

**Background:**

Staff will provide updates on the following policy areas of interest:

**A. State Policy Issues**

Staff will provide an update of recent public policy activities, including the implementation of legislation and the budget adopted by the 82<sup>nd</sup> Legislature as well as preparation for the 83<sup>rd</sup> Legislature.

Discussion topics include:

- Exceptional Item Requests
  - Health & Human Services Commission (HHSC)
  - Department of Assistive and Rehabilitative Services (DARS)
  - Department of Aging and Disability Services (DADS)

**B. Update on State Supported Living Center Monitoring Activities**

The Committee will receive an update on recent Department of Justice monitoring team reports of State Supported Living Centers. A summary of the monitoring reports is provided.

**C. Update on Federal Policy Issues**

TCDD Public Policy staff will provide an overview of the status and implementation of various federal legislative initiatives that impact people with developmental disabilities. Additional information is provided in meeting materials.

Discussion topics include:

- Federal Appropriations for DD Councils
- Implementation of the Affordable Care Act
- NACDD comments on the Notice of Proposed Rulemaking by CMS on Medicaid Home and Community Based Services Waiver rules

**Public Policy Committee**

**Agenda Item 12.**

**Expected Action:**

The Committee will receive updates on these items and may make recommendations for consideration by the Council.

**Council**

**Agenda Item 15. E.**

**Expected Action:**

The Council will receive a report from the Public Policy Committee and consider any recommendations offered from the Committee.

## PUBLIC POLICY ACTIVITIES SUMMARY REPORT

May 2012 – July 2012

### CHILDREN AND FAMILIES

- TCDD continues to participate in various child protective services meetings and work with stakeholders, advocates and self advocates.
- TCDD met with DFPS staff on alternatives to foster care and appropriate non-residential services for children.
- TCDD is a designated member of the HHSC Children's Policy Council and staff also participate on the System Reform Sub-Committee.
- TCDD participates on the HHSC Task Force on Children with Special Health Care Needs.
- TCDD participates as a designated member on the Texas Traumatic Brain Injury Advisory Committee currently focused on advocating for a Medicaid waiver for individuals with an acquired brain injury.
- TCDD continues to participate in the Texas Children's Mental Health Forums, developing a policy agenda to advance children's mental health in Texas.

### CRIMINAL JUSTICE

- TCDD provides input on continuity of care for offenders with developmental and/or mental health disabilities as a statutorily designated member of the Texas Council on Offenders with Medical and Mental Impairments.

### EDUCATION

- TCDD staff are assisting with the collection of personal stories related to Early Childhood Intervention Services in Texas to be used during the 83<sup>rd</sup> Legislative Session.
- TCDD staff participated with other advocate organizations in a meeting with Legislative Budget Board staff to provide input about Early Childhood Intervention Services in Texas.
- TCDD staff provided input to the Department of Assistive and Rehabilitative Services (DARS) on exceptional item requests in the 2014-2015 Legislative Appropriations Request, including recommendations to increase service hours and address caseload growth for Early Childhood Intervention.
- TCDD staff continue to monitor the Sunset review process of the Texas Education Agency.

### EMPLOYMENT

- TCDD staff continue to meet with the Texas Office for the Prevention of Developmental Disabilities (TOPDD) and Morningside Research to develop the 2012 Biennial Disability Report.
- TCDD worked with stakeholders and agencies to consider an application for a Projects of National Significance grant from the Administration on Intellectual and Developmental Disabilities for *Partnerships in Employment Systems Change*.
- TCDD staff provided input to the Department of Assistive and Rehabilitative Services on exceptional item requests in the 2014-2015 Legislative Appropriations Request including a recommendation to match vocational rehabilitation grant growth and expand services by Centers for Independent Living.
- TCDD staff is a designated member of the DARS Rehabilitation Council of Texas.

## **PUBLIC POLICY ACTIVITIES SUMMARY REPORT**

May 2012 – July 2012

### **GUARDIANSHIP**

- TCDD staff are researching alternatives to guardianship for medical decision-making for persons with cognitive disabilities.

