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HELP Committee Report Says States Have Failed to Fulfill Olmstead Mandate

The U.S. Senate Health, Education, Labor, and Pensions (HELP) Committee has released a report taking states to task for "failing' to fulfill the Americans with Disabilities Act (ADA) community living mandate as expressed in the Olmstead case. The report provides an overview of the states' "ongoing struggle to fulfill the community living promise of the ADA and Olmstead." While the HELP Committee acknowledges " a fundamental rebalancing of spending" on individuals with disabilities in institutions as compared to HCBS, the report suggests that "these numbers fail to paint a complete picture," pointing out that only 12 states spent more than 50 percent of Medicaid long-term supports and services (LTSS) dollars on home and community-based services (HCBS) by 2010 and that the population of individuals with disabilities under 65 in nursing homes actually increased between 2008 and 2012 despite 38 studies over the past seven years that have "clearly demonstrated that providing

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CMS Releases Model Streamlined Application for Exchanges, Medicaid

The Centers for Medicare & Medicaid Services (CMS) recently released the model single, streamlined application to determine eligibility for enrollment into Qualified Health Plans (QHPs) and for insurance affordability programs including advance payments of the premium tax credit (APTCs), cost-sharing reductions (CSRs), Medicaid, and the Children's Health Insurance Program (CHIP).

Beginning on October 1, 2013, as mandated by the Affordable Care Act (ACA), the new Health Insurance Marketplace, also known as the Affordable Insurance Exchange, and state Medicaid and CHIP agencies must use a single, streamlined application for determining eligibility. States may choose to use the model application, or may develop an

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2012 Report of the President's Committee for People with Intellectual Disabilities

The 2012 report of the President's Committee for People with Intellectual Disabilities (PCPID) has been transmitted to the White House. The report provides recommendations regarding managed long-term services and supports (MLTSS) for individuals with intellectual and developmental disabilities.

The purpose of the PCPID 2012 report to the president is to:

- Provide background on MLTSS to assist the intellectual and developmental disability community with understanding the changes occurring and ways to influence outcomes.
- Provide recommendations to the president and the secretary of the Department of Health and Human Services for consideration and possible action.

The report contains 15 recommendations in the following areas:

- Disability stakeholder engagement
- Choice and self-determination
- Consumer protections and rights
- Quality measurement, data collection, and research

It also recommends that states and the federal government engage disability stakeholders in the design, implementation, and oversight of MLTSS program to ensure consumer protections.

FMI The report is available at www.acl.gov/NewsRoom/Publications/docs/PCPID_FullReport2012.pdf and a summary at www.acl.gov/NewsRoom/Publications/docs/PCPID_AccessibleSummary2012.pdf.

NASDDDS

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EDITORIAL

Why the Companionship Rule May End Shared Living/Adult Foster Care and Payment to Family Caregivers

By
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Executive Director
NASDDDS

In December of 2011, the U.S. Labor Department (DOL) proposed regulations that will dramatically limit the companionship exemption to the wage and hour requirements of the Fair Labor Standards Act. Most significantly, the rules would make the exemption inapplicable to persons employed by third-party employers, who would instead be entitled to be paid not less than the federal minimum wage and overtime standards for all hours they are considered to be working. NASDDDS has provided comments to DOL addressing how the new rule will impact service systems for people with intellectual and developmental disabilities. We have met with numerous federal agencies, from the National Council on Disability to the Office of Management and Budget to Labor Secretary Tom Perez himself. Throughout, we have raised the concern that the rules will put at risk our members' ability to continue important service arrangements, including Shared Living and payment to family caregivers, that do not involve a conventional "employer-employee" relationship and that play a crucial part in state's efforts to fulfill the Olmstead mandate and its expression of the rights of people with disabilities to live and receive services in the most integrated setting possible. We now understand that publication of a final rule is imminent and states must be prepared for the likely outcomes of implementation.

Many people with intellectual and developmental disabilities (I/DD), particularly those with developmental disabilities, cannot live independently and need more than intermittent supports. Even though they may have considerable conversational skills or hold a part time job, the need for assistance with executive functions and self-care require that they be in the presence of someone who can step in to guide and support them promptly.

Groups homes developed for people leaving institutions in the 1970s have proliferated for people with I/DD up until the last decade. Group homes have become costly and are too often not really "home." Shift work, a growing shortage of direct care workers as the demand in long-term care systems grows, and group home regulations have led to regimented routines and sometimes impersonal care and as a result, dissatisfaction among self-advocates and families. Some group homes may be physically located in the community but are operated in such a manner that people are still segregated from community relationships and activities in ways that may challenge the Olmstead definitions of integration.

This dissatisfaction with group homes coupled with the inability of states to finance the expansion of group homes to keep up with the demands of the waiting lists have compelled states to develop other support options — ones that build on personal relationships. These options enable people with disabilities to live a typical life in their community, in relationship with people they know and know them. The activities and supports are individualized to their personal situation and are focused on their personal outcomes — and these options are less costly than group homes. The people providing support care about them outside the paid relationship.

