmental disabilities to seek, acquire and maintain competitive employment




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## Employment Training Program (ETP)

- Internship structure – OPWDD pays the employee’s wages for up to 18 months
- Participants learn basic life and employability skills by attending monthly training sessions
- The potential employer agrees to consider the intern for permanent competitive employment at the end of the job training period




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## What’s the Difference?

**ESEMP pilot project:**

- The individual is hired by the employer within 90-180 days
- There is a work requirement of at least 32 hours/month

**ETP:**

- The individual is a paid intern at a business in the community for up to 18 months
- The intern’s wages are paid by OPWDD
- The employer pays the person’s wages when the internship is over

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## Works for Me

- Showcases the talents and contributions to business by workers with developmental disabilities
- Recognizes business leaders who incorporate the employment of people with disabilities in their workforce strategy
- Save the Date: Event to be held on October 26<sup>th</sup>, 2011 from 10am to Noon at the Egg




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### Next Steps - Call to Action

- Who do you know that has expressed a desire to work? Help that person to get connected, find the appropriate employment supports.
- Contact your DDSO Employment coordinator!




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### Willowbrook Updates: Presented by Denise Pensky

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### Mark your Calendars!

DECEMBER 2011						
SUN	MON	TUES	WED	THURS	FRI	SAT
					2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

MSC Supervisors Video Conferences are held quarterly (March, June, September, December). Information on future dates will be announced via the MSC E-Visory.

The next session is December 2, 2011. Registration is through the OPWDD Training Catalog.

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**Thank You!**

**Please provide your feedback on this session.**

*An evaluation form was provided with the video conference materials. We are especially interested in your ideas for upcoming session topics.*

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# NCI DATA BRIEF

ISSUE 4

August 2011

## What does NCI tell us about older adults with intellectual and developmental disabilities?

Life expectancy for persons with intellectual and developmental disabilities (ID/DD) has increased dramatically in recent decades and continues to rise. As such, the number of elderly people with ID/DD is also increasing. This data brief describes NCI findings for older adults with ID/DD, defined as ages 65 and older, in order to shed light on their experiences and to inform state policy and program design.

The 2009-10 National Core Indicators (NCI) Adult Consumer Survey Report included descriptive and outcome data on 11,599 adults from 17 states and one sub-state entity<sup>1</sup>. Approximately 7% (833 people) were age 65 and older. The mean age for those 65 and older was 71.6 years, and the median age was 70 years.

The results described below were obtained through t-tests comparing adults ages 65 and over to those under 65. ***For the purpose of this Data Brief, only group differences that were significant at the  $p < .05$  level are reported.***