### **HEALTHCARE**

- TCDD joined Disability Rights Texas to provide comments on Texas' Application for the Dual Eligibles Integrated Care Demonstration Project.
- TCDD staff continue to monitor implementation of cost containment directives, including expansion of Medicaid managed care through 1115 Medicaid Flexibility waivers and Medicare Equalization.
- TCDD staff participate in the monthly My Medicaid Matters initiative and Cover Texas Now, an ad hoc healthcare advocacy coalition.
- TCDD provided support for printing My Medicaid Matters brochures in English and Spanish to inform legislators and the public about Medicaid services and why the Medicaid program is essential for many Texans with disabilities.
- TCDD staff monitor activities related to the Affordable Care Act and Medicaid.
- TCDD staff participate in relevant meetings, including the Department of State Health Services (DSHS) Council and the Council for Advising and Planning (CAP) for the Prevention and Treatment of Mental and Substance Use Disorders.
- TCDD continues to participate in adult mental health policy advocacy meetings organized by Mental Health America Texas identifying policy issues and recommending solutions.

### **HOUSING**

- TCDD provided input on state-funded research on how the issue of fair housing and impediments to housing are addressed by various state agencies and commissions.
- Staff continue to work with TDHCA and DSHS to problem solve the implementation of Project Access pilot for individuals with serious mental illness to transition from state psychiatric hospitals back to community.
- TCDD continue to work with TDHCA staff and attend board, stakeholder and monthly Disability Advisory Workgroup meetings.

### **LONG-TERM SERVICES AND SUPPORTS**

- TCDD provided a letter of support for the Texas Health and Human Services Commission's (Commission) application to participate in the federal Centers for Medicare and Medicaid Services' (CMS) Balancing Incentive Program (BIP).
- TCDD continues to participate in relevant DADS meetings, including the Promoting Independence Advisory Committee, Money Follows the Person Demonstration Advisory Committee, and Community-based Services Interest List Stakeholders.
- TCDD continues to participate in the Public-Private Sector Workgroup discussing current issues impacting the delivery of long-term services and supports for individuals with developmental disabilities.

## **PUBLIC POLICY ACTIVITIES SUMMARY REPORT**

May 2012 – July 2012

- TCDD continues to work with colleague organizations regarding the implementation of the settlement agreement with the Department of Justice concerning Texas State Supported Living Centers.
- TCDD collaborated with the DD Network Partners to develop and present a proposal to the Department of Aging and Disability Services to build expertise regarding *Person Centered Thinking* at the Austin State Supported Living Center.
- TCDD staff worked with DADS and HHSC staff to ensure that Home and Community-based Services (HCS) waiver participants continue to be eligible for the SNAP, or food stamp benefits.
- TCDD staff are working with DADS and HHSC staff to develop fair and transparent room and board agreements between HCS residential services providers and participants.
- TCDD continues to participate as a member of the DADS Aging and Disability Resource Center Advisory Committee (ADRC), and the DADS Lifespan Respite Services Advisory Committee.
- TCDD continues to collaborate with stakeholders to strengthen the role of service coordination in the HCS program by addressing issues associated with the service planning process and ensuring that consumers have meaningful input via planned focus groups.
- TCDD participates as a member of the SB 1857 Advisory Committee to provide input to DADS and the Board of Nursing concerning revised protocols for medication management in the HCS, TxHmL and ICF programs.
- TCDD staff participated in DADS strategic planning meetings associated with ongoing activities relating to Disability History and Awareness.
- TCDD staff provided feedback regarding a utilization review tool to be used to ensure adequate and appropriate service levels in the HCS and CLASS programs.
- TCDD staff monitored interim legislative committee hearings.
- TCDD staff provided input regarding how to correct implementation errors relating to the rollout of STAR managed care to waiver consumers in Rural Service Areas (RSAs).
- TCDD staff collaborated with the National Association of Councils for Developmental Disabilities (NACDD) to develop public input regarding CMS' proposed HCBS rules.
- TCDD provided input on the 2014-15 Legislative Appropriations Request (LAR) development for DSHS community mental health, institution to community transition, health care for children with special needs and school-based children's health and behavioral health programs.

### **TRANSPORTATION**

- TCDD continues to monitor various metropolitan planning organizations and review changes to the long-range transportation plan.