Two common forms of "relationship based options" are Shared Living and Paying Family Caregivers the person lives with.

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Shared Living

Shared Living is a situation in which the person with I/DD is invited into a family home, similar to the child foster care system. The primary difference between child foster care and Shared Living is that the Shared Living sponsoring agencies work to match the person with a disability and the people they will live with and there is an expectation that the relationship and arrangement will be long term. And indeed, many are — lasting more than a decade. Shared Living can be with a young couple or a retired couple, a family, a widow or widower, or a college student. Like child foster care, the life of the person with a disability is completely integrated with the life of the people they live with. They eat together, everyone cleans the house, they go shopping together, they celebrate birthdays, holidays are full of rituals, and they share social networks. Care is integrated into life's routines. The caregiver might fold the family's laundry while overseeing the person with a disability as they do their physical therapy exercises, or assist the person eating at the dinner table while eating with the whole family. It is not clear that one person provides assistance — the oldest son in the family might go to the store with the person; the husband might help the person take a bath but the wife might help make lunch.

Supports for the caregivers include training, a supervising coordinator to offer advice and assistance, a fixed number of respite care days and if the person's needs are significant, there may also be additional support people. If working age, the person may have a job coach.

Payment is typically a flat monthly rate to the designated caregiver. The amounts can range from $1500 per month ($18,000 annually) to $3200 per month ($38,400 annually) depending on the needs of the person. A number of states make use of section 131 of the Internal Revenue Code that permits certain provider reimbursements, called "difficult of care" payments, to be exempt from taxation. The costs of the supervising agency, training for the caregivers, respite care, and other services are in addition to the payment to the Shared Living provider.

The caregivers may have an outside job or may not. But they get compensation for incorporating the person into their family's life and routines. They don't keep time cards and in fact, that activity would be contrary to the experience. The support is merged into life's routines.

Most states have a model of Shared Living or Adult Foster Care in place in both disability and aging service systems. The state of Vermont, which has virtually no group homes in their DD system, used the Shared Living model called Developmental Homes to close their only institution.

Providers of Shared Living do not think they are using the companionship exemption to the wage and hour requirements in the Fair Labor Standards Act (FLSA) because the relationships and payments are so foreign to the wage and hour model. But the rule promulgated by the Department of Labor (DOL) and currently under consideration by the Office of Management and Budget (OMB) that would restrict the application of the companionship exemption will apply to these providers and fundamentally impact their ability to provide these types of service arrangements.

After the regulation is in effect, Shared Living and Adult Foster Care sponsoring agencies will evaluate their capacity to comply with the regulation. As "third-party employers," they will realize that at any time, an individual providing Shared Living or other similar supports can claim that the rule applies and that they should be paid for all hours up to 24 hours they are overseeing the person. Shared Living agencies cannot recoup the cost of back wages from any payer including Medicaid. The back wages are the agencies' liability. Realizing their financial liability with this model of service and their inability to defend

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against a back wage claim, they will have to determine whether they can continue to provide Shared Living services within the existing payment rate. Why not just pay caregivers all the hours they are supporting the person? The cost of supporting each person with 24-hour paid supports will, at minimum wage rates for multiple employees in order to avoid overtime, cost $75,000 per year (8736 hours x $7.25 = $63,000 + $12,000 for benefits) without factoring in the additional costs of supervision, training, respite services. This cost quickly surpasses the cost of a 24-hour staffed group home.

The only potential solution is to revise the program to make Shared Living a contracted service. This arrangement may avoid the impact of the companionship rule (although that is not certain) and provides full flexibility to the Shared Living provider. However, a direct contract eliminates the role of the sponsoring agency which recruits, trains, supervises and supports the Shared Living provider, arranges respite services and is responsible for emergencies and for arranging for a transition should the Shared Living provider discontinue providing services.

Paying Family Caregivers

Almost every state currently makes payments to family members that the person with a disability lives with. Initially employed in rural areas and for people with extraordinary health needs, the practice has expanded to all situations for both children and adults in almost all states.

Payments to family caregivers have enabled family members to stay at home rather than go out to work and therefore enabled them to provide support to their family member. In almost all states, these arrangements occur within an individual budget limit and within guidelines that often limit the number of family members that can be paid and the number of hours they may be paid. These restrictions are to ensure that the person receiving support is not overly dependent on paid family members and has the opportunity to receive supports from people outside the family and also to control costs.

If DOL's new rule applies to family caregivers, any family caregiver who receives their compensation through a provider agency, rather than directly from the family member they support, will need to be paid minimum wage and overtime for every hour they might possibly be called upon to support their family member. If DOL maintains what we understand to be their current understanding of "third party employer," this would even include family members who receive their paychecks through a fiscal intermediary, and may very possibly include any family member whose income is provided or reimbursed through Medicaid.

For purposes of evaluating the impact of the DOL's new Companionship Exemption Rule on individuals, the situation with paid family caregivers is somewhat different than Shared Living Providers. Since the person has been living with the family prior to a family member being paid, when the state terminates the practice of paying family caregivers to avoid claims for 24-hour payment and over time, the person will continue to live with the family. In place of paying family members, the state may pay outside caregivers to provide service in the home. When the worker's shift is over, they will leave the home, avoiding claims that they have worked additional hours beyond those scheduled.

