A Blueprint for Action:

Retirement Options and Opportunities for Older Adults with Intellectual and Developmental Disabilities

A Finger Lakes Region
Report from the
Golisano Retirement
Collaborative
January 2016

About this Report

Acknowledgments

This **Blueprint for Action** was prepared and is published by Lifespan of Greater Rochester, Inc. (Lifespan); and was developed in conjunction with the Golisano Retirement Collaborative (GRC), a dedicated group of planning partners from within the Finger Lakes region. Planning partner representatives who contributed to this work include the following community-based agencies, organizations and individuals.

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Forward: Informing Blueprint Development

In addition to the GRC planning partners, many others helped inform the call-to-action detailed in this blueprint report via focused discussion groups, presentations to the GRC planning partners and individual one-on-one interviews. These individuals include:

- Pre-retirement adults with intellectual and developmental disabilities
- Older adults with intellectual and developmental disabilities (I/DD)
- Caregivers: agencies and families
- Medicaid service providers
- Other professionals/experts in the fields of aging and I/DD, financial and legal planning and crisis management

As well, our work was informed by literature review and data gathered on the topic of retirement and the population of aging adults and individuals with I/DD. Key findings and insights from the comprehensive research are provided later in this report.

Blueprint Development: A Project Overview

This project was initiated by Lifespan in response to the following key factors.

1. The increasing population of older adults with intellectual and developmental disabilities.

- An estimated five million (all ages) Americans have an intellectual or developmental disability. Over 75% of those receiving services live with their families - the family being the primary support system. (Source: A Profile of Older Americans: 2014).

- Based on the 2010 Census, there are 850,600 people with I/DD age 60 and older. By 2030 their numbers will swell to 1.4 million due to increasing life expectancy and the aging baby boom generation.

- By 2025, the average age of the individual served by the Office of People with Development Disabilities (OPWDD) in New York State (NYS) will be 50 years of age. (OPWDD Website)

- In the Finger Lakes region more than 8% of individuals with I/DD are age 65 and older (993 individuals out of a total of 11,585 served as of 12/31/2015). 61% of individuals with I/DD are between the ages of 22 and 64. (InfoFacts Quarterly Information Report, OPWDD, 12/31/15)

- Since 2005, there has been a 35% increase in number of individuals with I/DD age 65+ in the Finger Lakes region. (InfoFacts Quarterly Information Report, OPWDD, 12/31/15)

2. Strategy and actions of the Center for Medicare and Medicaid Services (CMS) and NYS to transform services for individuals with intellectual and developmental disabilities.

- CMS and NYS have defined a Transformation Agreement (TA) designed to better meet the needs of individuals and families in a person-centered way, including more self-directed options.

- The TA includes a new specialized system of managed care where the habilitation model is being transitioned to a model of community inclusion. A strong emphasis is being placed on "private-sector-employment-for-all" while sheltered workshop participation is expected to decline precipitously and workshop individuals are encouraged to find competitive employment in their communities.

Even with its many merits, the TA does not fully accommodate for the transitioning of older adults with I/DD into meaningful retirement options and opportunities. Through Lifespan's experience, we know that not all will want to seek or be able to engage in competitive employment as the retirement stage of life approaches.

To this end, Lifespan presented a grant proposal to the B. Thomas Golisano Foundation to secure funding, support and partnership in the development of this blueprint. Having been awarded project funding, the GRC was formed and a cross-section of planning partners agreed to participate in the endeavor. The work of the GRC has culminated in the development of the retirement blueprint and preparation of this blueprint report detailing the call-to-action for retirement options and opportunities for older adults with I/DD.

A Blueprint for Action: Next Steps

The project commenced in March of 2015 with a GRC kick-off meeting and continued through the end of 2015 with a rigorous schedule of blueprint research, planning and report preparation activities. The completed blueprint and this report was distributed to planning partner executives and the Golisano Foundation in January, 2016. Additional presentations will follow throughout early 2016 to other key stakeholders including but not limited to New York State ARC (NYSARC), New York State Office for the Aging (SOFA), the NYS Office for People with Developmental Disabilities (OPWDD).

As the stakeholder presentations get underway in 2016, Lifespan will seek funding and identify resources to implement the blueprint in conjunction with existing and new partners. As with other similar efforts, this is an excellent example of successful collaboration, avoiding an ineffective and costly agency-by-agency approach. Together, the community can rise to the

occasion to ensure that older adults with I/DD have meaningful options and opportunities in their retirement years.

A Blueprint for Action: The Report

This report consists of a table of contents, executive summary, research findings, a blueprint for action and an outline of next steps. This report is accompanied by a number of exhibits that support the content of this report in additional detail.

A special thank you is to all who informed and contributed to the development of the blueprint and the preparation and publication of this blueprint report.

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Executive Summary
A Blueprint for Action: Now is the Time

Retirement is a new and emerging stage of life for individuals with intellectual and developmental disabilities (I/DD). Forty years ago, the average lifespan was such that most adults with I/DD were not expected to live to middle age, never mind old age.[1] Increased life expectancy and an aging baby boom generation have created the need for greater retirement options and opportunities for individuals with I/DD.

For the average person, retirement can be a stage of life that is filled with meaningful activities. It is a much different picture for people with I/DD. Many aging individuals with I/DD are and have been participating in day or sheltered workshop programs for a long time. The prospect of retirement is frightening and unfamiliar to them and their families. People with I/DD have little or no retirement income. The sheltered workshop is often a place for socialization and support and not simply place of employment. By their own admission, Medicaid Service Coordinators are reluctant to address the issues because of a lack of meaningful resources.

> *"I know that by the time I retire, my parents will be gone. I worry I will not have enough money for the things I need – a place to live or a reason to get out of bed in the morning. I don't know what the government or society is going to do for me."*
>
> Focus group participant

In the Finger Lakes region, we are called to action not only by the ever increasing numbers of older adults with I/DD in our communities, but also by the strategy and actions at the federal and state levels of government to transform services for individuals with I/DD in New York State (NYS). The Centers for Medicare and Medicaid Services (CMS) and New York State's "*Transformation Agreement*" provide a unique opportunity for people with I/DD, their families and community-based organizations to collaborate with the NYS Office of People with Developmental Disabilities (OPWDD) and other entities to bring about the change required to support a successful and meaningful retirement for individuals with I/DD.

Primary Objective

Every individual with an intellectual and/or developmental disability in the Finger Lakes region of New York State has the opportunity, choices and resources to engage in meaningful and enriching retirement experiences.

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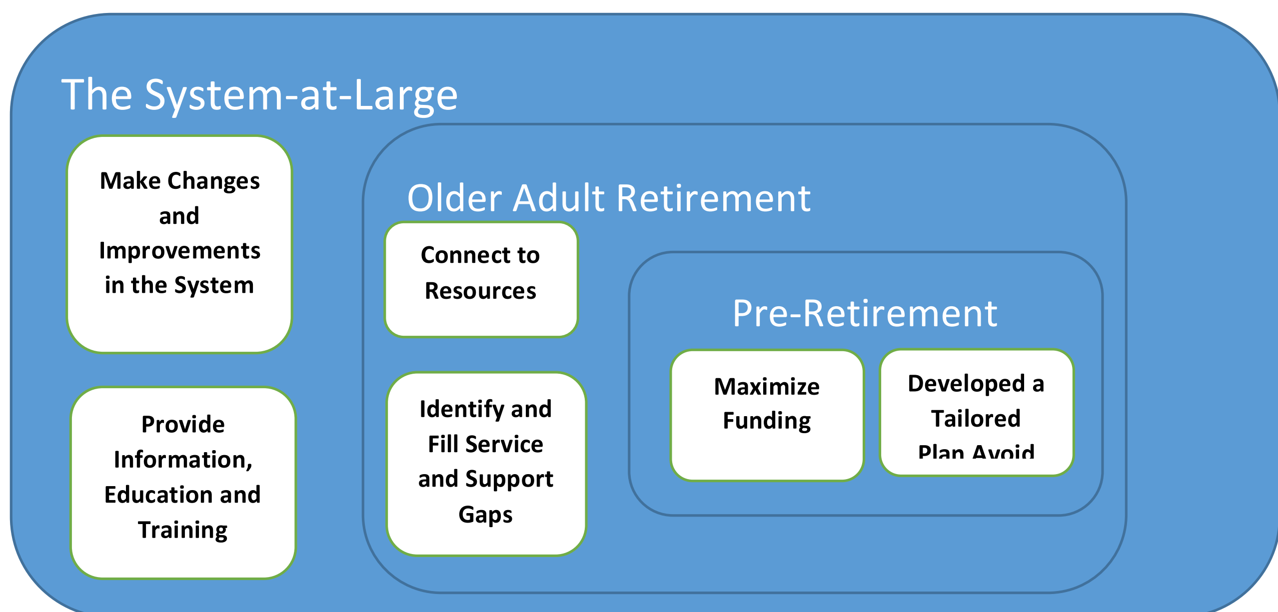
[1] Janicki, Matthew. "Longevity Increasing Among Older Adults with an Intellectual Disability." Aging, Health and Society.

Goals

1. Significantly increase the number of individuals with intellectual and developmental disabilities at the age of 40 and older who have created a personal retirement plan.
2. Create alignment and continuity of access between funding and regulatory systems to ensure a comprehensive, person-centered, self-directed approach to retirement planning and enjoyment for each individual with an intellectual and/or developmental disability.
3. Greatly improve the satisfaction of the complete retirement experience for all individuals with intellectual and developmental disabilities.

A Blueprint for Action: Essential Elements for a Successful Retirement

To achieve the primary objective and goals set forth above the planning partners of the Golisano Retirement Collaborative (GRC) have developed a "Blueprint for Action" for the Finger Lakes region. Following is a summary overview of the **vision for change and essential actions** the GRC finds import to be addressed so that individuals with I/DD can enjoy a successful retirement; and for our region to ensure options and opportunities are available for everyone with I/DD.



Call to Action:

The GRC calls for the development of three Task Forces to develop implementation strategies, secured resources and immediately start pilot projects. The Task Forces will work together, sharing information and progress toward the common goal achievement.

Task Force #1 – Pre-Retirement Stage

- Expand Future Care Planning to include retirement planning.
- Provide greater access to planning experts.
- Increase the number of people who have access to life/financial plans for retirement.

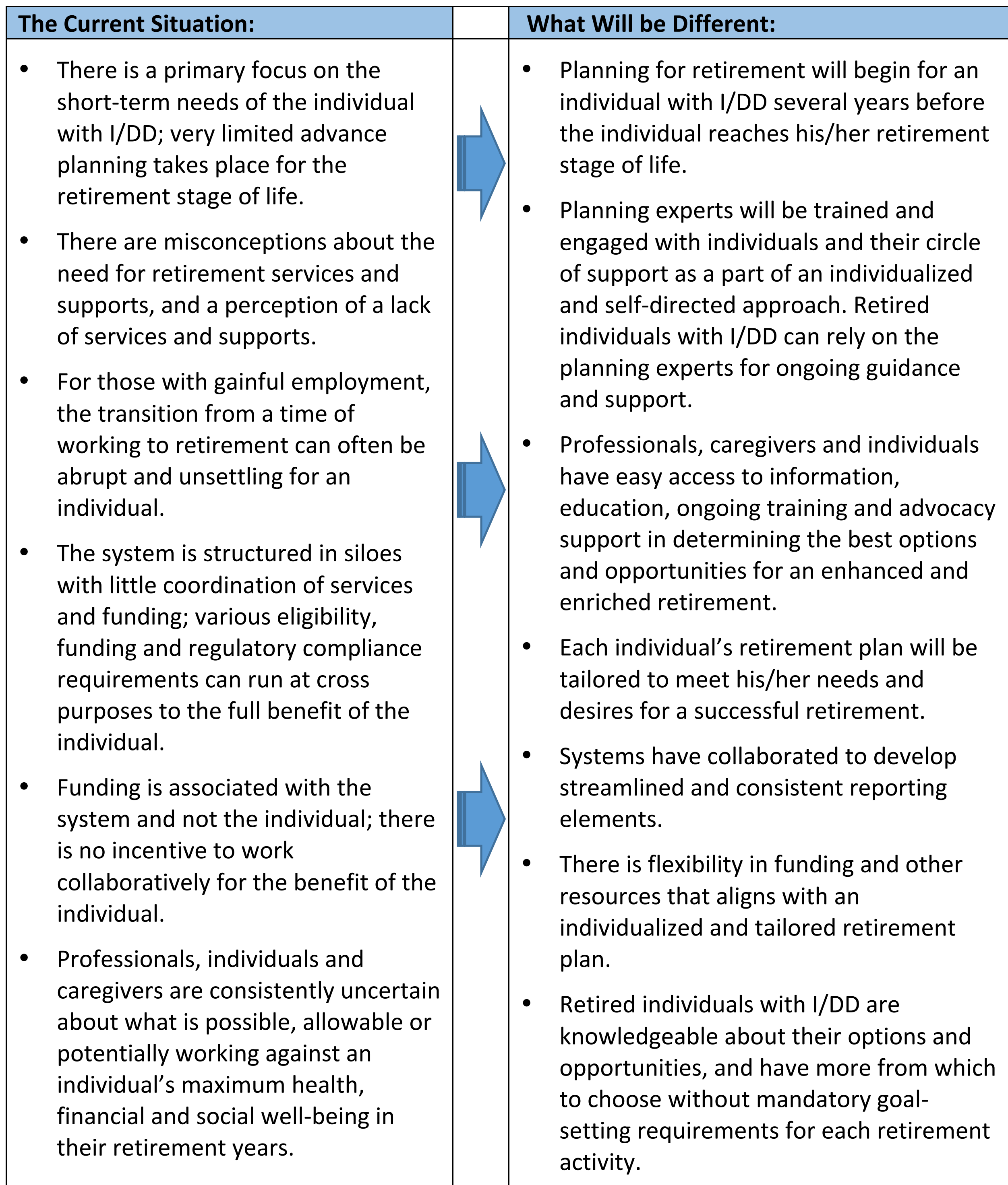
Task force #2 – Older Adult Retirement

- Develop comprehensive resource matrix.
- Provide greater access and understanding of Self-Direction.
- Explore community destination & other aging services models for all older adults.

Task Force #3 – Changing the System at Large

- Identify and address funding and regulatory barriers.
- Embrace stronger collaborations between systems – No Wrong Door.
- Provide greater training for both the OPWDD providers and aging service providers.