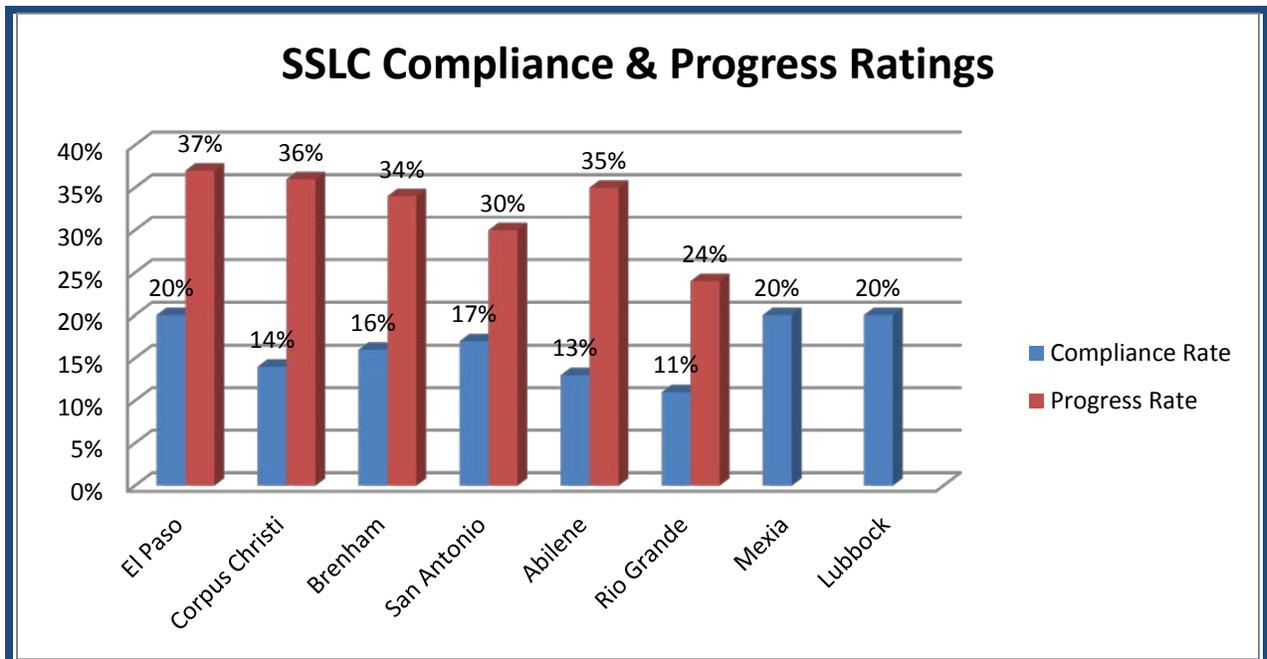
### **EMERGENCY MANAGEMENT**

- TCDD staff have continued participation on the Texas Disability Task Force on Emergency Management.

# State Supported Living Centers Monitoring Update

In June 2009, the State of Texas/Department of Aging and Disability Services (DADS) and the U.S. Department of Justice (DOJ) entered into a Settlement Agreement (SA) that covers the 12 State Supported Living Centers (SSLC) and the Intermediate Care Facility (ICF) component of Rio Grande State Center. As determined by the SA, three monitors, each with a monitoring team, are responsible for monitoring the facilities' compliance with the SA and related Health Care Guidelines. The monitoring teams examine activities in 20 different aspects of care provided to residents in each facility to determine the status of each facility's compliance with provisions of the U.S. DOJ Settlement Agreement. Within each section, there are a varying number of more specific provisions. Each provision is rated as in substantial compliance or noncompliance with the terms of the Settlement Agreement. There also are provisions that are not rated if the monitoring team had insufficient information.

Baseline reviews of the facilities were conducted from January through May 2010. The first round of compliance reviews were completed from July 2010 to January 2011. The second compliance reviews of each facility began in February 2011 and concluded in mid-July 2011. Council members received an update on the third compliance reviews in May 2012. This summary covers the reports issued in the fourth round of compliance reviews completed thus far.



This chart shows the proportion of compliance with all of the provisions evaluated in the monitoring reports. The rate of provisions that were showing progress is also provided, where available.

## El Paso State Supported Living Center (EPSSLC)

EPSSLC was found to be compliant in 32 of 171 provisions, or 19 percent of the time. Between July 1 and December 21, 2011, 39 incidents of restraint occurred, where nine individuals were subject to restraint. One individual was restrained 21 times, accounting for 54 percent of the restraint incidents. Between July 1 and November 20, 2011, there were 13 confirmed cases of neglect and one case of abuse. EPSSLC had taken a number of steps to better assess and address risk factors; however, staff were not

adequately trained on monitoring risk factors and providing necessary supports to prevent and address risk, according to DOJ monitors. Although the monitors pointed out several improvements in the medical and nursing departments, the report indicated that issues remained in the nursing department. For instance, nurses were not following accepted standards of practice and implemented improper interventions. The monitors noted improvements in moving individuals to the most integrated community setting, although there was an annual rate of only six percent of EPSSLC residents transitioning to the community. 58 individuals (five percent of the EPSSLC population) were not referred due to legally authorized representative preference.