### PROFILE

#### Demographics

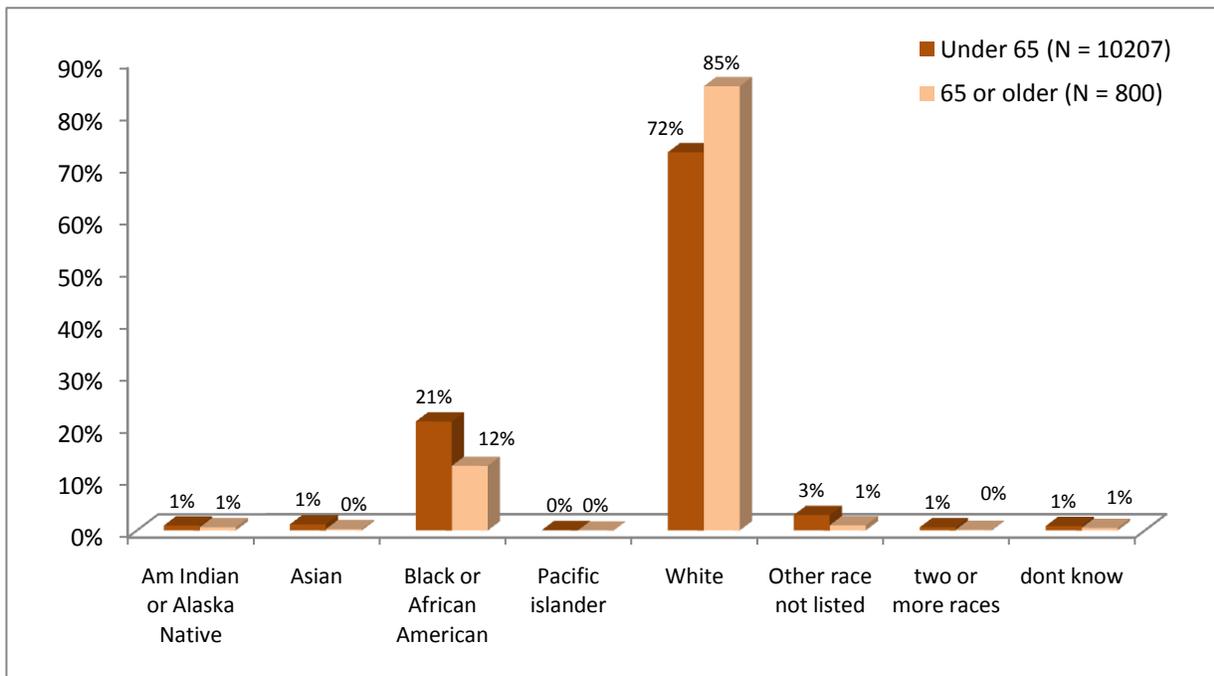
Adults with disabilities ages 65 years and older differed from those under 65 on several demographic characteristics. As shown in Figure 1, those 65 and older were more likely than those under age 65 to be white (85% vs. 72%) and less likely to be Black or African American (12% vs. 21%). A much higher proportion of individuals under 65 were male (57%) than female (43%); however, the proportion of males was lower than the proportion of females in the older adult group (49% male, 51% female).

There were significant differences between older and younger adults in terms of type of residence (see Figure 2). Those 65 and older were significantly more likely to be