An additional option is to engage families as independent contractors. As with Shared Living, this arrangement provides flexibility to the family caregiver but eliminates the fiscal intermediary and oversight agency. Given the recent investigations by the Office of Inspector General into fraud in personal care services, a state would be advised to develop some mechanism for assuring that services contracted for are provided.

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A Different Paradigm of Support

Clearly, Shared Living and Paying Family Caregivers are both practices that add much value to our system for supporting individuals with developmental disabilities. These practices have played a key role in our efforts toward satisfying the mandate of Olmstead and fulfilling our responsibility to respect and honor the rights of people with disabilities to live and receive settings in the most integrated setting possible. But, as important as this consideration is, the argument for making sure the broadening of wage and hour protections for direct support workers does not lead to the end of Shared Living and paid family caregivers does not end there. NASDDDS has argued that these arrangements should be exempt from the new rule because they are fundamentally different from the types of employer/employee relationships DOL is seeking to effect. The arrangements differ in that:

1. No one is being denied a fair wage. Shared Living caregivers and family caregivers are providing supports in their own home, are not required to reserve their time exclusively for the person they are supporting, are doing tasks that benefit everyone in the household at the same time they are providing care, and their care giving responsibilities are often shared with others in the household. There is a level of convenience for the caregiver that distinguishes these relationships from a formal employer-employee relationship.

2. They are founded on personal relationships and commitment which provide the richness of family and community, a typical life rather than a "group home" life, and opportunities for "belonging." People with disabilities are part of a relationship and as such experience reciprocity — they give as well as receive which allows for the opportunity to experience dignity. This experience suffers from shoehorning these relationships into an employer-employee paradigm.

3. They represent a different way of thinking about support: it integrates natural supports and the need for financial assistance to sustain those natural supports. The arrangement is advantageous for both the person with a disability and the caregivers.

4. The impending long-term care crisis demands that we find less costly models to provide services to people needing care. Without services, families are the fall back. While families are committed, they do not have unlimited reserves to provide care and will give up, resulting in the need for facility-based care for the person. By supporting families and Shared Living caregivers financially, but within some reasonable bounds, everyone wins: the person continues to live in the community with people he/she has relationships with; the families maintain their care giving role and receive an income that enables them to remain at home in that role; and public funds will support more people.

Without the ability to continue to use public funds to support people who care about and for a person with a disability or who is older, who provide support because they value the relationship but need reimbursement to sustain their ability to support the person, congregate care may ironically become the only affordable option.

Responding to this editorial, a DOL spokesperson said, "We are not in a position to comment right now because we are in the rulemaking process. As you may know, after the public comment period for a proposed rule is closed, the department analyzes the input it has received and may make changes to the rule before it is issued as final. We take all of the comments we receive very seriously, including those

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we received that raised concerns about the issues your editorial addresses. Because this process is ongoing, it is premature to make any assumptions about the impact of the final rule. WHD [Wage and Hour Division] will of course work with stakeholders such as your organization to answer questions about the impact of the rule and provide compliance assistance once the final rule has been published."

FMI The Notice of Proposed Rulemaking promulgating the regulation can be found at webapps.dol.gov/FederalRegister/HtmlDisplay.aspx?DocId=25639&Month=12&Year=2011. NASDDDS' comments on the NPRM are available at www.nasddds.org/pdf/CompanionshipExemptionComments.pdf.

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HCBS is more cost-effective than providing services in an institution."

Section 1 of the report includes information on terminology used throughout the report, background on HCBS generally, and a description of the Olmstead decision and its subsequent impact on federal and state activities. Section 2 explores states' experiences with federal HCBS tools. Section 3 provides information on the states' spending on institutions, HCBS, and the populations served by HCBS. Section 4 analyzes the states' progress in moving individuals with disabilities into the community. Section 5 discusses the states' Olmstead planning efforts and suggestions for effective Olmstead implementation. Finally, section 6 sets forth the committee's recommendations for moving forward.

Committee Chairman Tom Harkin (D-IA) "generally found that many state leaders and Medicaid directors are working hard to provide more HCBS in an era of rising costs and growing populations." However, the report argues that "most states continue to approach community living as a social welfare issue and not as a civil rights issue," contending that "state leadership appears not to view the provision of HCBS as a means to guarantee that individuals with disabilities are able to exercise their civil rights as citizens by receiving supports that allow them to make their own decisions and fully participate in the life of their communities." The report also points out "a continued focus on providing care in settings that are 'less institutional' but also are not the most integrated setting." The committee acknowledges difficulty assessing states' progress "because of a lack of consistent classification, tracking, and reporting of both eligible populations and populations served." HCBS, the committee says, "are fragmented between states and within states, and coverage for certain individuals with disabilities lags behind others."