A Vision of Change: Creating the "Tipping Point"



The Current Situation:		What Will be Different:
• There is a primary focus on the short-term needs of the individual with I/DD; very limited advance planning takes place for the retirement stage of life. • There are misconceptions about the need for retirement services and supports, and a perception of a lack of services and supports. • For those with gainful employment, the transition from a time of working to retirement can often be abrupt and unsettling for an individual. • The system is structured in siloes with little coordination of services and funding; various eligibility, funding and regulatory compliance requirements can run at cross purposes to the full benefit of the individual. • Funding is associated with the system and not the individual; there is no incentive to work collaboratively for the benefit of the individual. • Professionals, individuals and caregivers are consistently uncertain about what is possible, allowable or potentially working against an individual's maximum health, financial and social well-being in their retirement years.		• Planning for retirement will begin for an individual with I/DD several years before the individual reaches his/her retirement stage of life. • Planning experts will be trained and engaged with individuals and their circle of support as a part of an individualized and self-directed approach. Retired individuals with I/DD can rely on the planning experts for ongoing guidance and support. • Professionals, caregivers and individuals have easy access to information, education, ongoing training and advocacy support in determining the best options and opportunities for an enhanced and enriched retirement. • Each individual's retirement plan will be tailored to meet his/her needs and desires for a successful retirement. • Systems have collaborated to develop streamlined and consistent reporting elements. • There is flexibility in funding and other resources that aligns with an individualized and tailored retirement plan. • Retired individuals with I/DD are knowledgeable about their options and opportunities, and have more from which to choose without mandatory goal-setting requirements for each retirement activity.

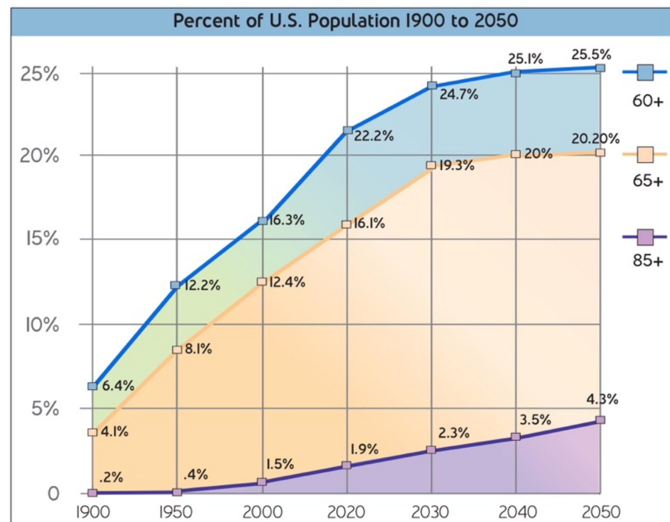
Changing the system for people. The story of Sam.

The Current Situation	Desired Future State
Sam is 60 years old and lives in an OPWDD certified home. He worked at a local grocery store for 25 years. Sam is advised to retire when his job performance was failing over a period of time along with noted cognitive decline. Sam wasn't planning to retire and never talked about it with anyone. When Sam's service coordinator asks him what he wants to do in retirement, he says. *"I don't know"*. Sam is worried about losing his paycheck. He asks if he can return to the sheltered workshop where he worked before going to work at the grocery store. (New sheltered workshop enrollments are no longer allowed per regulation.) Sam asks to stay home 1 or 2 days a week. Problem: In-home day habilitation is not allowed; by regulation, the person must receive habilitation in the community. The residence is not funded to provide day staff to be with him at home. In-home volunteer companions are not an option; they can't provide supports that paid residential staff do per DOL. Sam's service coordinator suggests tours of community programs and senior centers. Medicaid Transportation can't transport to non-Medicaid funded programs. Sam lives outside the radius for senior center funded transportation. Sam is anxious about going to an unfamiliar place.	When Sam is 45 years old, his service coordinator asks him if he would like to develop a plan for retirement. Sam is connected with Future Care Planning Service and is assisted in protecting his retirement savings. Eligibility for benefits and entitlements is secured. Access to funds for activities in retirement is assured. A retirement planning specialist, Sam and his Circle of Support create a financial and life plan of his choosing that is in line with his valued outcomes. As Sam reaches age 60 and demonstrates cognitive decline and diminished job performance, his service coordinator and Circle of Support suggest that he re-visit his retirement / life plan and explore some options to choose from. Sam's service coordinator utilizes a Service Resource Matrix and consults with NY Connects/No Wrong Door and finds several options for day-time activities that fit Sam's preferences and valued outcomes as identified in his life plan. Sam has time to visit community options before retirement. Sam hires an OPWDD broker and accesses funding for a community class into his schedule. Sam has the funds he needs to access additional activities of his choosing and utilizes self-directed staff to accompany him.

II. Research Findings
An Unmet Need in Our Communities - Why We Must Act Now

A Looming Convergence Creates an Age Wave

Almost 50 million Americans are 65 or older (13%). By 2030, 72 million Americans will be 65 or older (19%).[2]



An estimated four million Americans have an intellectual or developmental disability. Sixty percent of those receiving services live with their families; the family being the primary support system. By 2025, the average age of the individual served by the Office of People with Developmental Disabilities (OPWDD) in New York State will be 50. (OPWDD website)

Based on the 2010 Census, we estimate there are 850,600 people with developmental disabilities age 60 and older living in the nation. By 2030 their numbers will swell to 1.4 million due to increasing life expectancy and the aging baby boom generation.[3]

In Our Region

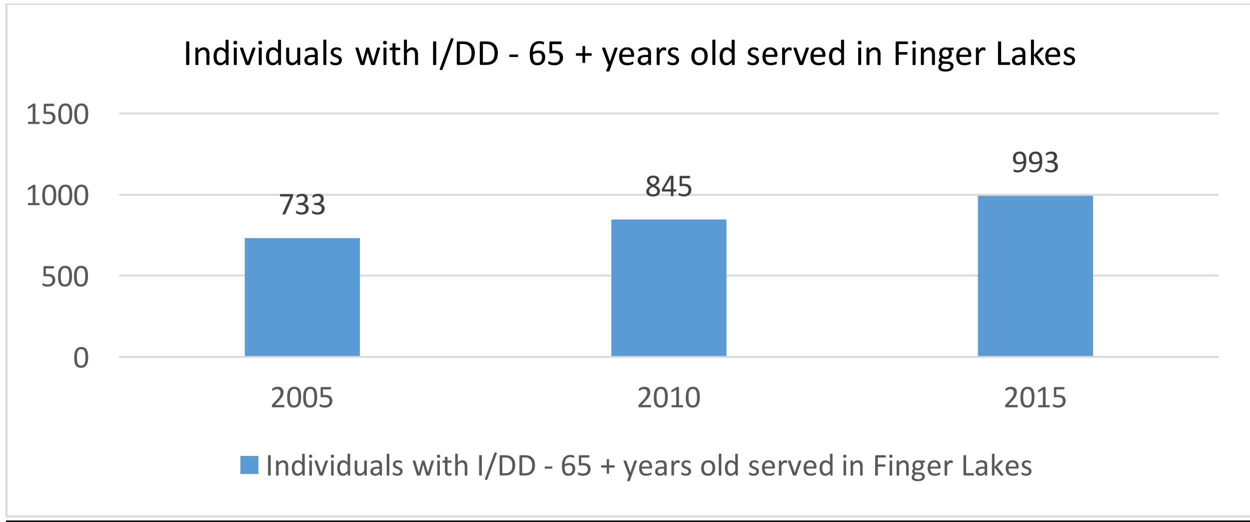
In the Finger Lakes region more than 8% of individuals with I/DD are age 65 and older (926 individuals out of 11,585 served as of 12/31/2014). 61% of individuals with I/DD are between the ages of 22 and 64.[4]

- 3,795 (33%) of individuals live in OPWDD certified homes. The remaining 67% live in the community with family or alone.
- 3,671 (32%) receive Family Support funded services; respite, recreation, reimbursement. (Individuals must live with family to receive this funding.)
- 5,371 (46%) receive Day Services or Employment Supports.

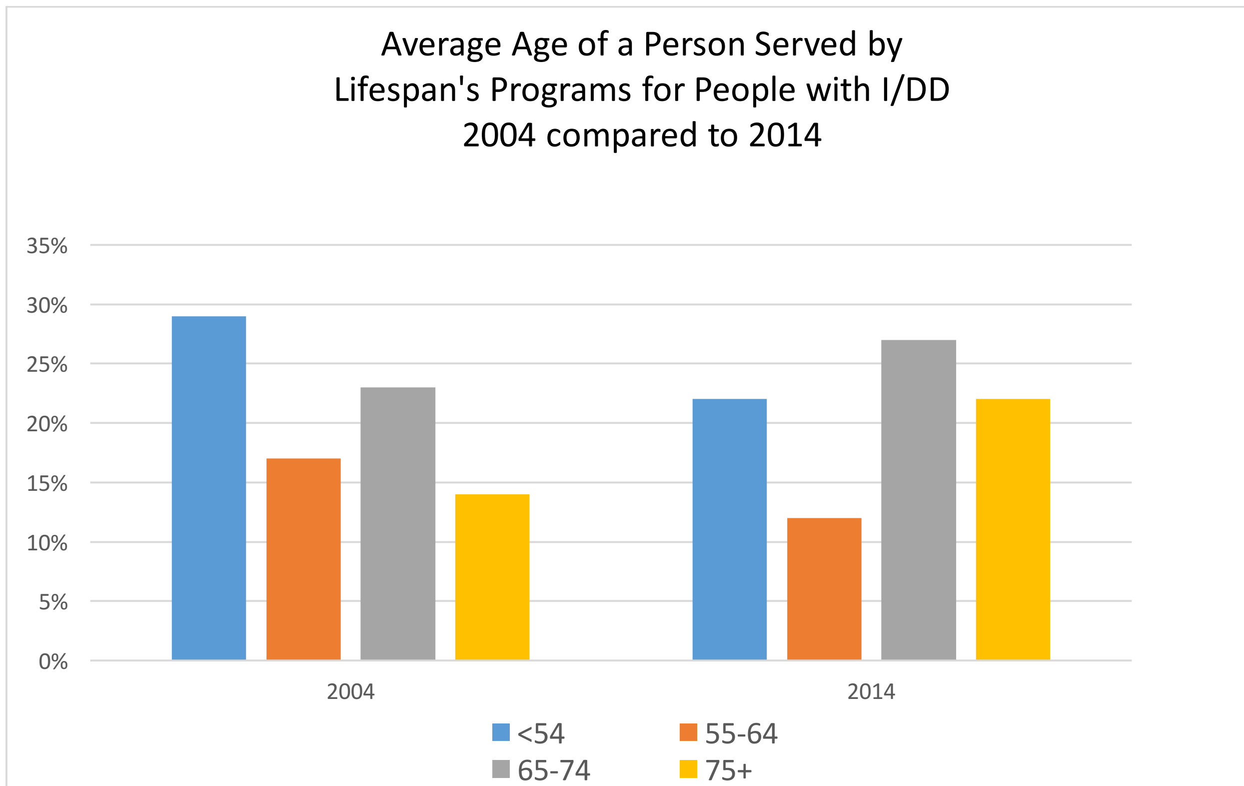
We estimate that over 3,500 individuals in our region are in the life stage to plan for retirement.

[2] U.S. Census Bureau, 2010, Profile of General Population & Housing Characteristics.
[3] U.S. Census Bureau, 2008, Projections of the Population b Age and Sex.
[4] InfoFacts Quarterly Information Report, OPWDD, 12/31/14

In our region: A 35% increase in the 65+ population in 10 years.
(OPWDD INFOFACTS Report)



Lifespan has been serving older adults with developmental disabilities since the late 1980's. At that time, "old age" for someone with a developmental disability was 45+ years of age. Ten years ago, 46% of the people Lifespan served in programs for people with I/DD, were younger than 64 years of age. In 2014, 18% were younger than age 64. 22% were older than 75.



The CMS/OPWDD Transformation Agreement

In 2013, OPWDD submitted the People First Waiver application to the Centers for Medicare and Medicaid Services (CMS). This waiver began the process of transforming the system for people with I/DD in New York State. The new plan represents the culmination of two years of examination, discussion, and system redesign in collaboration with thousands of stakeholders.

Together, NYS and CMS have identified a series of shared goals that will improve opportunities for individuals with developmental disabilities in the areas of employment, integrated living, and self-direction of services. These goals are captured in a transformation agreement.

They include:

- Developing new service options to better meet the needs of individuals and families in a truly person-centered way, including allowing for more self-direction of services;
- Creating a specialized managed care system that recognizes the unique needs of people with disabilities that is focused on a habilitative model of services and supports;
- Ensuring that people live in the most integrated community settings;
- Increasing the number of individuals who are competitively employed;
- Focusing on a quality system that values personal outcome goals for people, such as an improved life or access to meaningful activities; and
- Working to make funding in the system sustainable and transparent.[5]

When we focus on the goal to increase competitive employment for people with I/DD, we uncover some of the real challenges.

- 40% of workshop participants are over the age of 50.[6]
- All workshop participants will be educated about competitive employment options. **OPWDD estimates that 50% of individuals will not be interested in transitioning to competitive employment,** have medical, adaptive or behavior support needs that create barriers to employment, or are ready to retire. Alternative options for these individuals include: Community Habilitation, Self -Direction, or Day Habilitation.[6]

While the Transformation Agreement does have a sentence about the need to develop retirement strategies for those who don't want to pursue employment, the plan gives no specifics about how people will develop their retirement plan.

[5] Information from: www.opwdd.ny.gov/transformation-agreement/home

[6] NYS Plan to Increase Competitive Employment for People with DD, approved May 1, 2015.

III. A Blueprint for Action: Gathering Perspective

The project commenced in March of 2015 and continued through the end of 2015. The Golisano Retirement Collaborative (GRC), as the group was called, had a rigorous schedule of blueprint research, planning and report preparation activities. The group of collaborative partners met over 20 times (schedule in the appendices).

Our Methods and Process

In addition to the GRC planning partners, many others helped inform the call-to-action detailed in this blueprint report:

Discussion Groups with people with I/DD and family caregivers: 42 participants

- Older Adults
- Pre-Retirement Adults
- Medicaid Service Coordinators
- Caregivers: Agencies and Families

In-Depth Interviews: Professionals in financial and legal planning.

- Anna Lynch, Esq.
- George Gray, Esq.
- Miles Zatkowski, Esq.
- James Traylor, CLU, ChFC, ChSNC

Presentations to the GRC planning partners from local and national experts (presentations in the appendices).

- Philip McCallion, Ph.D.
- Angela Czerkas, OPWDD
- Trilby deJung, Esq. and Geoffrey Hale, Esq.
- Seth Keller, M.D. and Kathie Bishop, Ph.D.

Data and Information Gathering

- Statistics regarding our region
- Books, literature and other resources

Key Findings – The Voice of Our Stakeholders

The As Is…To Be…Experience

Since retirement is an emerging life-stage for individuals with intellectual and development disabilities, we asked stakeholders to discuss the planning process now – both the strengths and the weaknesses. It quickly became apparent that few older adults with I/DD have/had

planned for retirement. For most individuals, not enough thought and/or planning has been given to what happens way down the road or even around the next bend. For individuals and caregivers who have given it some thought, there is concern…even fear and worry…perhaps some denial and avoidance as a result.

Older Adults with I/DD Discussion Group Comments

The topic of retirement is/was rarely even discussed, let alone planned for in advance. For some, it came as a complete surprise when one day they were working and the next day they were not; and life was never the same.

Question: "What do you want in retirement?"