living in a group home (39% vs. 27%), a specialized institutional facility (25% vs. 20%), or a nursing facility (5% vs. 1%). Older adults were somewhat less likely to live in an independent home or apartment (9% vs. 11%). Not surprisingly, older adults were also significantly less likely to live in a parent's or relative's home (29% vs. 5%).

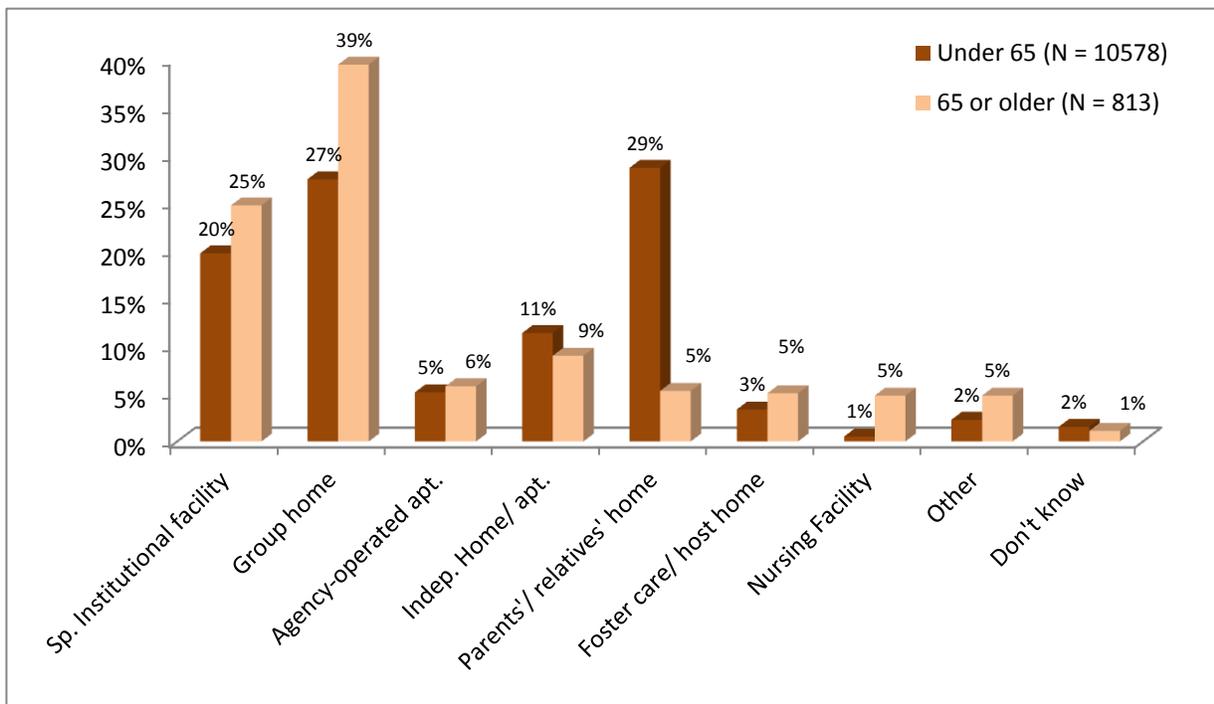
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<sup>1</sup> The 2009-10 NCI Adult Consumer Survey Report included: Alabama, Arkansas, District of Columbia, Georgia, Illinois, Kentucky, Louisiana, Maine, Missouri, North Carolina, New Jersey, New York, Ohio, Oklahoma, Pennsylvania, California's Regional Center of Orange County, Texas, and Wyoming.