The report urges state leaders to "approach Olmstead implementation efforts by first focusing on the concept of the most integrated setting, and then setting reasonable timeframes and measurable goals to ensure that all individuals with disabilities are offered the most integrated setting." While many of the states have "laudable paper plans," the committee writes, "they lack enforceable benchmarks and targets directed at consistently transitioning people with all types of disabilities out of institutional settings and into living situations that allow individuals to exercise the autonomy and the rights guaranteed by the Constitution and the ADA in a way that is cost-effective for that state."

Following a hearing last year before the HELP Committee to assess the progress that had been made to implement the Olmstead decision, Chairman Harkin sent letters to the governors of all 50 states requesting information on HCBS, to "clarify whether states are ensuring that all populations of individuals with disabilities have the opportunity to live independently, while also providing the necessary services and supports in a cost-effective manner." The chairman asked for six specific sets of information about different aspects of the Olmstead initiative:

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1. For each year from fiscal year 2008 to present: the number of people who moved from nursing homes, intermediate care facilities (ICFs) for individuals with intellectual or developmental disabilities, long-term care units of psychiatric hospitals, and board and care homes (often called adult care homes or residential health care facilities), to living in their own home, including through a supportive housing program.
2. The amount of state dollars that will be spent in the current fiscal year serving individuals with disabilities in each of these settings: nursing homes, ICFs for individuals with intellectual or developmental disabilities, board and care homes, psychiatric hospitals, group homes, and their own homes, including through a supportive housing program.
3. For each year from fiscal year 2008 to present, the extent to which the state has expanded its capacity to serve individuals with disabilities in their own homes, including through a supportive housing program, along with the amount of state dollars spent on the expansion (which may include reallocated money previously spent on segregated settings) and the specific nature of the capacity added.
4. The contents of each state's Olmstead plan for increasing community integration.
5. Any policy recommendations for measures that would make it easier for the state to implement Olmstead's integration mandate effectively and take advantage of new available federal assistance.
6. Any successful strategies that the state has employed to implement Olmstead effectively, particularly strategies that could be replicated by another state or on a national scale.

The chairman received substantive responses from 31 states, and letters from two declining to provide a substantive response due to pending litigation related to the Olmstead decision. Committee staff held follow-up discussions with 11 states selected based on geographic diversity, number and types of programs used, spending on programs, length of time in programs, and population in programs. The follow-up discussions included requests for additional information about spending, as well as broad questions related to the cost-effectiveness of various HCBS programs. Committee staff also reviewed existing reports on state spending on HCBS and consulted with stakeholders involved in Olmstead advocacy and implementation.

State and federal efforts, the committee says, should focus on helping people live in their own homes. Virtually all people with disabilities, the report states plainly, "can live in their own apartment or house with adequate supports. Accordingly, for virtually all people with disabilities, the most appropriate integrated setting is their own home." The report calls for Congress to amend the ADA to clarify and strengthen the law's integration mandate in a manner that accelerates Olmstead implementation and clarifies that every individual who is eligible for LTSS under Medicaid has a federally protected right to a real choice in how they receive services and supports. Further, according to the report, Congress should amend the Medicaid statute to end the institutional bias in the Medicaid program by making HCBS a mandatory service, and require "clear and uniform" annual reporting of the number of individuals served in the community and in institutions, together with the number of individuals transitioned and the type of HCBS living situation into which they are transitioned.

The committee calls on states to "more fully examine the enhanced federal funding available under new federal programs designed to encourage states to transition more individuals into community-based settings and shift away from waivers, which allow states to set caps on the number of individuals served." The Centers for Medicare & Medicaid Services (CMS) should finalize its proposed rule defining what type of setting qualifies as home and community-based, and should require incremental state

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spending goals for national Medicaid LTSS for 2015, 2020, and 2025 to ensure that the proportion of spending on HCBS continues to increase, according to the report, and Congress should increase the federal share of Medicaid expenditures for states that achieve these benchmarks and reduce the federal share for states that do not. The Department of Justice (DOJ) should expand its Olmstead enforcement efforts, to include investigations of segregated employment settings for individuals with disabilities and the inappropriate placement of young people with disabilities in nursing homes, according to the report.

The HELP Committee calls for CMS, the Administration on Community Living (ACL) at the Department of Health and Human Services (HHS), the Office for Civil Rights (OCR) at HHS, the Department of Housing and Urban Development (HUD), the Civil Rights Division at the Department of Justice (DOJ), the National Council on Disability (NCD), and the National Institute on Disability and Rehabilitation Research (NIDRR) to create "a high-level interagency task force within six months of the issuance of this report…and should deliver a consistent message to states about their Olmstead obligations and the federally created tools that can help them comply with the decision." The task force should review and comment on proposed federal regulations and proposed sub-regulatory guidance that have the potential to impact Olmstead implementation, and collaborate with the National Governors Association (NGA) and other appropriate entities to create a technical assistance program for states that helps them to develop and implement Olmstead plans. ACL and HUD should collaborate to develop and implement a national action plan to expand access to affordable, integrated, accessible, and "scattered site" housing for people with significant disabilities, consistent with the Olmstead decision.

FMI The report is available at www.harkin.senate.gov/documents/pdf/OlmsteadReport.pdf.