### **Corpus Christi State Supported Living Center (CCSSLC)**

CCSSLC was found to be in compliance with 22 of 171 provisions assessed by the DOJ Monitoring Team. This constitutes a rate of compliance of about 14 percent. Some progress in the area of restraint that was attained in the previous review was offset by a staff vacancy. Monitors also expressed concern that strategies to reduce target behaviors and prevent the use of restraint were not being implemented. Monitors commended CCSSLC for improved procedures and protections to prevent and address abuse, neglect, and incidents. Staff were not conducting comprehensive assessments in the areas of nursing, speech and communication, psychiatry, skill acquisition and physical and nutritional supports. According to monitors, "Adequate assessments are the foundation for good individualized planning." Monitors noted progress in the area of preventing and addressing risk factors. The monitoring team also observed improvements in habilitation, training, education and skill acquisition programs, commenting that the level of engagement had improved. Although there were improvements in referring individuals for transition to the most appropriate community setting, individual plans did not adequately define the necessary protections, support, and services to ensure health and safety. Of the nine individuals who transitioned to the community in 2011, four experienced significant adverse outcomes, which monitors attributed to inadequate transition plans and the quality of supports community providers offered to these individuals.

### **Brenham State Supported Living Center (BSSLC)**

Brenham SSLC was found to be in compliance with 19 percent of the provisions in the SA. There were several areas where BSSLC lost ground compared to previous reviews and in fact declined from reaching standards to being in noncompliance, such as use of restraint, integrated clinical services, psychiatric care and services, nursing care, and pharmacy services and safe medication practices. In addition to eliminating some skill acquisition programs, individual support plans did not include a focus on learning skills necessary for community living. The monitoring team observed that BSSLC was making progress toward compliance in the area of abuse, neglect, and incident management, recommending that the SSLC improve documentation of serious injuries and improve the investigative process for incidents to rule out abuse and neglect as a contributing factor. The monitors highlighted progress made by the Medical department in reorganizing and with engaging all staff in achieving compliance with the SA. Although several individuals were referred and in the process of community transition, the monitoring team expressed concern about BSSLC's failure to identify needed services, supports, and obstacles to successful community transition.

### **San Antonio State Supported Living Center (SASSLC)**

SASSLC was found to be compliant in 27 of 161 of the provisions assessed by the monitoring team, or 17 percent compliance. Between August 25, 2011, and February 3, 2012, 131 restraints were performed on 12 individuals. There were two confirmed cases of physical abuse and 25 confirmed cases of neglect from August 3, 2011, to December 26, 2011. There were 38 serious incidents at SASSLC that did not involve allegations of abuse or neglect. There were an increased number of injuries for fiscal year 2012,

and the number of serious injuries involving fractures or sutures more than doubled compared with the previous fiscal year. SASSLC was encouraged to improve reports to determine progress toward reducing the number of injuries. SASSLC was in the initial stages of developing a new risk assessment process, and monitors commented that the facility had taken minimal steps toward compliance in the area of risk. Although there were no items in compliance in the habilitation, training, education, and skill acquisition programs area, the monitors made note of improvements that occurred since the last review, including the establishment of a team to oversee compliance with the SA and a skill acquisition monitoring tool. Less than two percent of individuals living at SASSLC were transitioned to the community annually. However, ten individuals were on the active referral list, which is the largest number on the list since the SA was initiated.