**Figure 1. Race/Ethnicity**

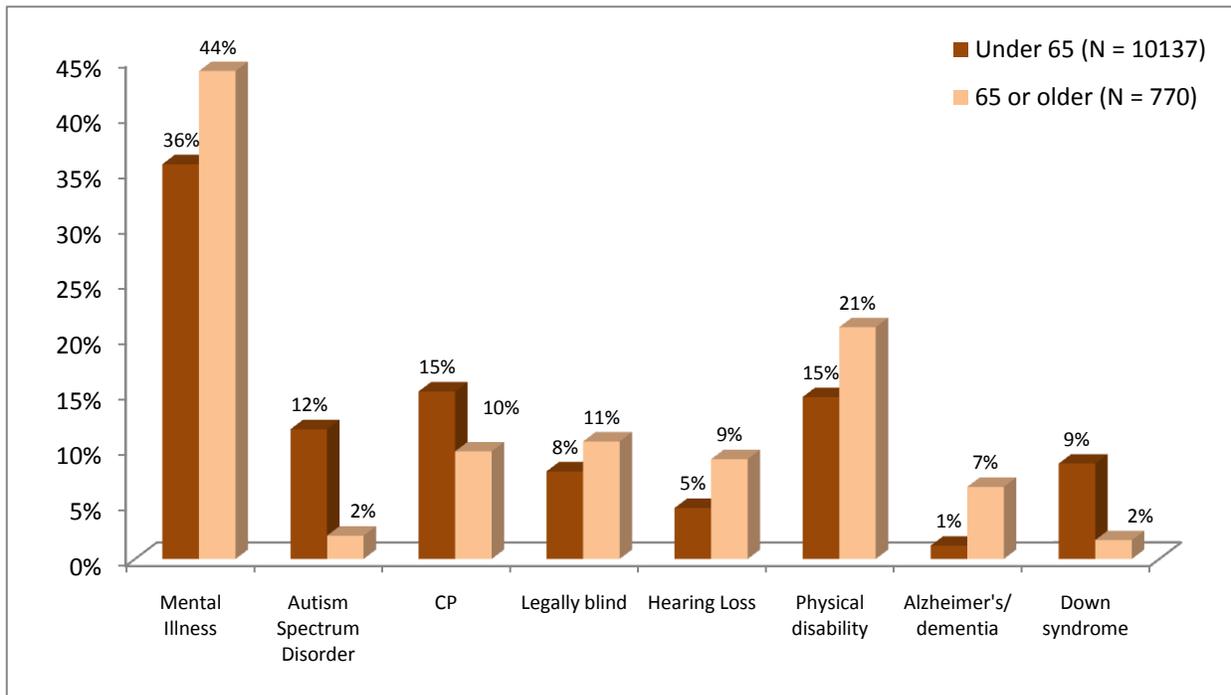


**Figure 2. Residence**



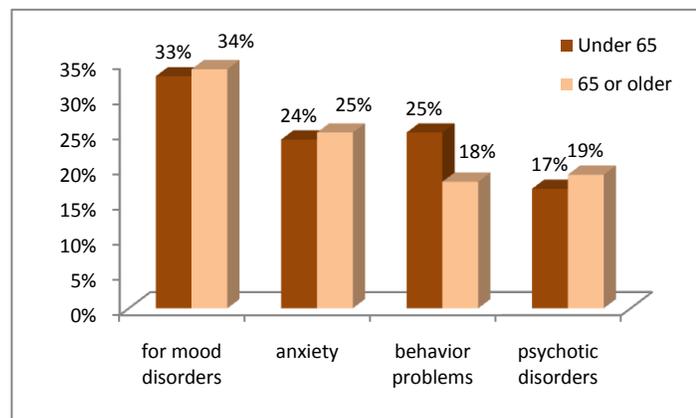
Older individuals with ID/DD had a somewhat different profile with respect to the presence of other medical and psychological conditions than did individuals less than 65 years of age (see Figure 3). Older adults were more likely to have a diagnosis of Alzheimer’s disease or other dementia (7% vs. 1%). They were also more likely to have a physical disability (21% vs. 15%), hearing loss (9% vs. 5%), or be legally blind (11% vs. 8%). Interestingly, they were also significantly more likely to have a diagnosis of mental illness or a psychiatric disorder (44%) than those less than 65 years of age (36%). On the other hand, they were significantly less likely to have a diagnosis of Cerebral Palsy (10% vs. 15%) or Down syndrome (2% vs. 9%). They were also less likely to be diagnosed with Autism Spectrum Disorder (2% vs. 12%) than those under 65 (12%).

**Figure 3. Other Disorders**



Even though the older group was significantly more likely to be diagnosed with a mental illness, they were no more likely to take various types of psychotropic medications (see Figure 4) than were adults under 65 years of age. In fact, they were less likely to take psychotropic medications for behavior problems than the younger group (18% vs. 25%). Approximately 52% of the older group and 51% of the younger group took at least one kind of psychotropic medication.