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"alternative" application that is approved by CMS. For states in which there is a federally facilitated marketplace, the state's Medicaid/CHIP agency must accept the model form and may, in addition, develop an alternative application approved by CMS.

Section 1413 of the ACA directs the Secretary of Health and Human Services (HHS) to develop and provide to each state a single, streamlined form that applicants may use to apply for coverage in QHPs and insurance affordability programs, including APTCs, CSRs, Medicaid, and CHIP. Individuals must be able to submit the application online, by mail, over the telephone or in person and the application may be submitted to a marketplace, state Medicaid agency, or to a CHIP agency. The application must be structured to maximize an applicant's ability to complete the form satisfactorily, taking into account the characteristics of individuals who may qualify for the programs by developing materials at appropriate literacy levels and ensuring accessibility. A state may develop and use its own single, streamlined application if approved by the secretary.

The marketplace will begin accepting applications for coverage on October 1, 2013, for coverage that starts on January 1, 2014. This initial open enrollment period extends to March 31, 2014, but the marketplace will also accept applications and make eligibility determinations (including a determination as to whether an individual qualifies for a special enrollment period) throughout the course of the year. Medicaid and CHIP agencies must also make available the single streamlined application as of October 1, 2013, in addition to their applications already in use for those who want to apply for coverage effective before January 1, 2014.

Individuals whose eligibility is established by their participation in the Supplemental Security Income (SSI) program will not be affected by this change. However, individuals whose income exceeds SSI

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eligibility but who participate in Medicaid through a special eligibility program (e.g., Medicaid Buy-In), and those individuals living in the nine "209(b)" states that do not tie Medicaid eligibility to SSI eligibility, will now use the new application for eligibility redeterminations. To the extent that the model application, and any alternative application, does not clearly ask questions about whether a person has a disability in order to determine whether they should be eligible for Medicaid on the basis of that disability, Medicaid applicants with disabilities in states that are taking advantage of the opportunity in the ACA to expand their Medicaid programs run the risk of being assessed on the basis of their modified adjusted gross income (MAGI) and enrolled in the Medicaid expansion plan. These plans must be benchmarked against major health insurance plans in the state and are unlikely to have a robust long-term services and supports (LTSS) component. Therefore, working LTSS recipients, as well as those living in 209(b) states, run the risk of being mis-enrolled and losing access to crucial supports.

FMI To view the application, go to www.cms.gov/CCIIO/Resources/Forms-Reports-and-Other-Resources/Downloads/AttachmentB_042913.pdf.

DSM-5 Updates Autism, MR Definitions

The American Psychiatric Association (APA) has released the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) at its annual meeting beginning Saturday in San Francisco. The new version marks the first major update since 1994. The DSM-5 contains much-discussed changes to the definition of autism, as well as less controversial changes to the diagnosis formerly known as "mental retardation," now known as "intellectual disability."

The DSM-5 eliminates the diagnosis of Asperger's syndrome and instead folds it, along with childhood disintegrative disorder and pervasive developmental disorder, not otherwise specified, into the broader category of "autism spectrum disorder," with clinicians indicating a level of severity. Individuals will have to meet a more specific set of criteria to obtain the new diagnosis. In response to concerns that some with the developmental disorder could lose the label entirely and, with it, needed services, the new DSM includes a note specifying that "individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder."

The new manual also includes a change to its listing for "mental retardation," replacing the term with the more commonly accepted "intellectual disability." Additionally, plans called for the diagnosis to be adjusted to put less emphasis on IQ score and allow more consideration for clinical assessment, with the severity of impairment based on adaptive functioning rather than IQ test scores alone. By removing IQ test scores from the diagnostic criteria, but still including them in the text description of intellectual disability, DSM-5 seeks to "ensure that they are not overemphasized as the defining factor of a person's overall ability, without adequately considering functioning levels." The authors of the DSM-5 note that IQ or similar standardized test scores should still be included in an individual's assessment. In DSM-5, intellectual disability is considered to be approximately two standard deviations or more below the population, which equals an IQ score of about 70 or below.

FMI More information on the DSM-5 can be accessed online at www.dsm5.org. A fact sheet describing the new intellectual disability diagnosis can be found at www.dsm5.org/Documents/IntellectualDisabilityFactSheet.pdf.

NIDRR Announces Research Priorities on Community Living, Employment

The National Institute on Disability and Rehabilitation Research (NIDRR) has announced new research priorities for the Disability and Rehabilitation Research Projects (DRRP) and Centers Program. The new priorities include Community Living and Participation of Individuals with Disabilities (Priority 1), Health and Function of Individuals with Disabilities (Priority 2), and Employment of Individuals with Disabilities (Priority 3). The Assistant Secretary for the Office of Special Education and Rehabilitative Services (OSERS) may use these priorities for competitions in fiscal year (FY) 2013 and later years, either to limit grantees to focusing only on the priority or to award extra points to grant applications that will focus on the particular priority. Essentially, the priorities are a way for NIDRR to express its research funding goals. The priorities are effective June 6, 2013.