Answer: An easier-going lifestyle, a break in the usual routine and no particular schedule. It could be sports, travel, leisure, spending time with friends and family, taking a nap, watching television, going shopping or to church, or taking a walk. It's working on the computer, playing cards or going bowling. It is time to relax. *"Doing what I want when I want."*

Caregiver Discussion Group Comments

"Our loved ones need and want what everybody else needs and wants. Why can't they have it? They should have it!"

Caregivers often see retirement as a set of challenges for their loved one - including health, financial, and additional structural constraints within the system. The family caregivers report feeling overwhelmed and worried about what happens to their loved one when they are gone.

> ***"I don't think about retirement for my son because I cannot picture it. It should be more than just a light version of the status quo."***

"I am his everything." "I try to do it all, but sometimes I just can't." "I need to know he is going to be taken care of when I am gone." What financial resources will be available? They worry about increasing health problems. They don't see the roadmap. They don't see that any planning for this stage of life is developing for their loved one.

(Note: We often see fear, worry and uncertainty give way to "safe and rational decisions/ solutions" that are suitable, but not ideal for the individual with I/DD or for the family. In some cases the caregiver and their loved one are aging at the same time despite their difference in age. A point in time comes when the caregiver needs caregiving.)

Medicaid Service Coordinators (MSC) & Agency Staff Discussion Group Comments

MSC's said that they don't have the right options. Staff and other professionals can't confidently talk about the future without information, training and understanding of what is ahead and what the options are for individuals. They can see how things could be better. Sometimes they are

met with resistance, which is compounded when they encounter an entitlement mentality from other caregivers or individuals.

"We end up the bad guy."
"It should not be this hard."
"There are too many 'game-over moments' in our work."
"Everyone is speed-dating…looking for answers and opportunities."

As professional caregivers, they need to feel support, have the ability to decompress, and have the opportunity to complete the puzzle to success.

We have an often unwieldy alphabet soup of points of engagement, oversight and funding. There may be no "wrong door", but once you are inside a labyrinth is presented and must be effectively navigated. We have rules, regulations and requirements that embody inherent conflicts of interest, leaving individuals with the contradiction of limited choice among the various options that already exist…too many best kept secrets…and sometimes a default to perpetuate the system.

The good news is that diligence toward excellence persists and there are success stories from which we can learn and repeat.

Legal and Financial Professionals Discussion Group Comments

The legal and financial experts report that planning is tough for everyone, but having an intellectual or developmental disability can add an additional layer of complexity.

It is never too soon to engage experts, advisors, gatekeepers and stakeholders; but, more importantly everyone must be working together to make the best lifestyle, financial, and health care decisions and provisions. *"What you don't know can hurt you!"* They stressed that by working together a person can maximize the benefits of available resources, achieve personal satisfaction and can avoid or mitigate crisis.

The essential elements of a solution include access to information, education, training, advocacy and taking action in a pro-active vs. reactive manner. This kind of planning will allow people to "*get beyond the necessities in life to an enhanced and enriched life."*

Information from Presenters

Experts in the field spoke to the GRC at various times during the planning process. (Powerpoint presentations are in the appendices.)

Retirement and Older Adults with Intellectual and Developmental Disabilities, Dr. Phil McCallion, SUNY Albany, April 23, 2015

The Assessment and Care of Adults with Intellectual and Developmental Disabilities and Dementia, Seth M. Keller, MD, Past President of the AADM, Co-Chair NTG, May 18, 2015

An Introduction to Self-Direction, Angela Czerkas, OPWDD Region 1, June 2, 2015

The Aging and IDD Population and Managed Care, Trliby de Jung J.D., Finger Lakes Health Systems Agency, June 18th, 2015

OPWDD Waiver and Medicaid Managed Care, Geoffrey A. Hale, Senior Attorney Empire Justice Center, June 18th, 2015

While each presenter focused on a different aspect of aging – from longevity to recreation to health concerns - one thing was very clear, no place has a comprehensive service/program to help individuals with the retirement transition. Most places in the country have not thought of how we are going to support individuals in retirement, and the basic consensus is that individuals with I/DD want what everyone wants in retirement – an opportunity to enjoy unstructured life.

Other Communities

While some small projects may exist across the country, the only comprehensive planning project to address retirement was done in Nova Scotia, Canada, funded by the Public Health Agency of Canada. The report "*Next Stage: Retirement Planning for People with Developmental Disabilities*," found that the aging service system and the system for people with developmental disabilities ran parallel but never crossed. *"There is a lack of cross sector planning. You know, we have many different groups here that have a lot of the same issues and if we all got together…<we could find effective solutions.>"*

The report calls for:

- Transition planning from work to retirement.
- Building capacity within the aging and disability sectors and for cross system collaborative to foster social inclusion.[7]
- Policy Discussion: developing strategies for aging in place.

Innovative Retirement-Type Projects That Were Reviewed for Ideas

Men's Sheds – Australia. This project helps men transition into retirement. Many older adults with developmental disabilities are a part of the "sheds." They are places where men make furniture, restore bicycles for a local school, make bird traps, fix lawn mowers or making a "cubby" house. Young men or people with disabilities work side-by-side with other older men to obtain new skills and socialize. The Men's Shed movement has now become one of the most powerful tools in addressing health and wellbeing and helping men to remain valued and productive members of the community.

[7] The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities. School of Health and Human Services, NSCC. Page. 53.

Village Movement – Amsterdam, Netherlands *(This model is not in keeping with the Transformation Agreement or our philosophy of an inclusive environment. We are listing it because we may be able to learn from this supportive environment.)* Amsterdam has built "villages" to offer support to older adults and people with dementia. The model could easily be adapted to include people with I/DD. At first glance, it looks like any other village complete with shops, restaurants and even a movie theater. There are apartments surrounding a courtyard. Around-the-clock care is provided by 240 "villagers" who are actually trained geriatric nurses and caregivers dressed in street clothes. Older adults work and/or volunteer in the village. This model helps residents remain active and gives them a sense of purpose. It has proven to reduce agitation, reduce medications and increase quality of life. It also has given caregivers a sense of relief that their loved one lives independently but in a supportive environment.

Town Square for Aging – Buffalo, NY. The Town Square for Aging is a collaborative project by 25 agencies that creates a one-stop center for older adults, offering such services as primary and specialty care, behavioral health as well as retail services like banking and legal services and opportunities for socialization. There is a café in which individuals can get lunch, socialize and/or work in the Town Square. It is inclusive model. The project, led by the Weinberg Campus and its affiliated programs. It serves both individuals living in senior apartments as well as all individuals in the community who opt to remain in their own homes.

Meeting Basic Needs

The Planning Partners Collaborative often touched on the importance of meeting essential needs in order for a person with I/DD to achieve retirement goals and aspirations.

While the Planning Partners Collaborative recognizes that meeting basic needs may be out of scope for the focus of the Blueprint for Action, it is acknowledged that optimal life planning cannot be effective if the individual's and caregiver's basic needs for good health and healthcare, housing and transportation are not met.

IV. A Blue Print for Action: Retirement Options and Opportunities for Older Adults with Intellectual and Developmental Disabilities.

The GRC agreed that a Blueprint for Action was in order to facilitate the process of retirement planning and foster the development of a new way for people with I/DD to live in their retirement years. This Blueprint for Action details our **vision for change and essential actions** so that individuals with I/DD can enjoy a successful retirement and that we have a full array of options and opportunities for everyone with I/DD.

Primary Objective

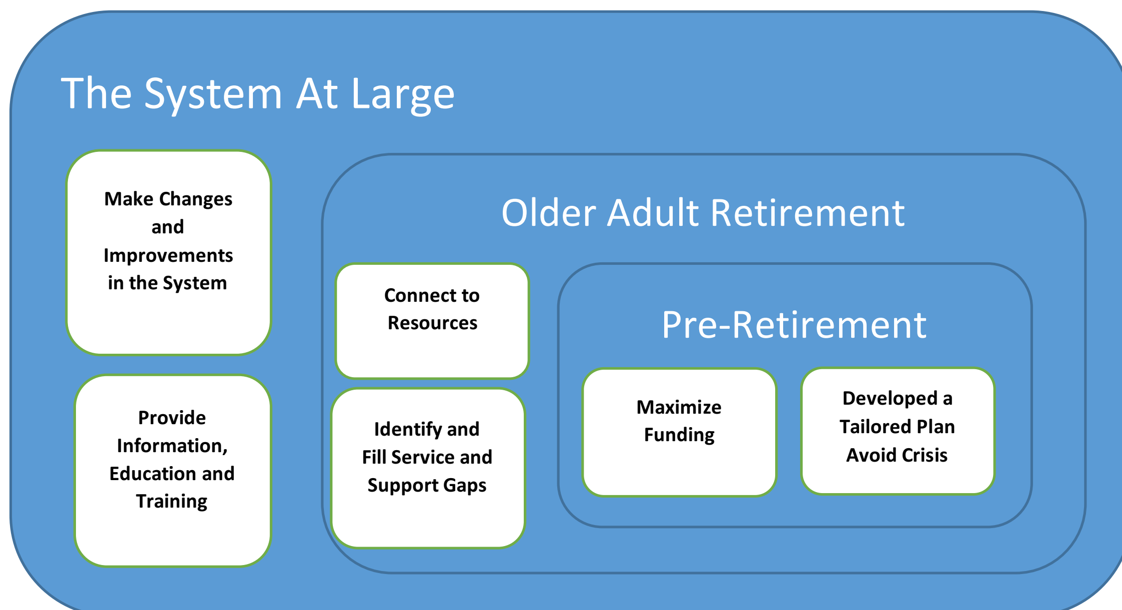
Every individual with an intellectual and/or developmental disability in the Finger Lakes region of New York State has the opportunity, choices and resources to engage in meaningful and enriching retirement experiences.

Goals

1. Significantly increase the number of individuals with intellectual and developmental disabilities at the age of 40 and older who have created a personal retirement plan.
2. Create alignment and continuity of access between funding and regulatory systems to ensure a comprehensive, person-centered, self-directed approach to retirement planning and enjoyment for each individual with an intellectual and/or developmental disability.
3. Greatly improve the satisfaction of the complete retirement experience for all individuals with intellectual and developmental disabilities.

Essential Elements of the Blue Print

In order to create a tipping point for positive change and beneficial outcomes for individuals with I/DD, the GRC has developed the following essential components for a successful retirement.



Call to Action

The GRC calls for the development of three Task Forces to further define and refine successful retirement planning and processes for individuals with I/DD. The Task Forces will work together, sharing information and progress toward the common goal achievement.

Task Force #1 – Pre-Retirement Stage

Make it possible and easier for every person to maximize their combined personal, philanthropic and public funds for their benefit before and during their retirement years. Help individuals/caregivers map out a retirement plan, so that people can have a fulfilling life in retirement and a void crisis.

- Expand Future Care Planning to include retirement planning.
- Provide greater access to planning experts.
- Increase the number of people who have access to life/financial plans for retirement.
- Educate families about the NYS Achieving a Better Life Experience (ABLE) ACT that will allow families the opportunity to set up tax-free 529A savings accounts for disability-related expenses.

Action Steps/ Details for Task Force #1

- Future Care Planning Service becomes the advisor that has cross-system understanding and expertise specific to retirement.
- Future Care Planning Service informs, guides and assists individuals and families in creating ABLE accounts which is a tax-advantaged "529-style" funding vehicle for individuals with intellectual and developmental disabilities. This financial vehicle could be funded by families and use by loved ones to pay for life essentials and to enhance their quality of life after certain criteria are met, e.g., reaching a certain age or life stage.

  (The NYS Assembly and Senate passed A6516-2015, ABLE legislation that will allow families the opportunity to set up tax-free 529A savings accounts for disability-related expenses; ABLE was signed into law by Governor Cuomo on 12/22/15. Assets in ABLE accounts will be exempt from a $2,000 cap on conventional savings accounts; exceeding that cap voids eligibility for Medicaid and Supplemental Security Income (SSI) benefits. ABLE accounts are different from a special needs or pooled trust in that it will provide more choice and control for the beneficiary and family. The cost of establishing an account will be considerably less than either a Special Needs Trust (SNT) or Pooled Income Trust. With an ABLE account, account owners will have the ability to control their funds and, if circumstances change, still have other options available to them. Determining which option is the most appropriate will depend upon individual circumstances. For many families, the ABLE account will be a significant and viable option in addition to, rather than instead of, a Trust program.)

- Cross-train other professionals who can engage individuals, families and caregivers in the discussion. In some cases, a point-person or "planning guru" might be the best arrangement to work with each individual and their circle of supports.
- Include advance planning discussions with other Medicaid Service Coordinator duties at least twice per year and at key transition touch points: eligibility, transition to adulthood, and then at the transition to retirement. Incorporate discussion about transition to retirement as a practice in the Individual Service Plan review process.
- Establish a "clearinghouse" or "411-like model" as a type of concierge resource. This resource would expertly knowledgeable about what is available, or how to make it possible for an individual to fulfill their wishes/desires and achieve their *Valued Outcomes*, based upon potential community-based options.
- Create a clearinghouse/concierge capability that can "catalog" options/opportunities.

Task force #2 – Older Adult Retirement

Develop an easier way for people to understand retirement options, programs/services and community resources. Create inclusive models in which people can access services from any service system or community group.

- Develop comprehensive resource matrix with retirement options.
- Provide greater access and understanding of Self-Direction.
- Increase the capacity and expand existing inclusive retirement programs (e.g. senior companions with people with I/DD in senior centers,
- Explore inclusive community destination model for all older adults, including people with I/DD (e.g. Town Square in Buffalo).

Action Steps/Details for Task Force #2

- Enhance existing "Angie's List" type services that offer comprehensive companion services for individuals. Families and caregivers need on-demand and advance planned companion options that are trusted, safe and affordable.
- Create a matrix of all available resources based upon need and the funding source(s), including issues/barriers to overcome. (Agencies need help understanding available affordable housing options that already exist, but are underutilized. Include in the matrix.)
- For older adults not currently enrolled in OPWDD services, communicate the availability of resources (through United Way funding) to assist individuals to become eligible for OPWDD.
- Survey existing entities to see what is available.
- Canvas service coordinators for best resources to use when they are trying to fill needs.
- Expand caregiver.com to include services for I/DD; explore to determine if this is a viable option for companion services and/or direct support.
- Communicate available transportation services. Fully utilize mobility management options.
- Pilot an Uber-like service for older adults with interested I/DD agencies so that transportation service can be responsive to individual needs. Research viability of this option.
- Create or access a mechanism for evaluating the performance of service providers via transparent / public and standardized "scoring" capabilities, access and satisfaction such as Personal Outcomes Measures (POMS).
- OPWDD/other entity establish a function to specialize in guidance related to aging and I/DD.
- Ensure that older adults with I/DD access existing aging services and give the proper supports so the transition is successful.

Task Force #3 – Changing the System at Large

Identify and call out systemic barriers and advocate for change in our government-based entities and among peer organizations and agencies that inhibits individual choice, community collaboration and optimal funding approaches. Create opportunities for effective and accessible training, education and information among all stakeholders. There are too many scenarios where professionals do not know how to help, where individuals do not know what they do not know, and where the lack of information and knowledge can be harmful.