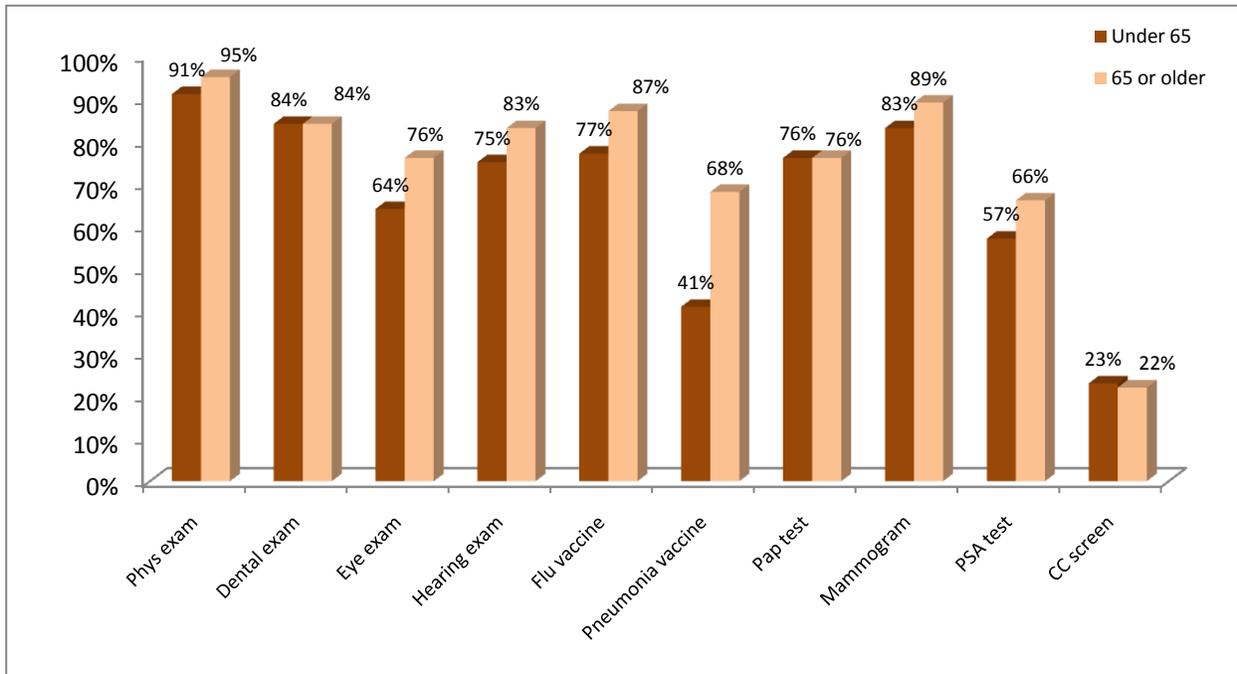
**Figure 4. Psychotropic medication**



## Medical Care

As described in Figure 5, adults with disabilities who are 65 years of age and older receive some preventive health care procedures at slightly higher rates than those under age 65 years. They were somewhat more likely to have had a physical exam in the past year (95% compared to 91% of those under 65), and significantly more likely to have had vision (76% vs. 64%) and hearing (83% vs. 75%) exams. Older adults were also significantly more likely to be vaccinated for the flu in the past year (87% vs. 77%), and pneumonia over their lifetimes (68% vs. 41%).

**Figure 5. Medical Exams**



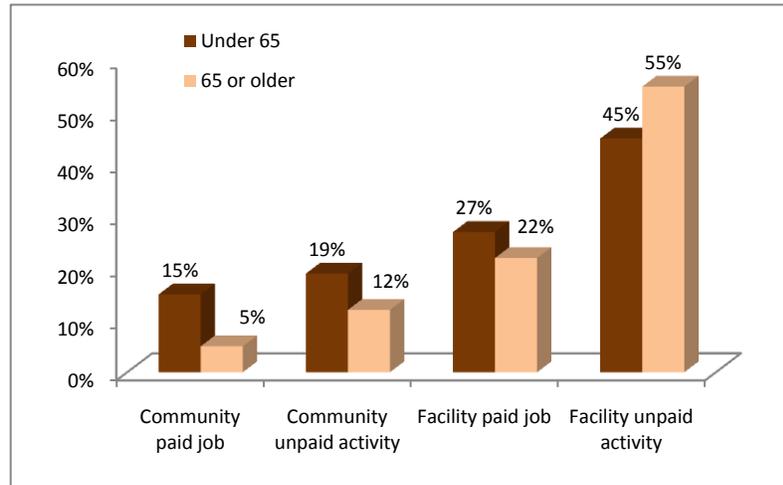
Overall, the older group received medical care at higher frequencies than the younger group. Thirty-nine percent of those 65 years and older accessed medical care at least once a month, compared to 21% of the younger group. Older adults were also somewhat more likely to be receiving clinical services (48% vs. 45%). Furthermore, adults 65 and older received assistive technology services and transportation services at higher rates (30% vs. 20%, and 71% vs. 67% respectively). They were also more likely to report that they received needed services (94%) than were the younger group (86%).

Additionally, a significantly lower proportion of older adults were reported as being obese (22%) as compared to the proportion of younger adults (30%), though older adults were much less likely to be independently mobile (54% vs. 76%).

## Work and Day Activities

As shown in Figure 6, adults with disabilities 65 years and older were less likely than those under 65 to participate in community-based jobs, facility-based jobs, and community-based unpaid activities. They were, however, considerably more likely to be engaged in a facility-based unpaid activity during the day (55% vs. 45%). While this figure may include people who go to generic activity centers for seniors, it is likely that the majority are in sheltered day/workshop programs geared specifically towards people with intellectual and developmental disabilities.