### **Abilene State Supported Living Center (ABSSLC)**

ABSSLC achieved compliance in 21 of 161 provisions of the SA, which comprises 13 percent of provisions. Regarding the use of restraint, the monitoring team brought attention to a number of areas that had improved, including a decline in the use of restraint and a tracking system for restraints used more than three times in 30 days for any individual. ABSSLC increased compliance in the provision of abuse, neglect, and incident management since the last review. During the 2011 calendar year, there were 53 confirmed cases of abuse and 78 cases of neglect at ABSSLC. While the number of deaths, serious injuries, and incidents of choking declined in 2011, the number of sexual incidents, suicide threats, and unauthorized departures increased compared to the previous year. Monitors expressed concern that risk assessments did not begin within five working days of a determination of increased risk. Further, risk action plans had little focus on prevention or minimizing risk through additional assessments. Skill acquisition programs were limited in scope and often not reflective of the needs identified in current assessments. Opportunities for learning were limited, and engagement level of individuals was low. Individual plans generally did not include recommendations on community transition, and ABSSLC was still at the initial stages of identifying obstacles to movement to the most integrated setting appropriate for the individual's needs.

### **Rio Grande State Center (RGSC)**

RGSC achieved compliance in 18 of the 161 requirements of the SA, which constitutes a rate of compliance of 11 percent, the lowest among facilities being reviewed for a fourth time. However, monitors praised RGSC staff for changing the living environments of individuals by establishing smaller groupings of individuals to provide greater privacy and less distraction during medication administration. The monitors observed improvements in the use of restraint. Although restraint use declined in the use of medical restraint and crisis intervention, monitors recommended the development of support plans to further reduce reliance on medical restraint. Progress in the area of abuse, neglect, and incident management was reversed in seven components that were found to be in substantial compliance during the time of the previous review. One provision that was in non-compliance in the previous review was found to be in substantial compliance in the current review. The monitors characterized the frequency of late reporting of allegations of abuse and neglect as "alarmingly high." The monitoring team expressed concern about risk assessments of individuals, saying they were inadequate to determine risk level. In addition, risk assessments were not necessarily completed when individuals had a change in health status that should have resulted in a risk screening. In the area of habilitation, training, education, and skill acquisition programs, monitors commented that although efforts were made, no provision showed improvement. However, the number of individuals referred for community living increased significantly since the last review, from nine to 15 individuals. The monitoring team recommended additional resources to enable referrals to result in actual moves.

### **Mexia State Supported Living Center (MSSLC)**

MSSLC was compliant in 28 of 171 areas assessed by DOJ monitors, slightly more than 20 percent compliance, in the fourth review. Compared to the third review, MSSLC improved compliance by 0.15 percent. The monitoring team expressed optimism regarding new management at MSSLC to move forward with treatment, intervention, support, service and compliance with the SA. Between September 1, 2011, and February 29, 2012, 226 restraints were used, a 31 percent decrease from the previous six month period and a 53 percent decrease from the same time in the previous year. There was also a 61 percent reduction in the use of restraints used for medical or dental treatment since the third compliance review. During the previous six months, there were 22 confirmed cases of physical abuse, one case of sexual abuse, three cases of emotional/verbal abuse, and six cases of neglect. MSSLC was not tracking all incidents or injuries. Between August 1, 2011, and February 27, 2012, there were 1,386 injuries at MSSLC, which included 36 serious injuries resulting in fractures or sutures. According to monitors, many of these injuries were the result of behavior issues, including peer-to-peer aggression. Although monitors observed that progress was made in the area of at-risk individuals, they also pointed out that MSSLC staff were not accurately identifying risk factors, which monitors said “should be a primary focus for the facility to ensure the safety of each individual.” MSSLC was making progress toward compliance in the area of ensuring that individuals were in the most integrated setting appropriate to their needs. Almost 9 percent of individuals were placed in the community on an annual basis, with another 11 percent on the active referral list. Monitors recommended improvements in identifying needed supports in the community for those transitioning.

### **Lubbock State Supported Living Center (LBSSLC)**

LBSSLC achieved compliance in 28 of the 171 provisions assessed by the monitoring team, which comprises 20 percent compliance with the DOJ SA. This is an increase of 1 percentage point from the third compliance review. The monitoring team applauded LBSSLC’s diligent monitoring and evaluation of the use of restraint and development of alternative interventions. The monitoring team also commended LBSSLC for its zero tolerance policy on abuse, neglect, and exploitation, as well as timely investigation of serious incidents. Regarding at-risk individuals, there was little evidence that individuals were being assessed in a timely manner or that plans were being implemented in the required timeframe. Risk assessments were completed on an inconsistent basis, with staff members utilizing different methodologies, which resulted in varying quality of the plans for addressing risk. The monitoring team observed that individuals at LBSSLC were not adequately engaged in activity, recommending that staff improve methods used to estimate engagement and the implementation of skill acquisition programs. Since the previous review, three individuals transitioned to the community. The monitoring team called on LBSSLC to improve identification of needed services and supports in addition to individual preferences and strengths.