- Identify and address funding and regulatory barriers.
- Embrace stronger collaborations between systems – No Wrong Door.
- Ensure that develop easy use of programs between systems – reduce "game over" moments.
- Provide greater training for both the OPWDD providers and aging service providers.

Action Steps/Details for Task Force #3

- Identify the "game-over" moments and barriers and the possibilities via real-life examples. Compare the way it is to the way it should be by example.

- Review duplication and redundancy that exists in the system. Integrate community organizations that can provide support and guidance across funding streams.

- Communicate the role of NY Connects (No Wrong Door) as the single point of entry, information and assistance and guidance across systems. Partner with NY Connects to expand the system to include all government-based entities: OPWDD, OMH and others.

- Identify regulations most burdensome and advocate for change. (*For example, current regulations and funding limitations prevent an individual living in an OPWDD certified setting from receiving in-home OPWDD habilitation during the day. Additionally, volunteers are not allowed to perform "work" that would otherwise be expected of a paid OPWDD residential staff person.)*
- Standardize the form/format/language of the application to apply for services across the system. (Identify duplication of data required on various forms. Collect information once in a centralized database. Apply this approach until all information is collected once and centralized for all users. Avoid the individual having to tell their "story" again, and again.)
- Illustrate processes/workflows that are cumbersome and suggest specific improvements.

- Coordinate regulations for like services under funding streams. Identify ala carte vs. bundled service packages and rules around them.
- Create a hub of information and training options that are timeless and sustainable, especially when the information is continuously changing.

- Train and educate older adults and their families on the availability of flexible funding via Self-Direction and waiver service approved under 1915c: Individual Directed Goods and Services, Live-In Caregiver, family reimbursed respite and allowing higher staff pay-rates.

- Assure effective messaging about ongoing changes in the system to avoid conflicting and confusing information and wasted opportunities. (e.g. Commissioners Correspondence Unit. Commissioner Forum/Bulletins.)

- Utilize waiver service brokerage. Systematically listen to individuals, families, caregivers and providers; continuously improve the system, services based upon input and feedback.

- Initiate a listening forum: a venue for communication to occur regularly.

- Develop opportunities that fit outside the 9:00-5:00 time frame.

- Avoid looking to the government-based entities to solve all the issues.

A Vision of Change: Creating the "Tipping Point"

The Current Situation:		What Will be Different:
• There is a primary focus on the immediate and short-term needs of the individual with an intellectual and/or developmental disability (I/DD); very limited advance planning takes place for the retirement stage of life. • There are misconceptions about the need for retirement services and supports individuals with I/DD, and a perception of a lack of services and supports. • For those with gainful employment, the transition from a time of working to retirement can often be abrupt and unsettling for an individual. • The system is structured in siloes with little inter-silo understanding or coordination of services and funding; various eligibility, funding and regulatory compliance requirements can run at cross purposes to the full benefit of the individual. • Funding is associated with the system and not the individual; there is no incentive to work across the system collaboratively for the benefit of a given individual. • Given the dynamic environment, professionals, individuals and caregivers are consistently uncertain about what is possible, allowable or potentially working against an individual's maximum health, financial and social well-being in their retirement years.		• Planning for retirement will begin for an individual with an intellectual and/or developmental disability (I/DD) several years before the individual reaches his/her retirement stage of life. • Planning experts will be trained and engaged with individuals and their circle of support as a part of an individualized and self-directed approach. Retired individuals with I/DD can rely on the planning experts for ongoing guidance and support. • Professionals, caregivers and individuals have easy access to information, education, ongoing training and advocacy support in determining the best options and opportunities for an enhanced and enriched retirement. • Each individual's retirement plan will be tailored to meet his/her needs and desires for a successful retirement. • Systems have collaborated to develop streamlined and consistent reporting elements. • There is flexibility in funding and other resources that aligns with an individualized and tailored retirement plan. • Retired individuals with I/DD are knowledgeable about their options and opportunities, and have more from which to choose without mandatory goal-setting requirements for each retirement activity.

Changing the system for people. The story of Sam.

The Current Situation	Desired Future State
Sam is 60 years old and lives in an OPWDD certified home. He worked at a local grocery store for 25 years. Sam is advised to retire when his job performance was failing over a period of time along with noted cognitive decline. Sam wasn't planning to retire and never talked about it with anyone. When Sam's Service Coordinator asks him what he wants to do in retirement, he says. ***"I don't know***". Sam is worried about losing his paycheck. He asks if he can return to the sheltered workshop where he worked before going to work at the grocery store. (New Sheltered Workshop enrollments are no longer allowed per regulation.) Sam asks to stay home 1 or 2 days a week. Problem: In-home day habilitation is not allowed; by regulation, the person must receive habilitation in the community. The residence is not funded to provide day staff to be with him at home. In-home volunteer companions are not an option; they can't provide supports that paid residential staff do per DOL. Sam's Service Coordinator suggests tours of community programs and senior centers. Medicaid Transportation can't transport to non-Medicaid funded programs. Sam lives outside the radius for Senior Center funded transportation. Sam is anxious about going to an unfamiliar place.	When Sam is 45 years old, his Service Coordinator asks him if he would like to develop a plan for retirement. Sam is connected with Future Care Planning Service and is assisted in protecting his retirement savings. Eligibility for benefits and entitlements is secured. Access to funds for activities in retirement is assured. A retirement planning specialist, Sam and his Circle of Support create a financial and life plan of his choosing that is in line with his valued outcomes. As Sam reaches age 60 and demonstrates cognitive decline and diminished job performance, his Service Coordinator and Circle of Support suggest that he re-visit his retirement / life plan and explore some options to choose from. Sam's Service Coordinator utilizes a Service Resource Matrix and consults with NY Connects / No Wrong Door and finds several options for day-time activities that fit Sam's preferences and valued outcomes as identified in his life plan. Sam has time to visit community options before retirement. Sam hires an OPWDD Broker and accesses funding for a community class into his schedule. Sam has the funds he needs to access additional activities of his choosing and utilizes self-directed staff to accompany him.

Elephants in the Room

We discussed some very difficult topics regarding conflicts of interest, the payment process to agencies and the need to develop full choices and options for people regardless of funding mechanisms. We want to ensure that full choices and options are offered.

Each Task Force will address the following:

- Conflicts of Interest
- Illusion of Choice
- Bureaucracy – The misalignment of different governments departments that often work at cross purposes.

Consequences of Not Acting

It is always difficult to predict the consequences of not acting, except we know some of the stories. Individuals who are prematurely institutionalized. Individuals who are placed in day programs and lose their life-long friendships that we developed in their workshops.

V. A Pathway Forward - A Community Working Together

It is our intention to create the task forces to develop the implementation plans. Our activities include:

1. Presentation to the Golisano Foundation - January 27, 2016.
2. Distribute the report to and meet with regional and statewide stakeholders at the Office of People with Developmental Disabilities (OPWDD).
3. Identify key initiatives and resources for implementation of the Blueprint Recommendations.
4. Form three community-based task forces to implement the blueprint for action. Identify and launch early pilot project opportunities.
5. Undertake a stakeholder presentation "roadshow" to create awareness, educate, garner partnerships and secure funding support and implementation resources. Make a comprehensive list of stakeholders/conferences and schedule presentations for 2016.

Timeframes
Short-term: January – June 2016 (presentations, task force commencement).
Medium-term: July – December 2016 (begin implementing actions).
Long-term: Beyond 2016 (continue implementing actions and measure outcomes/results)**.**

Special thanks to the B. Thomas Golisano Foundation for funding the project. We are deeply grateful for their continued efforts to support innovative projects, develop new ideas and support agencies that serve people with I/DD.

A Blueprint for Action:

Retirement Options and Opportunities for Older Adults with Intellectual and Developmental Disabilities

APPENDIX

Golisano Retirement Collaborative Planning Partners Meeting Schedule 29

PRESENTATIONS:

Retirement and Older Adults with Intellectual and Developmental Disabilities 30
Dr. Phil McCallion, SUNY Albany, April 23, 2015

The Assessment and Care of Adults with Intellectual and Developmental Disabilities and Dementia 44
Seth M. Keller, MD, Past President of the AADM, Co-Chair NTG, May 18, 2015

An Introduction to Self-Direction 53
Angela Czerkas, OPWDD Region 1, June 2, 2015

The Aging and IDD Population and Managed Care 69
Trliby de Jung J.D., Finger Lakes Health Systems Agency, June 18, 2015

OPWDD Waiver and Medicaid Managed Care 75
Geoffrey A. Hale, Senior Attorney Empire Justice Center, June 18, 2015

The Golisano Retirement Collaborative will work together to prepare a comprehensive blueprint of retirement options and opportunities for individuals with intellectual and developmental disabilities. Our blueprint will be submitted to NYS OPWDD and distributed to regional stakeholders on or before December 31, 2015; with an interim report provided to agency leaders and the Golisano Foundation in September and October respectively.

Golisano Retirement Collaborative
Updated: November 19, 2015

Meeting Schedule: Retirement Blueprint Planning/Preparation Activities and Deliverables

Planning partners will meet twice per month on the schedule below from **3:00p.m. – 5:00p.m** unless otherwise indicated.

March 9, 2015 Collaborative Kick-Off Meeting	**May 5, 2015 and June 17, 2015** **10:00 a.m. – 11:30 a.m.** Older Adult/Pre-Retirement Discussion Group	**July 10, 2015** Guest Speakers: Seth Keller, M.D. Kathie Bishop, Ph.D.	**September 8, 2015** Planning Partner Meeting	**November 3, 2015** Planning Partner Meeting **Finalize Blueprint Recommendations with Actionable Detail** **Review Draft Report Outline**
March 26, 2015 Planning Partner Meeting	**May 21, 2015** **12:00 p.m. to 1:30 p.m.** Care Giver Discussion Group	**July 23, 2015** Planning Partner Meeting ***Research Summary Review***	**September 24, 2015** Planning Partner Meeting **Agency Leadership Update**	**November 19, 2015** Planning Partner Meeting **Review a Work-in-Progress Blueprint Report**
April 7, 2015 MSC Discussion Group Planning Partner Meeting	**June 2, 2015** Guest Speaker: Angela Czerkas	**August 4, 2015** No Planning Partner Meeting **Blueprint Framework Development**	**October 6, 2015** Planning Partner Meeting **Develop Blueprint Recommendations with Actionable Detail**	**December 1, 2015** Planning Partner Meeting **Review and Refine Draft Blueprint Report**
April 23, 2015 Guest Speaker: Philip McCallion, Ph.D.	**June 18, 2015** Guest Speakers: Trilby de Jung, Esq. Geoffrey Hale, Esq.	**August 20, 2015** Planning Partner Meeting	**October 22, 2015** Planning Partner Meeting **Develop Blueprint Recommendations with Actionable Detail**	**December 17, 2015** **Blueprint Presentation to Planning Partners and Agency Leadership**

Legal/Financial Interviews 6/3/15 6/12/15 6/23/15 6/25/15 Miles Zatkowsky, Esq., George Gray, Esq., James Traylor, CLU, ChFC, ChSNC and Anna Lynch, Esq.

A small project oversight team will meet monthly on the following dates: 2:00p.m. – 3:30p.m. (unless otherwise scheduled)					
3/20/15	5/26/15	7/28/15	9/29/15	11/24/15	
3/31/15	6/23/15	8/17/15	10/29/15	12/09/15	
4/28/15	7/21/15	9/17/15	11/12/15	12/22/15	

Final Blueprint Report Submitted to NYS OPWDD and Distributed to Regional Providers On or Before **12/31/15**

Tentative: *Presentation to the Golisano Foundation in January, 2016.*

Page **1** of **1**

Retirement & People with Intellectual and Developmental Disabilities

Philip McCallion, PhD

Center for Excellence in Aging & Community Wellness

University at Albany

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www.ceacw.org

The Challenge of Aging

- A Success Story
- How little we know about aging
- Promoting life long health
- Maintaining independence
- Postponing disability
- Reorienting services
- Supporting Retirement

Consumer Concerns

- Decline in skills
- Decline in community/family/friend participation
- Decline in health status
- Increase in problem/challenging behaviors
- Decline in Quality of life
- Increased risk for placement in restrictive settings
- Loss of day program or job

Aging and People With I/DD

- No generally accepted age which defines exactly when people become old
- Life long disability rather than newly onset disability in old age
- Relatively small additional disabilities may have large impact on independence
- Greater rates of chronic conditions
- No personal transportation
- Few with spouses or children
- Long term out of home placement for some
- Services systems who never expected to provide old age care or support those in retirement

The retirement challenge

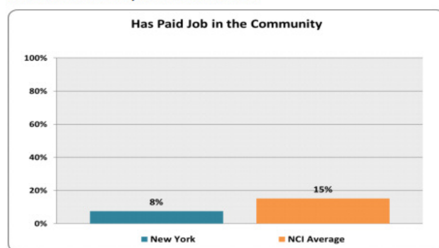
- By 2025, over half of the workforce in supported employment services will be over the age of 50 (McDermott et al., 2009)
- Despite declining productivity and health, in the absence of alternatives older people with intellectual disability continue working
- There are few, if any, funded mechanisms to support the transition to retirement
- Faced with urgent changes in client support needs, disability services are forced to implement ad-hoc retirement programs
- These programs tend to evolve into the “default” disability-specific day program and reflect existing service models

Bigby et al., 2011

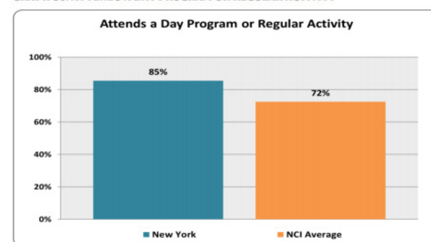
Building on Strengths and Interests

Employment & Day Programming in New York

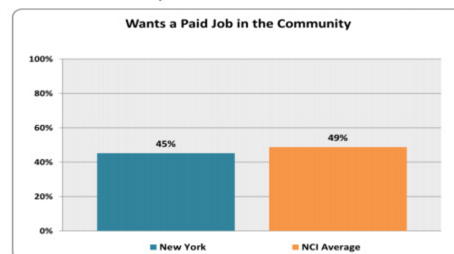
GRAPH 39. HAS A PAID JOB IN THE COMMUNITY



GRAPH 50. ATTENDS A DAY PROGRAM OR REGULAR ACTIVITY

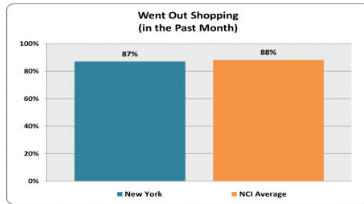


GRAPH 48. WANTS A PAID JOB IN THE COMMUNITY

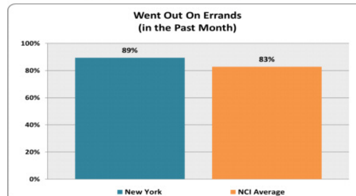


Activities to Increase & Continue in Retirement

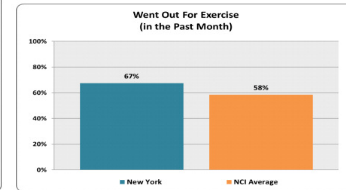
GRAPH 25. WENT OUT SHOPPING IN THE PAST MONTH