Figure 6. Work and Day Activities

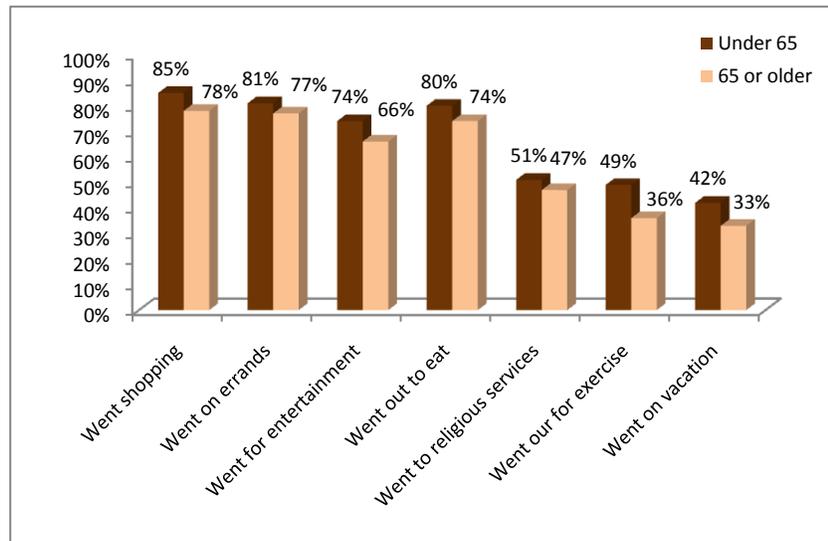


Of people who report not having a community job, only 25% of those 65 and older said they wanted one, as compared to 47% of those under 65.

## Community Inclusion

Older adults with disabilities were consistently less likely to take part in integrated community-based activities such going shopping, out for entertainment, or out to eat (Figure 7). Seventy eight percent (78%) reported going shopping in the community in the last month, compared to 85% of those under 65. Only 66% reported going out for entertainment in the last month, and 74% reported going out to eat or to a coffee shop in the same time period (compared to, respectively, 74% and 80% of younger adults).