July 2, 2012

NACDD Comments on 1915(i) NPRM

Re: CMS-2249-P2

Dear Administrator Tavenner:

The National Association of Councils on Developmental Disabilities (NACDD) appreciates the opportunity to comment on the proposed rule for the Medicaid Program: State Plan and Community-Based Services as published in the Federal Register at 77 FR 26362, May 3, 2012.

NACDD serves as the national voice of the state and territorial Councils on Developmental Disabilities. Created pursuant to the Developmental Disabilities Assistance and Bill of Rights Act, DD Councils, appointed by the governor in every State and Territory, are a Federal-State partnership with and for people with developmental disabilities and their families.

As stated in the Federal Register notice, this proposed rule reflects the intention of the Centers for Medicare and Medicaid Services (CMS) to revise and amend the regulations for the Medicaid Program; State Plan Home and Community-Based Services, a 5-Year Period for Waivers, Provider Payment Reassignment, and Setting Requirements for Community First Choice.

NACDD appreciates that the 1915(i) state option is a remarkable opportunity to provide many services and supports for people with developmental and other disabilities as part of a State Medicaid Plan without linking those services to eligibility for institutional level of care. We appreciate that the proposed rule goes a long way towards implementing this opportunity in a way that will well serve many people with disabilities.

NACDD reiterates our call for supporting living arrangements that “promote self-determination, independence, productivity, and integration in all facets of community life” as set forth in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act).

NACDD is pleased that the proposed rule includes Person Centered Planning as part of the 1915(i) Waiver and identifies characteristics that define Home and Community Based Services in a uniform manner for all waivers.

NACDD and our counterparts under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) the Association of University Centers on Disabilities (AUCD) and the National Disability Rights Network (NDRN) filed joint comments dated December 6, 2010 on CMS' ANPRM of June 22, 2010 (our "2010 Comments"). We append these 2010 Comments to these present comments because they address some of the issues in this NPRM in detail.

#### **§440.182 State plan home and community-based services**

We appreciate the opportunity for states to provide an expanded array of services to individuals with significant disabilities. We urge CMS to clarify in §440.182(c) that "other services requested by the state as the Secretary may approve" may include those services that have been, or could be, approved as "other services" under a 1915(c) waiver and to list specific examples of such services. The statute makes clear that any service within the scope of those permitted under a 1915(c) waiver may be provided through the 1915(i) option; the regulations must make that clear as well.

For example, we think it critical that CMS include specific language regarding transition services in the regulation itself. The preamble of the proposed rule (Background section (E)(2.)) states that "recognizing that individuals leaving institutions require assistance to establish themselves in the community, we would allow States to include in a section 1915(i) benefit, as an "other" service, certain transition services to be offered to individuals to assist them in their return to the community." We urge that the regulation itself clearly state that transition services can be covered under a 1915(i) option, and that they can be provided to individuals moving into a home and community based setting. The regulation should also specify examples of the types of supports that may be covered as transition services, including , at a minimum, the same as those now allowed for 1915(c) waivers, such as security deposits required to obtain a lease; set-up fees or deposits for utility or service access (e.g. telephone, electricity, heating); essential furnishings and moving expenses, and health and safety assurances (such as pest eradication, allergen control or one-time cleaning prior to occupancy).

CMS has, for waivers, defined those transition costs cited above as being outside the definition of "room and board" and therefore allowable. The same rationale should apply under Section 1915(i).

#### **§441.656, §441.530 Requirements and Limits applicable to Specific Services**

We support CMS's proposed list of qualities of home and community-based settings in Section 441.656(a) (1) (for state plan home and community-based services) and Section 441.530(a) (1) (for attendant services and supports in home and community-based settings). The qualities described include key characteristics that make a setting home-based or community-based.

We recommend some modifications:

1. CMS should add language to subsection (ii) to clarify the intent. This subsection currently reads “the setting is selected by the individual from among all available alternatives and is identified in the person-centered service plan.”

We propose that it should read: “the setting is selected by the individual following a meaningful opportunity to choose from among alternatives, including the setting that is the most integrated setting for the individual.” We also propose changing the second half of subsection to read “as documented in the person-centered service plan.” The plan should also document the alternatives available to the person, the choice made by the person, and the reasons for the choice.