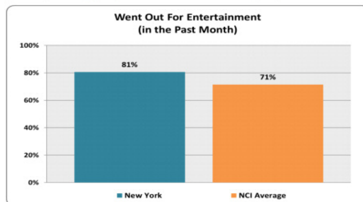
GRAPH 27. WENT OUT ON ERRANDS IN THE PAST MONTH



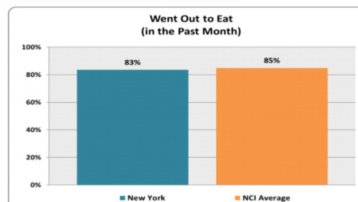
GRAPH 35. WENT OUT FOR EXERCISE IN THE PAST MONTH



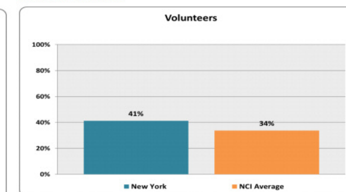
GRAPH 29. WENT OUT FOR ENTERTAINMENT IN THE PAST MONTH



GRAPH 31. WENT OUT TO EAT IN THE PAST MONTH

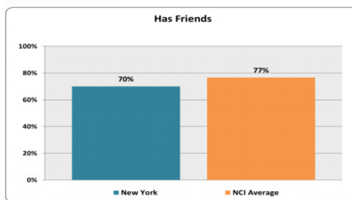


GRAPH 51. VOLUNTEERS

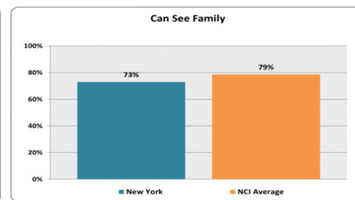


Relationships

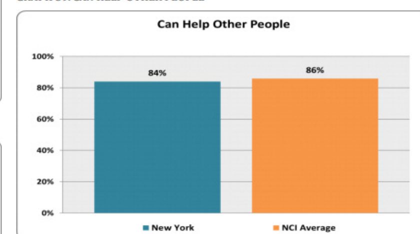
GRAPH 53. HAS FRIENDS



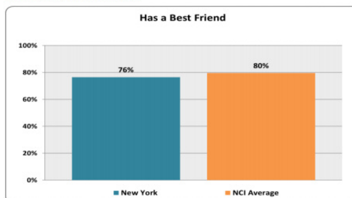
GRAPH 55. CAN SEE FAMILY



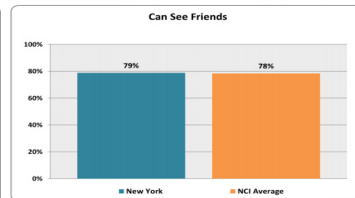
GRAPH 59. CAN HELP OTHER PEOPLE



GRAPH 54. HAS A BEST FRIEND

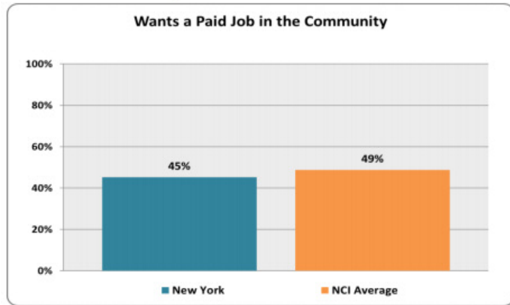


GRAPH 56. CAN SEE FRIENDS

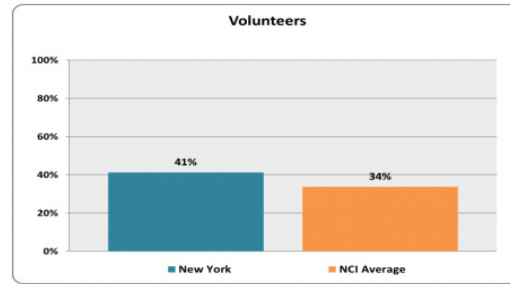


Opportunities in Retirement

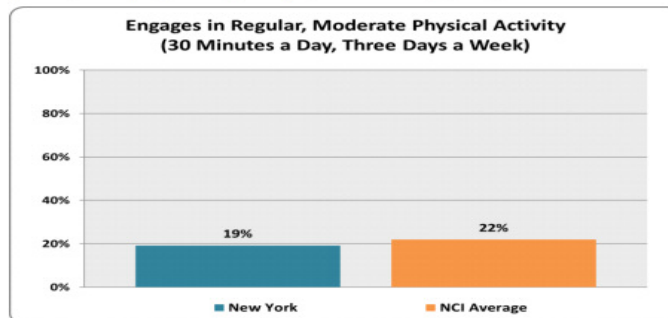
GRAPH 48. WANTS A PAID JOB IN THE COMMUNITY



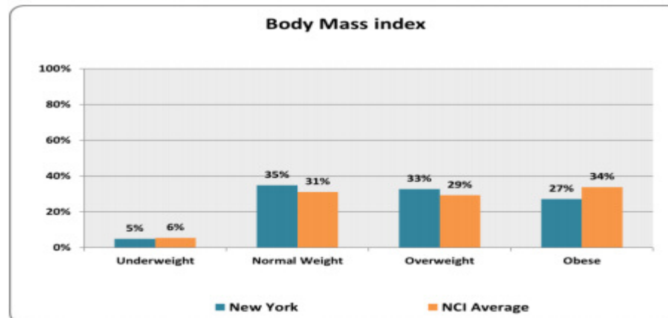
GRAPH 51. VOLUNTEERS



GRAPH 92. ENGAGES IN REGULAR, MODERATE PHYSICAL ACTIVITY



GRAPH 93. BMI (BODY MASS INDEX)



Good Health and its Relationship to a Good Retirement

Normal Aging

- Normal aging or "healthy aging" - describes the natural changes that occur in the absence of any disease.
- Some changes in the ability to think - a normal part of the aging process.
- Healthy older adults experience mild decline in some areas of cognition.
- Changes may occur in visual and verbal memory, visuospatial abilities, immediate memory, or the ability to name objects.

Successful Aging

- Relatively low risk of disease and disease-related disability
- Relatively high mental and physical functioning
- Active engagement with life including close relationships with others and participation in productive activities
- Acceptance of age-determined decrements and doing the best one can with what one has.
- Application of external resources to enlarge an individual's opportunities and facilitate behaviors that make for success in older age

(Baltes & Baltes, 1990; Riley & Riley, 1990; Rowe & Kahn, 1998; Kahn, 2002)

Psychological/Social Issues

- Decreased social contact – friends and family die- person may withdraw
- Resolving conflicts, losses, acceptance,
- Changes in physical appearance may be difficult
- Changes in roles/tasks that people can manage can make them feel they have less to contribute
- Managing leisure time-more "free time"
- Depression more common

Contributors to healthy aging

- Routine medical care is essential in maintaining good health.
- What's good for the heart is good for the brain!
- Extensive social support networks - sharing the aging process with other people who are experiencing the same challenges and joys.
- Good nutrition
- Brain training
- Falls prevention

Contributors to healthy aging

- Stay away from smoking and limit alcohol consumption.
- Maintain a high level of physical activity through exercise. Exercise facilitates the maintenance of muscle flexibility, strength, and mood.

Redesign of Traditional Retirement Options

Day Programming – Senior Center

- Design for aging years
- Different staffing
- Training for staff
- Health support component
- Integration in community programs

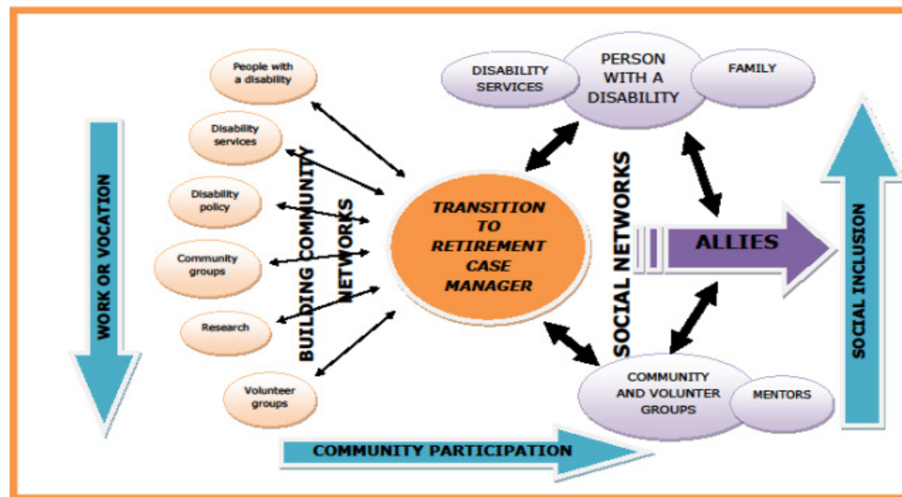
Day Programming – The Environment

- Small group and one-on-one spaces
- Appropriate lighting (reducing shadows) noise abatement, flooring (reducing glare/avoiding patterns) way-finding cues
- Fully accessible with adaptive toilets and a bathroom area (able to deal with toileting accidents)
- Spaces to wander safely inside and out with sitting areas
- Gardens/kitchen/snoezelen area/memory room/pottery kiln/beauty salon/adaptive exercise classes/pool access
- Bus trips/special occasion meals/holiday celebrations

A safe place but not at the expense of supporting continued independence

New Retirement Options

Transitional Person-centered Support Model



Retirement model for People with I/DD

› Theme 1. Selling Retirement

Break down retirement barriers	• Translating the notion of retirement as a positive thing • Giving ideas of what the possibilities are in retirement
Seeking the trust of others	• Establishing strong relationships with people, their families and staff • Exuding confidence that retirement was not setting people up to fail
Selling the Model	• Selling the idea of dropping one day at work • An insurance policy - guaranteed right of return to work • Provide concrete examples of group and activity types

› Theme 2. Breaking Down Barriers

Getting to know local communities	• Knowing what is available in each community • Identifying group dynamics including entry criteria (e.g. age, gender, address) • Getting to know key leaders in seniors community
Becoming a trusted community ally	• Strong existing relationships lead to easier access to groups for people with a disability • Two-way process of give and take • Adapt to different sub-cultures (e.g. Men's Shed, knitting group)
Breaking down disabling barriers	• Help de-mystify "disability" • Work through previous bad experiences with people with disabilities, or disability services • Minimise any perceived "threat" as an advocate for people with disabilities

› Theme 3. Constructing the reality – 5 stages

1. Planning	• Person-centred philosophy • Incorporate transition to retirement into existing planning frameworks
2. Finding	• Locating possible groups of interest • Asking the question – "is this possible"?
3. Building a new routine – 6 months	• Negotiating new routines with family and disability services • Travel, money, changes to work patterns, fitting in with group home rosters • Navigate trial periods
4. Mentors	• Identify potential mentors; recruit mentors • Provide training, encouragement and ongoing support to mentors
5. Ongoing support	• Create ongoing framework to monitor and support person and the group • Develop long-term communication pathways between key stakeholders

Next Steps

- Planning statistics
- Inventory of resources
- Potential partners
- Involvement of people with I/DD and their families and friends
- Special Olympics
- Consumer Education
- Staff training

The Assessment and Care of Adults with Intellectual and Developmental Disabilities and Dementia

Seth M. Keller, MD
sethkeller@aol.com
Past President of the AADMD
Co-Chair NTG
May 18, 2015

The US is getting Older: can you feel it?

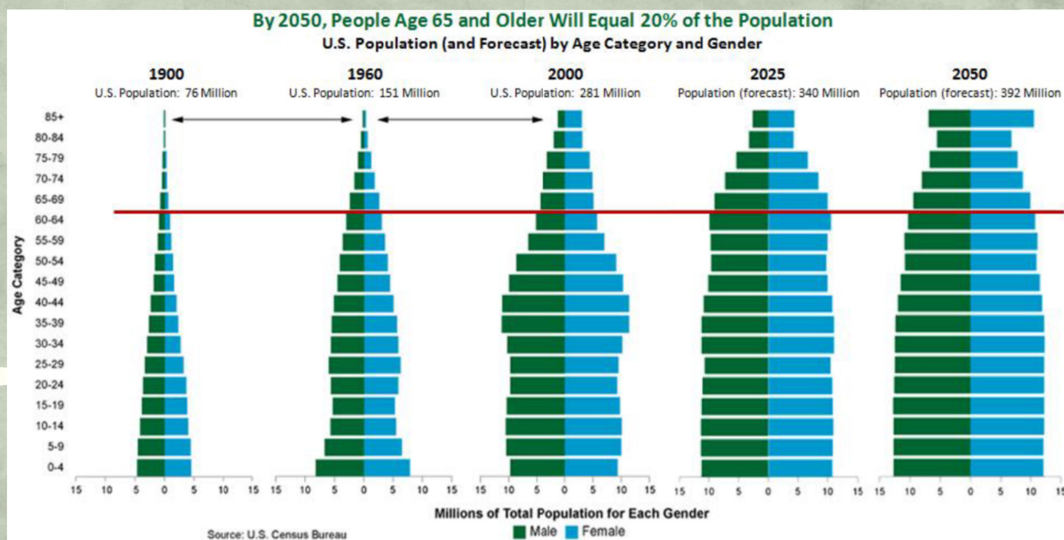
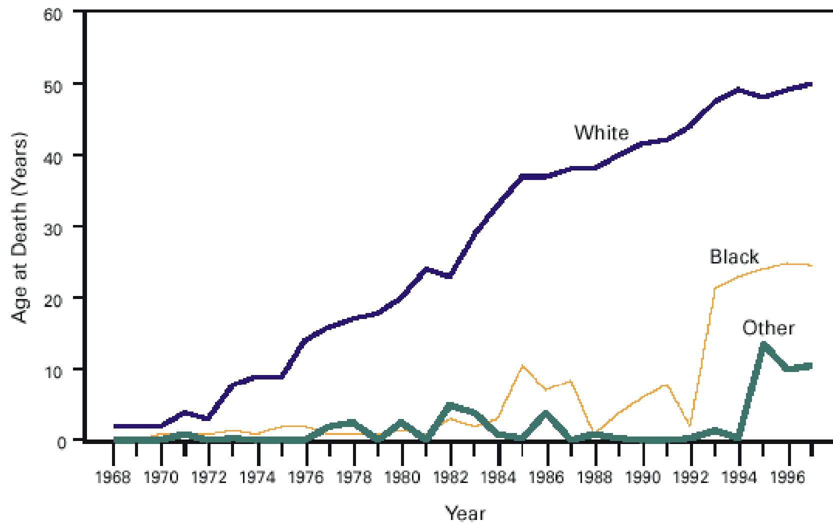
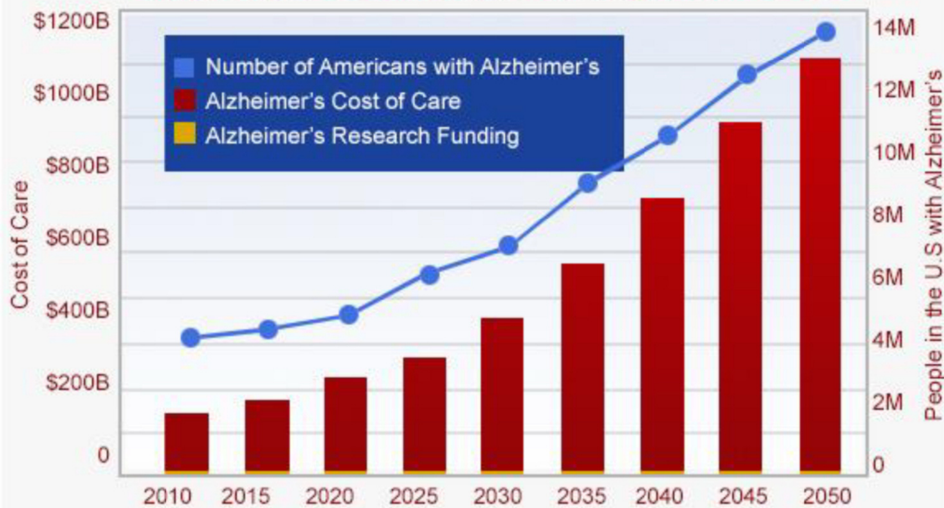