Figure 7. Community Inclusion

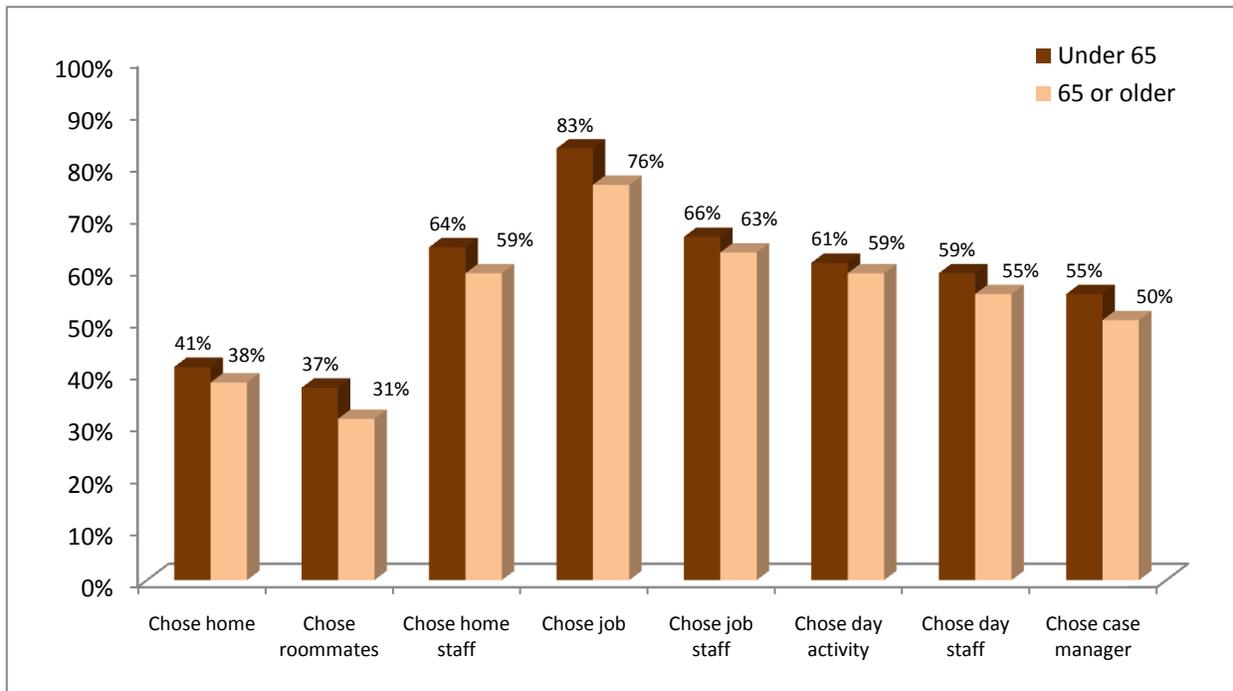


Forty seven percent (47%) reported going to community-based religious services, and only 36% said they went out for some sort of exercise or sport. Only one third (33%) of people 65 and over reported going on a vacation in the past year, compared to 42% of those under 65.

## Choice

Overall, individuals 65 and older tended to make fewer choices in their lives than do those under 65 (see Figure 8). Specifically, older individuals were less likely to choose their home (38%), roommates (31%), case manager/service coordinator (50%), their job (76%), their home (59%) and day staff (55%) than were younger individuals (41%, 37%, 55%, 83%, 64%, and 59%, respectively).

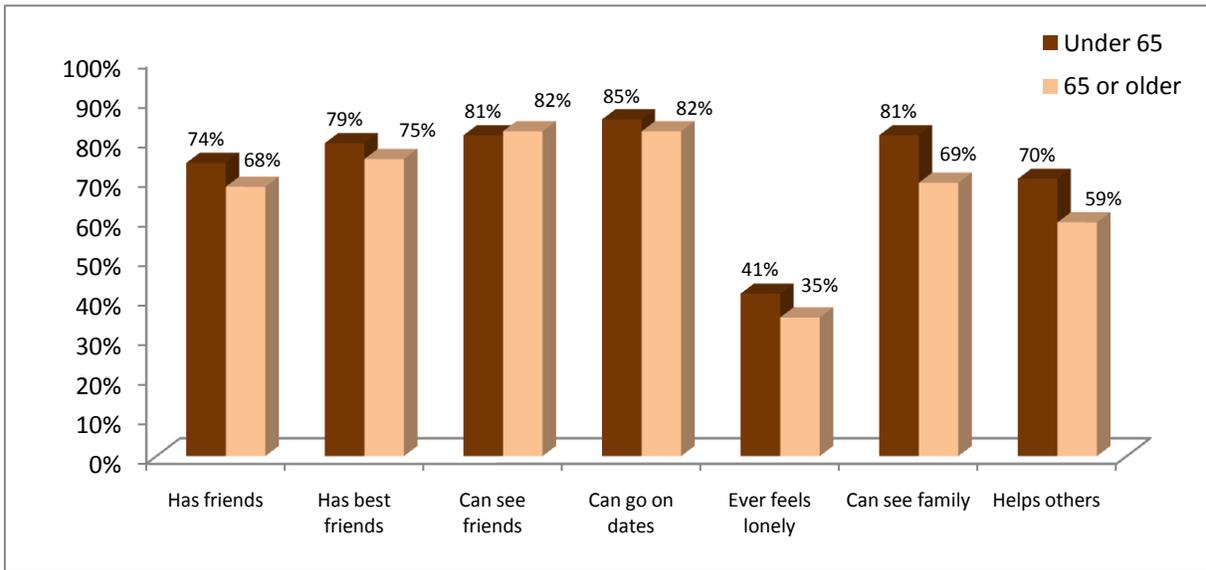
**Figure 8. Choice**



## Relationships with Friends and Family

The results regarding relationships, displayed in Figure 9, also reveal some differences between older and younger adults. Individuals 65 and older were less likely to report having friends (68%) or a best friend (75%), and less likely to be able to see their families when they wanted to (69%) than were younger individuals (74%, 79%, and 81%, respectively). They were also less likely to report helping others (59% vs. 70% of people under 65). Interestingly, however, the older group was more likely to report never feeling lonely (65% compared to 59% of the younger group).