2. While (a)(1)(vi)(A) defines the term “unit or room” to which the person has a legal right, (B) refers to rights or privacy etc. for “each individual in their sleeping or living unit.” Because there is no definition of each individual’s “sleeping or living unit” it is unclear to what area the individual’s rights pertain. It should be clarified that the “unit or room” to which the person is legally entitled is at least the space to which the rights in (B) should apply.
3. CMS should clarify that all settings in which the individual does not have a regular lease or full ownership should be considered provider-controlled. This should include foster care settings.
4. CMS should amend the language in both sections under subsection “vi” regarding modification of conditions in provider-owned or controlled residential settings to clarify that the specific assessed need must be of the individual, and should indicate that a determination has been made regarding the timeframe that the modification of conditions will be in effect. The restrictions should be documented in the individual’s person-centered service plan and verified as proportional to the specific safety need. The plan should also establish a schedule for review of the restrictions for effectiveness and continuing need.
5. CMS should also clarify under subsection “vi” of both sections that the “additional conditions” for provider-owned or controlled settings may not include that accepting particular services is a requirement in order to access housing. Housing should be provided separately from services.
6. CMS should allow departures from the “additional conditions” only in rare and extraordinary circumstances. CMS should, however, never permit departures from the additional conditions that individuals share units only at the individual’s choice, have the freedom to furnish and decorate their sleeping or living units, have the freedom and support to control their own schedules and activities, and are able to have visitors of

their choosing at any time. Allowing departures from key elements of home and community-based settings would be inconsistent with the common understanding of people with and without disabilities about what is a “home” and what it means to be part of “the community.”

7. In section 441.530(a)(2)(iv), the list of settings that may not be considered “home and community-based” in subsection (iv) should be modified to read “a hospital” (eliminating the qualifier “providing long-term care services”). Waiver services are often categorized as long term care services particularly by managed care organizations.
8. The following characteristics should be included as indications that give rise to a rebuttable presumption that a setting is not home and community-based:
  - a. Rather than creating a rebuttable presumption, CMS should state that the settings listed in Sections 441.656(a) (2) (v) and 441.530(a) (2) (v) are not home and community-based. As CMS has recognized in proposing a rebuttable presumption, settings located on the grounds of an institution, in a building that provides inpatient institutional care, or in a disability-specific housing complex function, for all practical purposes, as segregated institutional settings. They do not become home and community-based simply because residents are afforded privacy, the ability to choose whether to have a roommate, or other qualities of home and community-based settings. One of the most important qualities of a home and community-based setting is its location: a setting that is literally on the grounds of, in or synonymous with, an institution cannot be home and community-based.

If CMS embraces a rebuttable presumption, it should apply the presumption only to disability-specific housing complexes. The Settings on the grounds of an institution or in a building that provides inpatient care should never be considered home and community-based. In addition, with respect to disability specific housing, CMS should specify that the presumption may be rebutted only when (a) the setting meets all of the requirements for home and community-based settings in Sections 441.656(a)(1) and 441.530(a)(1) and (b) the setting was selected by the individual from among alternatives that included the most integrated setting appropriate for the individual.

- b. Sections 441.656(a)(2)(v) and 441.530(a)(2)(v) state that the Secretary will apply a rebuttable presumption that a setting is not home and community-based if it "is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or disability-specific housing complex." We assume that the reference to a "disability-specific housing complex" was intended to refer to settings located in a disability-specific housing

complex – as well as on the grounds of, or immediately adjacent to, such a complex. CMS should revise the sentence to make that clear.

- c. In addition, CMS should revise Sections 441.656(a)(2)(v) and 441.530(a)(2)(v) to include settings on the grounds of or adjacent to a privately operated institution. A private institution is no less institutional than a public one and should be treated the same for purposes of this provision.
9. CMS should also clarify that a “disability-specific housing complex” includes any building or group of buildings that house primarily (50% or more) people with disabilities.

#### **§441.659, §441.662 Independent Evaluation and Assessment**

NACDD supports independent evaluation and assessment to maintain the integrity of the process and eliminating obvious conflicts of interest, and recommend the following:

1. Eligibility for services under Section 441.659 (d) must be determined through an independent evaluation of each individual that is performed by an agent that is independent and qualified as defined in section 441.668. Section 441.668 should exclude a managed care organization from conducting the independent evaluation of individuals.
2. When performing an independent assessment under Section 441.662, the state must provide all eligible individuals with an independent assessment of needs which is performed by an agent that is independent and qualified as defined in Section 441.668. Section 441.668 should exclude both the state and a managed care organization from conducting the independent assessment of individuals.