The first new priority DRRPs is on Community Living and Participation of Individuals with Disabilities. To meet this priority, a DRRP must contribute to the outcome of maximizing the community living and participation outcomes of individuals with disabilities by conducting either research activities or development activities in one or more of the following areas, focusing on individuals with disabilities as a group or on individuals in specific disability or demographic subpopulations of individuals with disabilities:

i. Technology to improve community living and participation outcomes for individuals with disabilities.

ii. Individual and environmental factors associated with improved community living and participation outcomes for individuals with disabilities.

iii. Interventions that contribute to improved community living and participation outcomes for individuals with disabilities.

iv. Effects of government policies and programs on community living and participation outcomes for individuals with disabilities.

v. Practices and policies that contribute to improved community living and participation outcomes for transition-aged youth with disabilities.

The DRRP must also conduct knowledge translation activities (i.e., training, technical assistance, utilization, dissemination) in order to facilitate stakeholder (e.g., individuals with disabilities, employers, policymakers, practitioners) use of the interventions, programs, technologies, or products that result from the research or development activities conducted under this priority, and involve key stakeholder groups in the activities "in order to maximize the relevance and usability of the research or development products to be developed under this priority."

The priorities on Health and Function of Individuals with Disabilities and Employment of Individuals with Disabilities carry the exact same requirements regarding areas of research, knowledge translation activities, and stakeholder involvement.

FMI The new priorities were announced in the *Federal Register* at www.gpo.gov/fdsys/pkg/FR-2013-05-07/html/2013-10829.htm.

GAO Offers Alternative Methods for Calculating FMAP

The Government Accountability Office (GAO) has issued a report discussing alternative methods for determining Federal Medical Assistance Percentage (FMAP) rates for states. Prior GAO work has expressed concerns about the FMAP, noting that per capita income (PCI) "does not accurately represent states' populations in need of Medicaid services or states' ability to finance services, and does not account for geographic cost differences among states." In its analysis, GAO considered whether available data sources could be used to develop measures to more equitably allocate Medicaid funding. GAO reviewed its prior reports and other studies, examined data sources produced by federal agencies, and illustrated how selected data could be used to develop measures to allocate Medicaid funding. GAO based its analysis on "commonly used equity standards" and "focused its efforts on readily available data sources, which are not inclusive of all possibilities."

GAO's analysis indicates that measures of the demand for services, geographic cost differences, and state resources can be combined in various ways to provide a basis for allocating Medicaid funds more equitably among states. GAO identified multiple data sources that could be used to develop measures to allocate Medicaid funding to states more equitably than the current funding formula. To be equitable from the perspective of beneficiaries and allow states to provide a comparable level of services to each person in need, GAO asserts, "a funding allocation mechanism should take into account the demand for services in each state and geographic cost differences among states." To be equitable from the perspective of taxpayers, "an allocation mechanism should ensure that taxpayers in poorer states are not more heavily burdened than those in wealthier ones, by taking into account state resources," the agency says.

GAO identified at least one federal data source that could be used to develop measures of each of these aspects. Nationally representative federal surveys, such as the U.S. Census Bureau's American Community Survey (ACS) and Current Population Survey (CPS), are available data sources that can be used to directly estimate the number of persons residing in each state with incomes low enough to qualify them as potentially in need of Medicaid services, the report points out. These estimates "can then be adjusted to reflect variation in health services needs within the identified population, using additional information collected in the surveys or from data sources external to the surveys, such as Medicaid data on enrollment or spending." A measure of geographic cost differences should account for all components of health care costs, including the cost of the personnel who provide services, which represents the greatest share of costs, GAO argues. National data that can be used to estimate average wages for health care personnel by state include the Occupational Employment Statistics survey conducted by the Bureau of Labor Statistics (BLS). As a measure of state resources, GAO suggests accounting for all income, regardless of whether or not the state taxes the income. The Total Taxable Resources (TTR) measure, as generated by the Department of the Treasury from multiple data sources, comprises not only the income included in PCI but also other significant sources of taxable income. GAO points out that nationwide, the TTR measure of income was 42 percent larger on a per capita basis than PCI in 2010, and provided a more comprehensive measure of state resources.

FMI The GAO report is available at www.gao.gov/assets/660/654477.pdf. ⸎

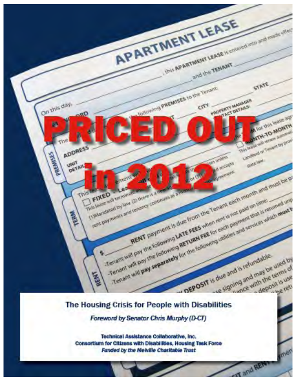
PPI Report Describes State Dual Initiatives

The Public Policy Institute (PPI) has released a report describing efforts by two-thirds of the states to integrate Medicare and Medicaid services over the next two years to remove adverse incentives and improve care coordination. To contain the growth of costs and improve care, the report indicates, many are moving to risk-based managed long-term services and supports models. This research, based on a

(PPI Report continues on page 13)

Priced Out in 2012 Examines Housing Issues for People with Disabilities

The Technical Assistance Collaborative (TAC) and the Consortium for Citizens with Disabilities (CCD) Housing Task Force have released the latest edition of their annual study of housing issues for individuals with disabilities study, *Priced Out in 2012*. The study demonstrates that the national average rent for a modestly priced one-bedroom apartment is greater than the entire Supplemental Security Income (SSI) payment of a person with a disability.