**Figure 9. Relationships**



### **ADDITIONAL ANALYSES**

The differences described above between older (age 65 and over) and younger (under 65) adults with disabilities could be explained in part by significant and large group differences in various key background variables, such as the state in which individuals lives, their likelihood of having a psychiatric diagnosis, frequency of medical care needed, mobility, and type of residence. To determine whether these factors accounted for any of the observed group differences described above, we will be conducting a series of regression analyses to examine differences between the two groups' responses to the NCI survey questions while controlling for the key variables. The results of these analyses will be published in a peer-reviewed journal.

### **SUMMARY OF FINDINGS**

Data collected on the health, support and services, behaviors, and outcomes of individuals with disabilities in 2009-10 by the National Core Indicators Adult Consumer Survey revealed some significant differences between older adults and adults who were under 65 years of age.

Overall, compared with younger individuals, older adults with intellectual and developmental disabilities tended to:

- ❖ have lower rates of Autism Spectrum Disorder, Down syndrome, and Cerebral Palsy
- ❖ have higher rates of a psychiatric diagnosis, Alzheimer's or other dementia, vision or hearing problems, and physical disability
- ❖ be more likely to live in provider-based settings (group homes, specialized institutional facilities, and nursing homes)

The data suggest that older adults fare worse in some areas than younger individuals. Specifically, older adults:

- ❖ were less likely to make choices in several areas of their lives, such as choosing their homes, roommates, jobs, service coordinators, and staff
- ❖ were less likely to have friends or be able to see family
- ❖ were less likely participate in community-based leisure activities, such as shopping, eating out, or going out for entertainment
- ❖ were less likely to have paid work
- ❖ were much more likely to be engaged in unpaid facility-based activities

However, the data also indicate that older individuals score higher on other important indicators. As a group, people over 65 years are:

- ❖ more likely to report never feeling lonely
- ❖ more likely to have regular medical exams and vaccinations
- ❖ more likely to report that they received the services they need

Although older adults were more likely to have a mental illness or psychiatric diagnosis, there was little difference between the two groups in terms of rates of psychotropic medication use for mood, anxiety, or psychotic disorders. In fact, both groups had similar and remarkably high rates of using at least one psychotropic drug (just over 50%).

The NCI data indicate that 55% of adults 65 and over participate in facility-based programs engaged in non-work activities during the day. It is not clear whether they are given an option to retire. Admittedly, the concept of retirement is a complicated one for people with ID/DD, particularly since the program model people with ID/DD typically retire *from* is no different from the model that people without disabilities typically retire *to*. This is an issue that will be receiving increasingly more attention as the population ages.

These findings should be considered in light of the fact that people who are older and have ID/DD face two sets of challenges. First, like people without ID/DD, they experience functional and cognitive declines during the aging process that limit their ability to actively care for themselves and engage in community life. Second, because of the nature and scope of their existing disabilities, people with ID/DD may require more comprehensive supports during the aging process.

It also is important to emphasize that some of the differences found between older and younger adults could be due to factors other than age itself. For example, the NCI data indicate that people living in more institutional-type settings are more likely to receive preventive health care than those living in the family home. Since older adults are more likely to live in institutions and group homes, this may account for at least some of the observed greater likelihood of their receiving needed medical exams and vaccinations.

The differences between older and younger individuals with ID/DD receiving services reflect a number of variables, as noted above, not the least of which are those related to the characteristics of different

state DD systems. People who are older tend to have been served by state systems for longer periods of time, and the fact that greater numbers are being served in more traditional day and residential programs may reflect past placement and service provision practices, rather than a planned approach to serving older individuals.

It also needs to be considered that people growing older in the near future will have had very different life experiences than the current 65+ cohort, especially in terms of experiencing institutionalization, family relationships, and self-advocacy. The data underscore the need to carefully track services and service outcomes for older individuals with ID/DD to ensure that supports are tailored to address quality of life areas that are of particular importance to older adults, including opportunities for the exercise of personal choice and control, participation in community activities, maintaining friendships and relationships with family and friends, and providing meaningful options for people of retirement age.