FIGURE 1. Median age at death of persons with Down Syndrome, by race — United States, 1968–1997

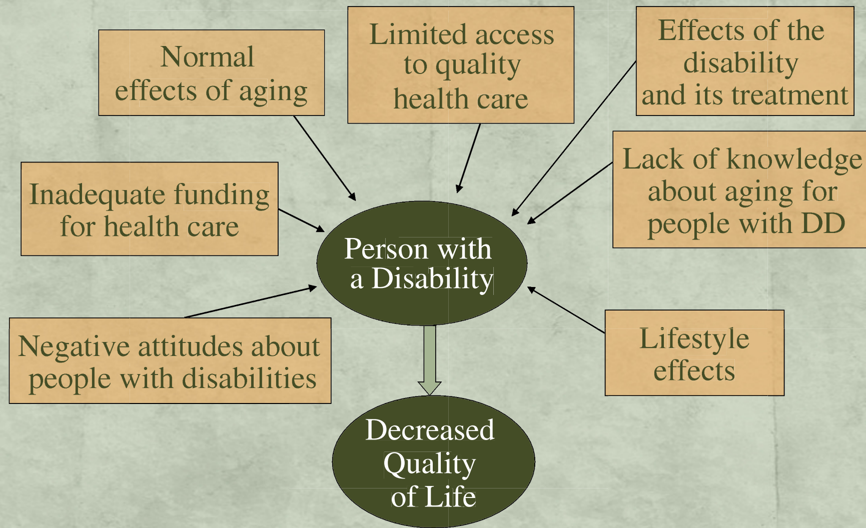


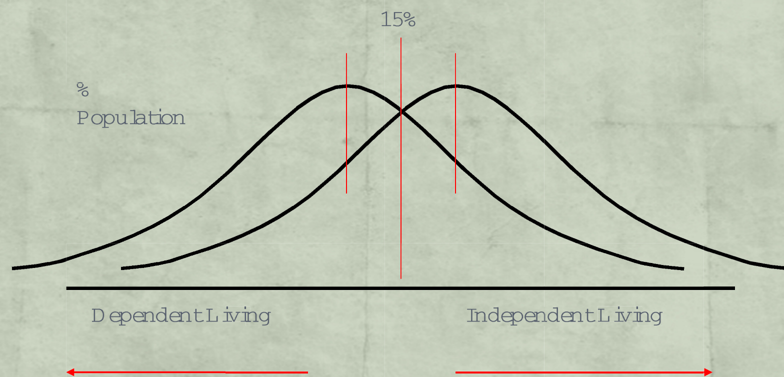
http://thesocietypages.org/socimages/2013/06/10/the-life-expectancy-of-people-with-downs-syndrom/

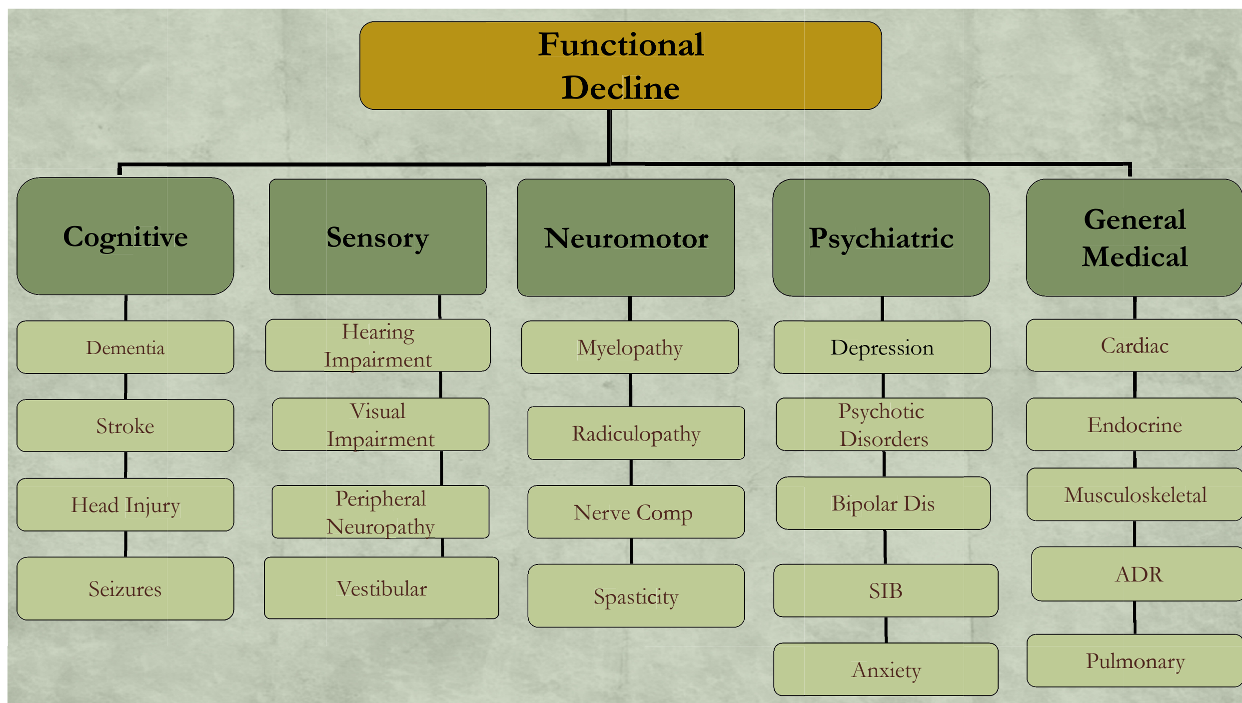
Alzheimer's Cost and Funding 2010 -2050



Source: Alzheimer's Study Group, A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Studt Group (March 2009); Alzheimer's Association, Changing the Trajectory of Alzheimer's Disease: A National Imperative (May 2010); National Institute of Health Office of the Budget website.


Aging With I/DD
Normal effects of aging
Limited access to quality health care
Effects of the disability and its treatment
Lack of knowledge about aging for people with DD
Inadequate funding for health care
Person with a Disability
Negative attitudes about people with disabilities
Lifestyle effects
Decreased Quality of Life


Small Change in Cognitive Capability could have Profound impact on Independence
15%
% Population
Dependent Living
Independent Living



Adverse Drug Reactions

TABLE 1. Common Medication Classes Associated With Possible Worsening of Cognitive Function in Patients With Dementia

Medication class	Examples	Comments
Antihistamines, especially first generation	Diphenhydramine Hydroxyzine Promethazine	Anticholinergic adverse effects, urine retention, confusion, sedation
Bladder agents	Oxybutynin Tolterodine	Anticholinergic adverse effects, urine retention, confusion, sedation
Certain pain medications	Meperidine Propoxyphene	Meperidine: increased risk of seizures with renal impairment
Tricyclic antidepressants	Amitriptyline Clomipramine Doxepin	Risks and benefits of this medication should be guided by a psychiatrist with familiarity with patients with I/DD
Certain antipsychotics	Chlorpromazine Clozapine Pimozide	Atypicals have been associated with increased mortality when used to treat behavioral problems in elderly patients with dementia, but no such studies have been conducted in Down syndrome or I/DD in general
Long-acting benzodiazepines	Clonazepam Temazepam Diazepam	Very sedating; caution for gait impairment, dizziness If a benzodiazepine is required for anxiety, consider short-acting agents (appropriately dosed): alprazolam, lorazepam

I/DD = intellectual and developmental disabilities.

Moran JA, et al "The national task group on intellectual disabilities and dementia practices consensus recommendations for the evaluation and management of dementia in adults With intellectual disabilities" Mayo Clin Proc 2013; 88(8): 831-840.
http://www.medpagetoday.com/TheGuptaGuide/Neurology/41094

Adults with Down Syndrome: Specialty Clinic Perspectives

Chicoine, B., McGuire D., Rubin, S.

Dementia, Aging and Intellectual Disabilities: A Handbook ed. by Janicki and Dalton (Taylor and Francis, 1999)

Diagnosed Disorders for 148 Adults Who Presented with a Decline in Function		
Disorder	Frequency	Percent of Diagnosed Disorders (%)
Mood	76	31
Anxiety	31	13
Obsessive-Compulsive	29	12
Behavior	23	9
Hypothyroid	22	9
Adjustment	12	5
Alzheimer's	11	4
B12 Deficiency	7	3
Menopause	7	3
Attention Deficit/Hyperactive	6	2
Gastrointestinal or Urinary	6	2
Sensory Impairment	6	2
Psychotic	4	2
Other Medical Conditions*	4	2
Cardiac Conditions	3	1
TOTAL	247	100

Benefits of Making Appropriate Diagnosis

- Diagnostic precision
- Potential medication treatment variations
- Developing expectations of residual life years
- Setting up care management plans on expected behavioral presentations and progression
- Communication and interaction variations
- Projecting expectations for change in care needs

Alzheimer's Disease in Down Syndrome

- Women with Down's syndrome are more at risk of developing Alzheimer's disease than men in the 40 to 65 age group
- People with Down's syndrome who develop Alzheimer's disease live, on average, 9-10 years from first symptoms
- Infrequently rapid decline can occur
- Late on-set seizures
- From diagnosis to death is on average 8.2 years
- Excessive production of Beta Amyloid from extra 21st Chromosome

Percentage of people with Down syndrome who develop dementia at different ages:

Age	percentage with clinical signs of dementia
30's	2%
40's	10-15%
50's	33%
60's	50-70%

Source: Neil, M. (2007). Alzheimer's dementia: What you need to know, what you need to do. Understanding intellectual disability and health. Accessed from http://www.intellectualdisability.info/mental-health/alzheimers-dementia-what-you-need-to-know-what-you-need-to-do.

Challenges to diagnosis and care

- Individuals with I/DD may not be able to report signs and symptoms
- Subtle changes may not be observed
- Commonly used dementia assessment tools are not relevant for people with I/DD
- Difficulty of measuring change from previous level of functioning
- Conditions associated with I/DD maybe mistaken for symptoms of dementia
- Diagnostic overshadowing
- Aging parents and siblings
- Lack of research, education, and training

Diagnosis of I/DD and Dementia

- Suspicion that pathologic decline in cognitive function is occurring
- Use of early warning screening and EDSD
- Avoid Diagnostic Overshadowing
- Workup and rule out/rule in accurate diagnosis
- Neurocognitive assessments
- Empiric diagnosis; Possible, Probable, Definite
- Usage of Biomarkers
- Autopsy proven

Early detection/screening

NTG-Early Detection Screen for Dementia' (NTG-EDSD)

- Usable by support staff and caregivers to note presence of key behaviors associated with dementia
- Picks up on health status, ADLs, behavior and function, memory, self-reported problems
- Available in multiple languages
- Use: to provide information to physician or diagnostician on function and to begin the conversation leading to possible assessment/diagnosis

ntg
National Task Group on Intellectual Disabilities and Dementia Practices

NTG-EDSD

v.1/2013.2

The **NTG-Early Detection Screen for Dementia**, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/ screening).

(1) File #: ______ (2) Date: ______

Name of person: (3) First ______ (4) Last: ______

(5) Date of birth: ______ (6) Age: ______

(7) Sex:

	Female
	Male

Instructions:
For each question block, check the item that best applies to the individual or situation.

(8) Best description of level of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

(9) Diagnosed condition (*check all that apply*)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

Current living arrangement of person:
- ☐ Lives alone
- ☐ Lives with spouse or friends
- ☐ Lives with parents or other family members
- ☐ Lives with paid caregiver
- ☐ Lives in community group home, apartment, supervised housing, etc.
- ☐ Lives in senior housing
- ☐ Lives in congregate residential setting
- ☐ Lives in long term care facility
- ☐ Lives in other: ______

http://aadmd.org/ntg/screening

Goals of Care of Dementia

- Maintaining QOL
- Prolonging life
- Prevent functional decline
- Slow progression
- Decrease psychiatric/behavioral problems
- Fall reduction program
- Dysphagia care/Aspiration awareness
- Seizure management
- Reduce hospitalization
- Watch for signs of abuse and neglect
- Caregiver support, what out for provider Burn out
- Cholinesterase Inhibition and Memantine
- Palliative Care
- End of Life Care
- Team approach to care
- ?Future pharmacologic/non-pharmacologic interventions

Progression of Disease;
Anticipatory Guidance

- Cognitive Skills will decline
- Support needs will increase
- Increase risks of falls, injuries
- Swallowing dysfunction, clots, pneumonia, bladder infections
- Seizures
- Watch for signs of abuse and neglect
- Watch for signs of caregiver burn out
- End of life decisions

Expected Outcomes

- Maintain Quality of Life as long as possible
- Prolong Longevity
- Improve and maintain behavior and cognitive function
- Reduction of medications for aberrant behavior
- Aging in Place; prevent or delay institutionalization
- Reduced ED and hospitalizations
- Reduced falls, injuries and fractures
- Training and education of support personnel
- Cost savings

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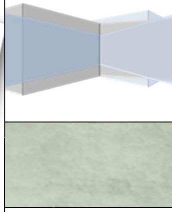
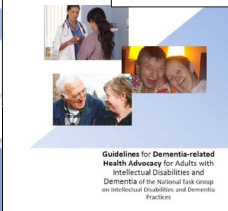
http://aadmd.org/ntg





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Office for People With
Developmental Disabilities

Golisano Retirement Collaborative

Planning Partners Meeting

An Introduction to Self-Direction

June 2nd 2015

2/12/16 2

Aging and People with I/DD

Statewide, 6.6% of the population served by OPWDD are 65 and older, approximately 8,555 people

Within Region 1, the percentage of those served increases to 8.1%.