PRICED OUT in 2012

The Housing Crisis for People with Disabilities

Foreword by Senator Chris Murphy (D-CT)

Technical Assistance Collaborative, Inc.
Consortium for Citizens with Disabilities, Housing Task Force
Funded by the Melville Charitable Trust

Priced Out in 2012 compares the monthly SSI payments received by more than 4.8 million non-elderly Americans with disabilities to the Fair Market Rents for modest efficiency and one-bedroom apartments in housing markets across the country, as determined by the U.S. Department of Housing and Urban Development (HUD). According to HUD, rent is affordable when it is no more than 30 percent of income; *Priced Out in 2012* reveals that as a national average, people with disabilities receiving SSI needed to pay 104 percent of their income to rent a one-bedroom unit priced at the Fair Market Rent.

The study, which was funded by the Melville Charitable Trust, notes that the reform and expansion of HUD's Section 811 Supportive Housing for Persons with Disabilities program and appropriations for the National Housing Trust Fund could help to create more integrated housing linked with community-based services and supports. TAC and CCD urge Congress to provide sufficient funding over the next five years to expand HUD's Section 811 approach and to expand affordable housing opportunities for SSI recipients.

FMI The report is available at www.tacinc.org/media/33368/PricedOut2012.pdf. ※

(PPI Report continued from page 12)

survey of 50 states and the District of Columbia conducted in the fall of 2012, finds that two-thirds of the states either have or will launch new initiatives to better coordinate care for people who are dually eligible for Medicare and Medicaid services over the next two years. PPI also points out that while some states are taking the opportunity extended by the Centers for Medicare & Medicaid Services (CMS) to test new models, a number of states are exploring or implementing alternative approaches to dual services integration outside of the CMS models.

The three key findings from the survey regarding state dual integration initiatives are:

- Two-thirds of all states are integrating or planning to integrate Medicaid and Medicare services for dual eligibles in state fiscal years 2013 and 2014.
- Most integration programs are broad in scope — statewide initiatives targeting all full-benefit duals and spanning most long-term services and supports.
- Most states are turning to risk-based managed care models to deliver integrated services to duals.

FMI The report is available at www.aarp.org/content/dam/aarp/research/public_policy_institute/health/2013/states-integrating-medicare-and-medicaid-AARP-ppi-health.pdf. ※

Tavenner Confirmed as CMS Administrator


Marilyn Tavenner

The U.S. Senate has confirmed Marilyn Tavenner as administrator of the Centers for Medicare & Medicaid Services (CMS). She is the first CMS administrator to be confirmed in more than nine years. Ms. Tavenner was the acting administrator for CMS, and previously served as principal deputy administrator.

Prior to assuming her CMS leadership role, Ms. Tavenner served for four years as the commonwealth of Virginia's Secretary of Health and Human Resources. Ms. Tavenner also spent 25 years working for the Hospital Corporation of America (HCA). She began working as a nurse at the Johnston-Willis Hospital in Richmond, Virginia, in 1981 and steadily rose through the company as the hospital's Chief Executive Officer and, by 2001, had assumed responsibility for 20 hospitals as president of the company's Central Atlantic Division. She finished her service to HCA in 2005 as group president of outpatient services, where she spearheaded the development of a national strategy for freestanding outpatient services, including physician recruitment and real estate development.

Michigan Focus of First CMS Survey of Direct Care Workforce

Through a grant from the Centers for Medicare & Medicaid Services (CMS) to the Michigan Office of Services to the Aging, PHI (Paraprofessional Healthcare Institute) Michigan conducted surveys of providers in the Medicaid MI Choice home and community-based services (HCBS) waiver, community mental health (CMH) waiver, and Home Help programs in 2012 to determine the size, stability, and compensation of the direct-care workforce. Information on health care coverage, core competencies, and training was also gathered through the surveys. Surveys were also completed by direct-care workers supporting participants in MI Choice and CMH self-determination waiver programs, and allowed for analysis of these workers based on their relationship to the participant. The surveys, the first statewide surveys of Medicaid-funded, (HCBS) providers designed to capture data and information on the direct-care workforce, have identified low wages, part-time hours, and the need for enhanced training as significant challenges to attracting and retaining direct-care staff to these programs.

Nearly 17,000 direct-care workers are employed by the 1000-plus provider organizations that responded to the three surveys. The starting hourly wage in the CMH program is $8.73, and $9.09 for the Home Help and MI Choice program; 60 percent of direct-care staff are employed part-time, at less than 36 hours per week; and only one third of HCBS providers reimburse their direct-care staff for mileage and or gas for travel between participants. The average annual turnover rate is 34 percent for direct-care workers. Fifty-eight percent of responding organizations offer health insurance to their direct care staff, although many have low participation rates as a result of the high cost for workers.