Roughly, 1 out of 10 individuals we serve are 60 years old or above

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What is Self-Direction?

- Self-Direction is NOT a service/program – it is a WAY in which services are delivered
- Self-Direction = the individual choosing the right mix of supports & services that work best for him/her
  - The "Who" – Staff and/or agency
  - The "What" – Types of supports needed
  - The "When" – hours of the day/week
  - The "Where" – location of service delivery

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What is Self-Direction, Cont.

- The individual and/or designee accepts the responsibility for helping manage (co-manage) his/her supports and services
- Providers develop structures to assist the person in self-directing their services – providers do not "deliver" self-direction

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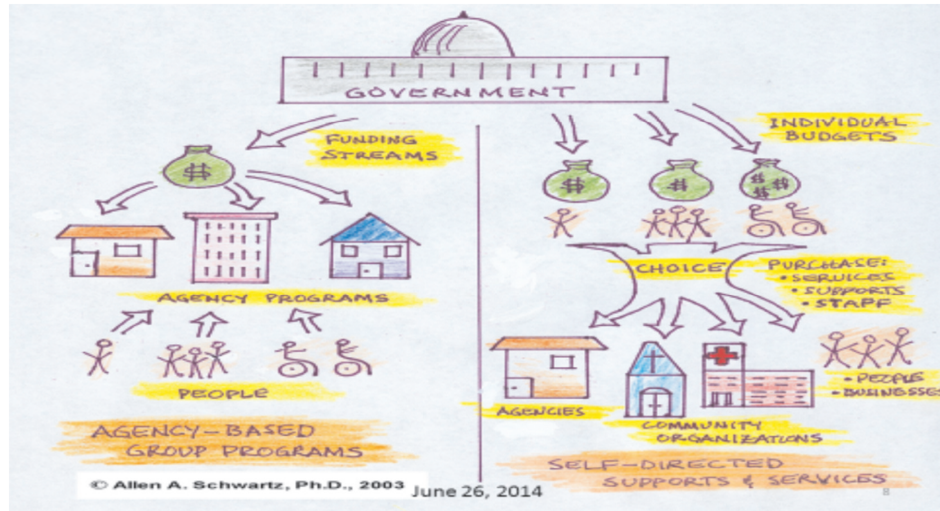
Self-Direction



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The Importance of Self-Direction

- OPWDD is emphasizing the use of Self-Direction because it provides the individual with:
  - ✓ The most control of their supports & service plan development
  - ✓ The ability to drive their person-centered planning process
  - ✓ A clear focus of the ***PERSON*** as opposed to a service delivery model

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The Importance of Self-Direction

- Offers participants:
  - Choice
  - Flexibility
  - The ability to enjoy ***meaningful*** relationships
  - The ability to experience ***personal*** health & growth
  - The option to live in the home/community of their ***choosing***
  - Work, volunteer, participate in activities ***they enjoy***

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Responsibility

When Choosing to self-direct, the individual and/or designee accepts the responsibility to co-manage those supports using:

A. Employer Authority – hiring, scheduling, and supervising the people (staff) who support you & the activities they support on your behalf

B. Budget Authority – exercising fiscally responsible control over their budget and the Medicaid/State funds used to support them

*Note: self-direction may include one or both of these responsibilities

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Types of Self-Directed Plans

There are 3 types of plans, each based on where you live, the supports/services you need, and the types of services you want to self-direct

1) OTR “Other Than Residential”
   - ✓ Available to all individuals

2) Residential Only “Res”
   - ✓ Available only for participants not living in a certified setting

3) BOTH Plan
   - ✓ Available only for participants not living in a certified setting

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Plan Development – Major Players

- The Individual – OPWDD eligible and HCBS Waiver enrolled
- The MSC
- The Regional Office Liaisons
- The Broker
- The Planning Team (aka COS)
- The Fiscal Intermediary

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Steps to Starting the Process

Step 1 - Discussion with those closest to you about the needed supports

- ❑ What supports are needed to achieve your valued outcomes?
- ❑ How much responsibility are you or your designee willing to take on?
- ❑ Health & safety – what is needed to ensure success?

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Getting Started, cont.

Step 2 - Review the services

- ❑ Review with MSC, Planning Team, and/or the Front Door Team what services are needed to meet support needs
- ❑ Based on the services discussed, you may decide to develop a self-directed budget

NOTE: Full Self-Direction (budget & employer authority) may not be a feasible option. However, you can continue to work with your MSC to submit any service requests to the DDRO and update your ISP as needed. The MSC can then help you talk with your current providers about co-managing your services, if wanted.

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Getting Started, cont.

Step 3 - Decision made to self-direct!

- ❑You will need to review your DDP2 with your MSC to ensure accuracy

The DDP2 assists in determining the amount of funding available to you for your service package –

- ❑ aka – PRA or Personal Resource Account

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Getting Started, Cont.

Step 4 – Finding a Broker!

Step 5 – Finding an FI!

- ❑ MSC submits a Request for Service Amendment (RSA) to the DDRO requesting a Broker and FI
- ❑ The DDRO reviews the request & sends out an authorization letter to the participant & MSC with a listing of available Brokers & FI agencies

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Getting Started, Cont.

Step 6 – Securing the chosen Broker & FI

- ❑ Broker Agreement signed between the individual and chosen broker, and the initial “start-up budget” is generated
- ❑ Agreement & Budget are submitted to the DDRO
- ❑ Agreement & Budget are processed through Central Office to secure the funding mechanism
- ❑ Formal notification sent to all parties confirming the Broker can begin working with the individual

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Getting Started, Cont.

Step 7 – Developing the Budget!

- ❑ Scheduling times to meet with your Broker and Planning Team to decide what supports/services need to be included in the Budget
- ❑ During development, you will decide how your PRA is used
- ❑ You will develop/Amend your ISP to incorporate the themes of your SD Plan into your profile, valued outcomes, safeguards, and any required Habilitation Plans
- ❑ Your ISP, SD Budget, and Hab Plans teach staff how to assist you

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Getting Started, cont.

Step 8 – Approval of the SD Budget

- ❑The individual & their Broker submit the final plan to the Self-Direction Liaison at the DDRO
- ❑The Budget & supporting documentation is reviewed for programmatic and fiscal accuracy
- ❑The Budget is submitted to Central Office to secure the funding mechanism
- ❑An Approval Letter is generated by the DDRO & sent to the Individual, MSC, Broker, and FI

Getting Started, cont.

Step 9 – Hiring Staff

- ❑You may have chosen to hire your own staff (employer authority), you will need to recruit and interview candidates
- ❑Once staff is chosen, the FI will need to perform all necessary background checks and other HR functions
- ❑If the staff is hired, you will co-manage/supervise with the assistance of your Broker & Planning Team

Getting Started, cont.

Step 10 – Launching the final product!

- ❑You, your Broker, your MSC, your FI, and Planning Team should meet to review the final Budget, ISP, Hab Plans, etc
- ❑A thorough review of roles, responsibilities, and expectations is conducted to ensure success of the plan

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Office for People With Developmental Disabilities

Self-Direction & Region 1

Growth & Trends following the 10/1/14 Conversion

CMS Transformation Agenda Targets

Target #1 *– Statewide, per CMS quarter, educate 1500 individuals & family members on Self-Direction and the options available*

Target #2 *– Statewide, increase the number of individuals who choose Self-Directed options as their OPWDD support of choice*

Self-Direction Training, defined

Titled "Introduction to Self-Direction," the goal of the training is 3-fold:

- Provide a cursory overview of what it means to self-direct
- Advise of the support choices available under the redesigned methodology
- Guide the audience on navigating the process from initial authorization to successful implementation

* Note – a consistent, statewide training was not established until March 2015
Training now required for all new self-direction participants

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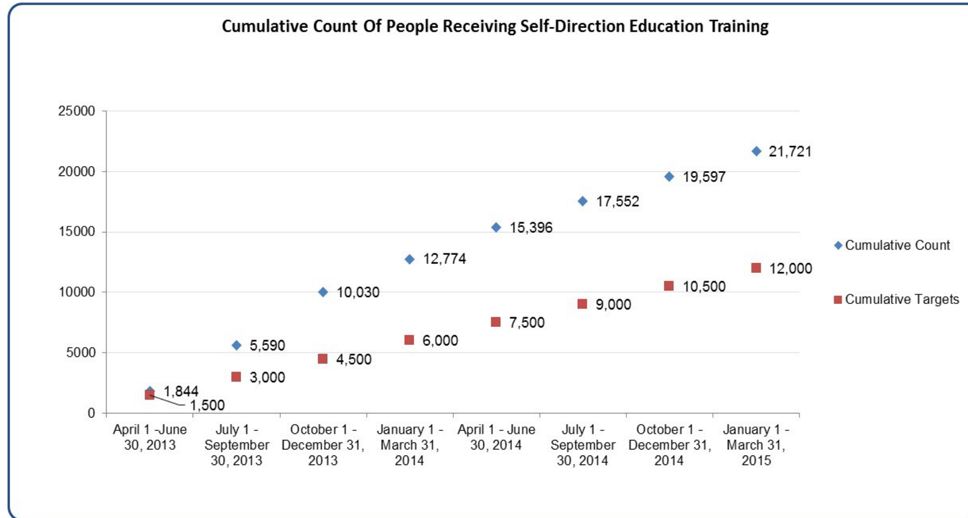
Stakeholder Training & Education



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The CMS "Countable" Self-Directed Service Options

Prior to 10.1.14

There were only 2 services where a new service enrollment "counted" toward the mandated self-direction targets.

Following 10.1.14

The substantial changes to CSS increased the landscape of self-directed opportunities for NYS & offered a flexible continuum of "authority" options for individuals choosing self-direction. "Countable" services increased to 9

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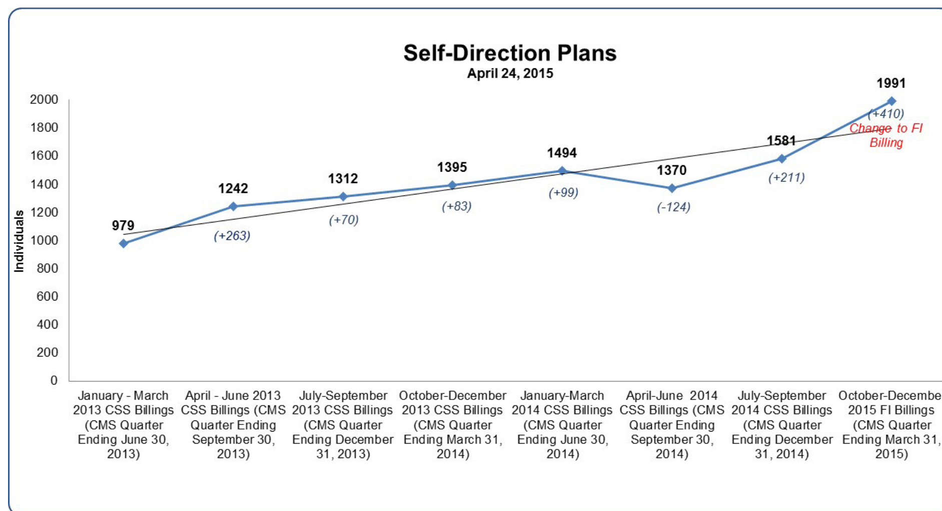
"Countable" services, defined

Service Type	Authority Level	Need FI & Budget	CMS Count
SH CH	Budget & Employer	Yes	1
AS CH	Employer	No	1
SH Respite	Budget & Employer	Yes	1
AS Respite	Employer	No	1
SH SEMP	Budget & Employer	Yes	1
Brokerage	Budget & Employer	Yes	1
IDGS	Budget	Yes	1
Live in Caregiver	Budget & Employer	Yes	1
Fiscal Intermediary	Budget	Yes	1

Key
SH = Self-Directed
AS = Agency Supported
FI = Fiscal Intermediary (former FMS)
PRA = Personal Resource Account as derived from DDP2
Budget = All OPWDD services budgeted within PRA, aka "Plan"
Employer Authority = Choose staff, not pay
Budget Authority = Choose staff, Negotiate pay, PRA threshold

Self-Directed Budgets



Agency Supported CH

Region	Count for CMS Quarter ending 12/31/14	Count for CMS Quarter ending 3/31/15
1	75	176
2	233	170
3	42	54
4	230	125
5	35	13
TOTALS	615	538

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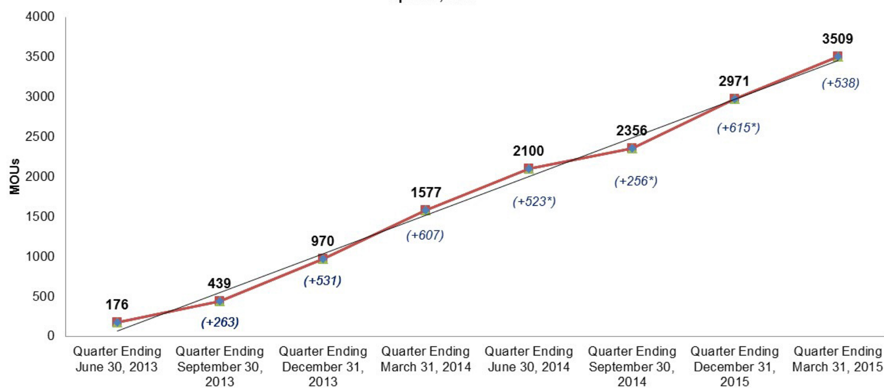

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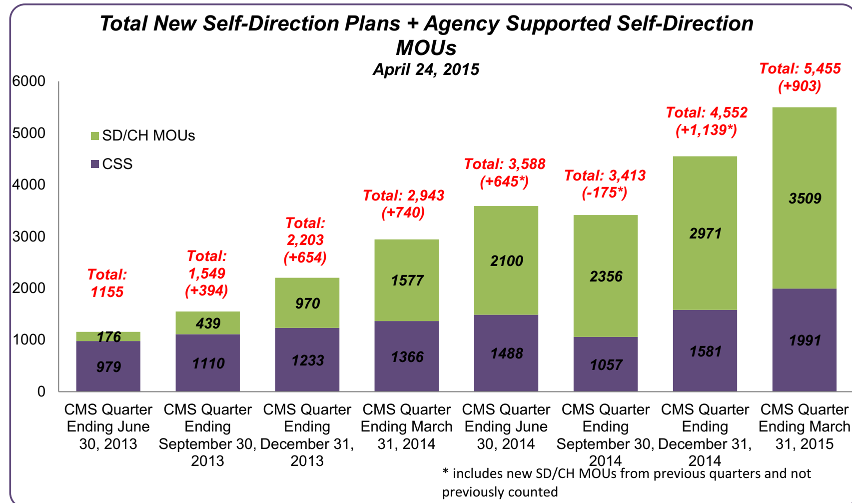
Full Budgets & Agency Supported CH



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Region 1 Growth

How does Region 1* measure up?

– Increased Agency Supported CH by 135%

– Increased the number of Broker/FI Service Authorizations by 130%

– Increased the number of SD Budgets being launched by 40%

– Added 3 Providers to the menu of available FI Agencies

*Numbers represent Finger Lakes

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Present Day Hurdles

- Formal ADM's outlining post conversion policy & practice just released April 2015
- The mindset of MSC's – Family focus groups communicated their MSC's are the ones that deter them from pursuing a self-directed option
- Historical parameters of the former CSS model – confusion, angst, belief that the transition reduced services available

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Present Day Triumphs

✓ Tight collaboration between WNY and FL offices = consistent communication and approaches

✓ Improved community footprint via the Self-Direction Info Sessions = educated awareness & desire to enroll

✓ Enriched partnership with the Front Door, Transition and Service Authorization

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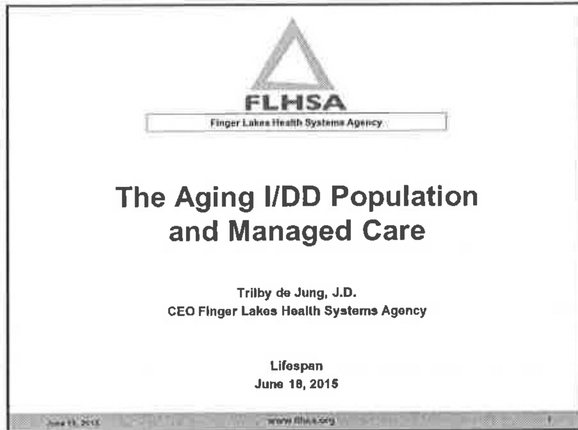

Where We Started: 2013

"People First" Waiver

Goals

- Improving access to services ("No Wrong Door")
- Implementing a Uniform Needs Assessment
- Implementing Care Management and Integrated Care Coordination
- Establishing a Sustainable Fiscal Platform. **The system would move from a fee-for-service to a capitated reimbursement system that pays for integration and coordination of care.**
- Incorporating Robust Community Supports
- Reducing Reliance on Institutional Settings
- Enhancing Quality Assurance

AK1

The Plan for DISCOs

A New Concept

- DISCOs (Developmental Disabilities Individual Support and Care Coordination Organizations) = the core of OPWDD's waiver proposal.
- Essentially a managed care organization – will need Art. 44 licensure – responsible for:
  - developing and maintaining a network of providers,
  - coordinating care of their members,
  - ensuring quality standards are met, and
  - serving as the fiscal intermediary (accepting capitated payments and paying contracted providers).

AK2

DISCO Structuring

Special Competencies

- private or public not-for-profit entities
- care coordination experience
- cultural competence
- regions

DISCO Payments

Capitation

- Partially- or fully-capitated
  - Under either model, eventually the only excluded services remaining in Fee-For-Service would be school supported health, early intervention, and certain residential services (OPWDD ICF/DD-DC/SRU).
  - Need to demonstrate an ability to manage risk.
- Paid for Medicaid services, including care coordination and the person's individualized budget under the self-direction option.
- Risk adjusted rates set by SDOH working with OPWDD.

DISCO Benefit Package

MANDATORY SERVICES INCLUDED IN PARTIAL CAPITATION RATE	MANDATORY SERVICES INCLUDED IN FULL CAPITATION RATE
□ Family and individual support, integration and community habilitation, Flexible goods and services, Home and Community-based clinical and behavioral supports1 □ Adult Day Health Care □ Assisted Living Facility □ Clinic Social Worker □ Day Treatment □ Dentistry □ DME and Hearing AIDS □ Home Care (Nursing, Home Health Aide, PT, OT, SP, Medical Social Services) □ ICF/MR □ Non Emergency Transportation □ Nutrition □ OASAS Inpatient □ OMH Institutional Program (PC/RTF) & private psychiatric hospitalizations □ Optometry/Eyeglasses □ OT, PT, SLP (in any venue) □ Personal Care □ Personal Emergency Response System □ Podiatry □ Psychotherapy □ Respiratory Therapy □ Skilled Nursing Facility □ Specialty Hospital	All services required in partially capitated rate PLUS the following services: o Chronic Renal Dialysis o Emergency Transportation o Inpatient Hospital Services (excluding private LT psychiatric hospitalizations) o Laboratories Services o Outpatient Hospital and Freestanding Clinic Services not identified in partially capitated rate o Pharmacy o Physician Services including services provided in an office setting, a clinic, a facility, or in the home. o Radiology and Radioisotope Services o Rural Health Clinic Services

DISCO Networks

Access & Quality

- State will assess existing plan criteria to determine applicability to the specialized ID/DD plans and develop any new provider access and network adequacy standards that may be necessary Must provide 24/7 access to medical services
- DISCOs will have quality assurance and continuous quality improvement/ performance improvement programs
- While DISCO members are to be afforded access to their current providers even if the providers are not part of a DISCO, that access will be **transitional.**
- Choice of at least two DISCOs in each region (but authority to just offer one)

Original Timeline

- Applications for pilot projects due out soon
- Target implementation date: October

2013

- Evaluations and studies
- Rates finalized in December

2014-2016

- Roll out successful DISCO models to larger geographies in the State beginning in 2014
- Statewide roll-outs to occur 2015 through October 2016

Dual Integration Initiative

- Overview
- OPWDD FIDA: Managed Care model for DD
- Statewide
- January 1, 2014, Target date
- Full duals over the age of 21 currently receiving services through OPWDD and *not* residing in an Office of Mental Health facility.
- Eligible Plans: 1-3 qualifying plans with a history of "high-quality care coordination" for the DD population. Must be an MLTC plan.

Where we are now: 2015

Where we are now: FIDA-IDD

- FIDA-IDD will be launched and enrollment will begin **January 2016** in 4 downstate regions
  - NYC, Westchester, Rockland, LI
- Total eligible population in this region: 10K
- Partners Health Plan will be the single MLTC to participate initially in FIDA-IDD downstate
- Plan design:
  - Medical
  - Behavioral
  - Supportive services
  - Habilitative services
  - Long term supports
  - Social services

Where we are now: DISCOs

- Started receiving applications fall of 2014 (only from NFP provider based DISCOs)
- New official implementation date: Jan. 2016 (but likely fall 2016)
- Transformation Panel convened early 2015
  - Stakeholder representatives
  - Will review state's approach to managed care for the DD population, and recommend changes to State's plan prior to submission to federal government for approval
  - Meetings have reviewed underlying assumptions of DISCO model
  - Commitment to managed care still there
  - Need to align with DSRIP and other reform initiatives

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Where we are now: DISCOs

- Transformation Panel, cont.
  - Look at need to align with DSRIP and other reform initiatives
  - Transformation Panel discussions have involved looking at
    - A model that reduces avoidable hospitalizations (consistent with DSRIP)
    - Having a comprehensive benefit design that maximizes collaboration and integrated care
    - Bundled payments and other value-based reimbursement mechanisms
    - Role of HIT and the needs of the DD system in this regard
    - New approaches to housing needs
    - The role of self-direction
    - Employment challenges

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DISCOs: Where are we going?

- FIDA-IDD likely to impact final DISCO implementation/design based on experience with that product
- FIDA-IDD not likely to replace DISCO because FIDA is a specific federal demonstration program only for duals
- Conceivable that Panel will make changes to align DISCO with DSRIP, value-based payment, and care coordination (including HIT) models
- Delay until fall 2016 at earliest – what happens in the meantime?

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FLHSA

Finger Lakes Health Systems Agency

Finger Lakes Health Systems Agency is the region's health planning center. Through extensive data collection and analysis, the agency identifies community needs, then brings together residents, hospitals, insurers, physicians and other community partners to find solutions. Located in Rochester, FLHSA serves the nine counties of Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne and Yates.

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OPWDD WAIVER AND MEDICAID MANAGED CARE

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June 18, 2015

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Overview of Presentation

- MRT and "Managed Care for All"
- Managed Care in Medicaid
  - Mainstream Managed Care
  - Managed Long-Term Care
- People First Waiver and DISCOs

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What is a *managed care* plan?

- A type of private health insurance plan paid a fixed amount per capita to authorize, pay for and provide all covered services.
- Enrollees must:
  - Follow the plan's rules, including:
    - Choosing a PCP
    - Obtaining referrals to specialists
    - Prior authorizations for services
    - In-network treatment
    - Plan formulary

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MEDICAID MAINSTREAM MANAGED CARE (MMC)

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What does MMC Cover?

- Model Contract, Appendix K
  - Inpatient Hospital Services; Physician Services; Radiology; Drugs (prescription and OTC); Rehabilitation; EPSDT; Home Health; Emergency Services; Vision; Dental; DME; etc.

Almost all services have now been 'carved in' to MMC

- Exceptions:
  - Behavioral health (for SSI-related only); will be carved in starting July 2015 (NYC) and starting July 2016 (rest of state)
  - Non-emergency transportation
  - Nursing home (already carved in downstate; upstate carve-in July 2015)

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Who gets Mainstream Medicaid Managed Care?

- All counties now mandatory
  - Now 3.44 million New Yorkers enrolled.
- EXCLUSIONS/EXEMPTIONS from MMC:
  - All Dual Eligibles.
  - All people with a Spend-down
  - Waiver Enrollees:
    - OPWDD, TBI, NHTD, Care at Home Waiver for Children
  - Individuals with other comprehensive health insurance;
  - Limited Medicaid:
    - Emergency Medicaid, Medicaid Cancer Treatment Program, TB-related services

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MANAGED LONG-TERM CARE (MLTC)

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Two Models for Managed Long-Term Care

- Partial Capitation
  - MLTC Plans
- Full Capitation
  - Program for All-Inclusive Care for the Elderly (PACE), or
  - Medicaid Advantage Plus (MAP)
  - Fully Integrated Duals Advantage (FIDA)
- Availability varies by County
  - http://www.wnylc.com/health/afile/114/371/
  - http://www.health.ny.gov/health_care/managed_care/mltc/mltcplans.htm

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Partially Capitated MLTC Plans

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- Plan provides Medicaid LTC package of services;
- Plan does NOT provide Medicare-covered services.
- Most primary and acute medical care is not in the MLTC service package, so client keeps her regular Medicare card (or Medicare Advantage plan) for all Medicare primary/acute care.

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MAP & PACE

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Plan provides all Medicare and Medicaid services, including Long Term Care services.

- PACE
  - PACE plans provide services through a particular site – a medical clinic or hospital. Because all providers are linked, potentially more opportunity for coordinated care.
- MAP
  - Traditional insurance model. Plan contracts with various providers.
  - CAUTION: Medicaid Advantage Plus (MAP) is not the same as Medicaid Advantage (MA). Both include all Medicare services, but:
    - MA provides Medicaid without LTC
    - MAP provides Medicaid with LTC
- Not everyone eligible for MLTC is eligible for PACE or MAP: Must need Nursing Home level of care.

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MAP & PACE

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MAP & PACE

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Who Must Join MLTC/MAP/PACE?

- Dual eligibles, who are:
  - Living in "mandatory" counties;
  - Age 21 or older; and
  - Receiving or in need of Medicaid Community-Based Long-Term Care services for >120 days in a calendar year
    - CDPAP
    - Certified Home Health Agency services (CHHA)
    - Adult Day Health Care (medical model)
    - Lombardi Waiver (Long-Term Home Health Care)
    - Private-Duty Nursing

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Who does NOT have to join MLTC?

- No Medicare (but MAY enroll if need home care and would otherwise qualify for nursing home care);
- Under 21 (but MAY enroll if over 18);
- Those Excluded from Mandatory MLTC even in mandatory county:
  - In TBI, NHTD or OPWDD ("Care at Home") waiver
  - Have Hospice Care or live in Assisted Living
- Need <120 days Community Based LTC;
- Need ONLY Level I PCS;
- Need ONLY Social Adult Daycare.

*** NOTE: Spend-Down does NOT keep patients out of MLTC as it does for MMC ***

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When will Populations Currently Excluded from MLTC be Carved-In?

Populations	*Planned Carve-in Date*
Nursing Home	7/1/15 for rest of NYS (effective 2/1/15 NYC and 4/1/15 for Long Island and Westchester)
NHTD waiver	1/1/17
TBI waiver	1/1/17
OPWDD waiver	Unclear because of possible changes to model
Assisted Living Program	1/1/16 (or later)

PEOPLE FIRST WAIVER

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People First Waiver

- Two Waivers:
  - OPWDD Waiver Services in Managed Care
  - DISCOs
    - Developmental Disabilities Individual Support and Care Coordination

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Waiver Services in Managed Care

- MMC and MLTC to include DD Services and Supports, including Service Coordination
  - Either provided directly by the plan or by a existing service coordination provider contracted with the plan.
- No scheduled date for inclusion as of today.

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DISCOs

- Modelled on MLTC
- Eligibility
  - All OPWDD Beneficiaries
  - Both Medicaid-Only and Dual Eligibles
- Enrollment
  - Voluntary Initially
  - Mandatory later

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DISCO Services

- Current OPWDD Services
- Long-Term Care Services
  - Personal Care; CDPAS; Adult Daycare; etc.
- OMH Behavioral Health Services
- OASAS Substance Abuse Services
- Acute Care Services may be included at a later date.
- Care Coordination
  - Annual Assessments
  - Interdisciplinary Teams

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Due Process Rights

- For any proposed Reduction, Termination, or Denial:
  - Plan must give advance written notice of change that is *timely* and *adequate*
  - Must describe all available appeal rights, procedures for initiating appeals, and the right to representation
  - Must give "Aid Continuing" if client requests appropriate appeal within ten days of receiving notice OR before the effective date, whichever is later

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Due Process Rights

- Right to request either:
  - Internal Appeal with the Plan
    - Request within 60 days;
    - Decision within 30 days, or 2 business days for expedited appeal;
    - Followed by External Appeal with the Department of Financial Services; or
  - Fair Hearing
    - Must request within 60 days;
    - Aid Continuing, if requested prior to proposed change
    - Decision within 90 days of the hearing request.

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Fair Hearings: Due Process Issues

Notice:

- Timely
  - 10 days prior to proposed action
- Adequate
  - Must describe proposed action
  - Specific reasons for the action Legal basis for the action
  - Right to conference/fair hearing
  - Right to representation.

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DISCO Enrollee Rights

- Timely Access to Care and Services;
- Information in a Manner and Language you Understand;
  - Translation and interpretation free of charge;
- Lead decision-making about your supports and services;
- Develop a Person-centered service plans that meets all of your assessed needs;
- Out-of-network Coverage;
- Complain to NYSDOH and OPWDD;
- Representative to speak for you.

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Questions?

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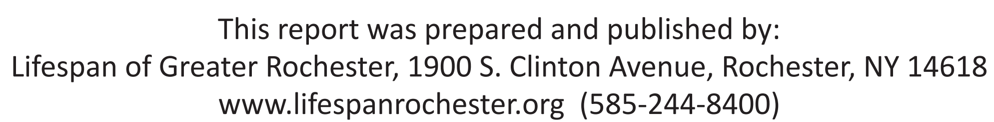
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