PHI Michigan also conducted companion surveys to learn more about the workers hired and supervised directly by participants in the MI Choice and CMH self-determination programs. Among the findings:

- Workers supporting self-directing participants are, overall, satisfied with their jobs.
- The majority of CMH workers supporting self-directing participants believe that training in certain core competencies should be mandatory.

(Michigan continues on page 15)

Equal Employment Opportunity Commission Issues Revised Publications on the Employment Rights of People with Specific Disabilities

The U.S. Equal Employment Opportunity Commission (EEOC) has issued four revised documents on protection against disability discrimination. The documents address how the Americans with Disabilities Act (ADA) applies to applicants and employees with cancer, diabetes, epilepsy, and intellectual disabilities. These documents are available on the EEOC website at "Disability Discrimination, The Question and Answer Series." The revised documents reflect the changes to the definition of disability made by the ADA Amendments Act that make it easier to conclude that individuals with a wide-range of impairments, including cancer, diabetes, epilepsy, and intellectual disabilities, are protected by the ADA. Each of the documents also answers questions about topics such as: when an employer may obtain medical information from applicants and employees; what types of reasonable accommodations individuals with these particular disabilities might need; how an employer should handle safety concerns; and what an employer should do to prevent and correct disability-based harassment.

FMI The documents are available at www.eeoc.gov/laws/types/disability.cfm. ❧

(Michigan continued from page 14)

- In MI Choice, 49 percent of workers are family members, compared to only 27 percent in the CMH-waiver programs.
- Most family members (65 percent) do not live with the program participant for whom they care.
- Family members who are paid caregivers tend to earn less than workers with no prior relationship to the participant.

Results of the three provider surveys are reported in an executive summary, "Findings from Surveys from Medicaid Home and Community-Based Provider Organization Surveys: Understanding Michigan's Long-Term Supports and Services Workforce." More on the survey findings on self-directed workers is reported in "Findings from Surveys of MI Choice and CMH Self-Directed Workers Executive Summary."

FMI The survey results are available at phinational.org/policy/state-activities/phi-michigan/resources/publications. ❧

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- **Ari Ne'eman**, President, Autistic Self Advocacy Network and Member, National Council on Disability and Chair, Policy and Program Evaluation Committee

Mathematica Examines Transition Policies in U.S. and 10 Other Countries

Mathematica Policy Research has released a report summarizing policies and programs of the United States and 10 other countries in the Organisation for Economic Co-Operation and Development (OECD) that aim to improve the transition of youth with disabilities to "appropriate and gainful employment." Although Mathematica points out that "the evidence of whether these policies and programs are effective is missing in most cases," the authors suggest "they have the potential to offer promising ideas for implementation or testing by the United States."

The paper resulted from work performed pursuant to a grant from the U.S. Social Security Administration (SSA), funded as part of the Disability Research Consortium. Mathematica health researchers are examining the barriers that inhibit a large portion of young Americans with disabilities from transitioning into adulthood with "gainful and stable" employment. They have identified four salient sets of barriers that prevent youth with disabilities from accessing support systems that would facilitate a successful transition from adolescence to adulthood:

- Insufficient employment supports (only 3 percent of youth with disabilities ages 14 to 24 exit services from vocational rehabilitation agencies in a given year).
- Few services targeted specifically to the needs of youth and young adults.
- Issues with access to adult services, a result of the adult service landscape's fragmentation — service agencies and benefit programs have different and varied eligibility requirements.
- Insufficient coordination of the transition from youth to adult services.

To identify policy solutions that will assist youth with disabilities in overcoming these barriers, the Mathematica team undertook an extensive literature review of the broad range of programs and policies that the United States and 10 other Organization for Economic Cooperation and Development (OECD) countries are using to provide income support and vocational rehabilitation to transition-age youth with disabilities. As a result of this literature review, the researchers identified programs and policies "that promote independence, and specifically employment, among program participants and that develop successful linkages among programs to coordinate targeting of, access to, and transitioning from youth to adult services."

According to Mathematica, several themes emerged from their review. First, countries have engaged in a range of efforts to promote employment, such as offering financial incentives to workers with disabilities and expanding employer supports. Second, investment in large-scale pilot projects has helped governments to identify what works in their countries. Third, most countries are operating programs at various government levels that are designed to improve access to adult services for people with disabilities (such as consolidating supports, improving the coordination of benefits and services, and promoting automatic eligibility for or access to programs). Finally, all countries have actively pursued solutions (such as increasing linkages to postsecondary education and increasing vocational supports) to the problem of inadequate coordination of youth and adult services. As the next stage of this study, Mathematica plans to conduct case studies on Germany and the Netherlands to provide "an in-depth review of the systems for supporting youth with disabilities and facilitating their transition to gainful employment."

FMI The report is available at mathematica-mpr.com/publications/PDFs/disability/Youth_Transition_WP.pdf?spMailingID=6150368&spUserID=MTU3ODMzNTQzMwS2&spJobID=73615626&spReportId=NzM2MTU2MjYS1.