The rule itself (rather than just the preamble p 26372) should indicate that services must be furnished to individuals with an assessed need, and must not be based on available funds.

#### **§441.656 State plan home and community-based services under the Act**

NACDD recommends that the regulation (rather than just the preamble, p. 26376)), include an explicit statement that a “a state may propose more than one set of Section 1915(i) benefits, with each benefit package targeted toward a specific population” and that the state may also target multiple populations under one set of benefits or offer different services to each of the defined target groups within the benefit.”

### **§441.659 Needs-based Criteria and Evaluation**

1. We recommend that the rule (rather than just the preamble p. 26369) explicitly clarify that the need for assistance with instrumental activities of daily living (IADLs) is a basis for eligibility for services under a 1915(i) option. The need for assistance with instrumental activities of daily living, such as the ability to manage finances and managing medications, is often critically relevant to individuals with disabilities.
2. We recommend that the rule (rather than just the preamble p. 26370) state that the inability to perform two or more ADLs is a required element of the independent assessment that is to be completed after an individual is evaluated as eligible to receive 1915(i) services.
3. We also recommend that the rule (rather than just the preamble, p. 26374), provide that FFP be available for evaluations (including both for medical services and administrative costs incurred for evaluation and assessment activities), even when an individual is subsequently found ineligible for 1915(i) services. Without this provision, individuals may not be able to access an evaluation in some circumstances.

### **§441.656, §441.659 Concern regarding interplay between Section 441.656 and Section 441.659**

We are concerned that the interplay between Section 441.659 and Section 441.656 might be interpreted to allow a state to change the needs-based criteria between the institutional and waiver level of care and the state plan home and community-based level of care with the net effect that some people who would have been eligible previously will have no access to services. For example, the proposed regulation would allow a state to adjust the needs based criteria for waiver services and institutional level of care so they are stricter than those for the State Plan benefit, while also allowing limits for the State Plan benefits to be specified according to age, diagnosis, disability or Medicaid eligibility group. We are concerned that this may result in the total exclusion from either benefit for some groups who were previously eligible for waiver or institutional level of care.

We do not believe that this is CMS' intent, and we recommend that CMS include in the rules provisions that would prevent prospective exclusion from either benefit any groups who would have previously qualified for the waiver or institutional level of care

### **In Conclusion**

NACDD thanks CMS for placing a high priority on defining what is and is not a Home and Community-Based Setting in supported living arrangements. We appreciate CMS' focus on providing services in the least restricted environment in the spirit of the *Olmstead* decision and

the DD Developmental Disabilities Assistance and Bill of Rights Act to “promotes self-determination, independence, productivity, and integration in all facets of community life.”

We appreciate your attention to these comments.

Sincerely yours,

A handwritten signature in black ink that reads "Peggy Hathaway". The signature is written in a cursive style.

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***Please note attached 2010 Comments***

## APPENDIX

Joint Comments filed by NACDD, AUCD and NDRN dated 12/6/12 on CMS' ANPRM of June 22, 2010 (our "2010 Comments").

### MEANINGFUL INCLUSION: WHAT DISTINGUISHES HOME AND COMMUNITY BASED SERVICES FROM INSTITUTIONAL LIVING

In June 2009, The Centers for Medicare and Medicaid Services (CMS) issued an Advance Notice of Proposed Rulemaking (CMS-2296-ANPRM) soliciting comments on the most effective means of defining home and community. The noticed intention of CMS was to publish proposed amendments to the regulations for implementing the Medicaid Home and Community Based Services waivers under section 1915 (c) of the Social Security Act.

We, the National Association of Councils on Developmental Disabilities (NACDD), the Association of University Centers on Disabilities (AUCD), and the National Disability Rights Network (NDRN), applaud the efforts of CMS to more explicitly describe the expectations that individuals with developmental disabilities should be served in their homes and communities. We believe that the standards for community living articulated in the Advance Notice of Rulemaking --*optimizing participant independence and community integration, promoting initiative and choice in daily living, and facilitating full access to community services*-- reflect the values and goals that many individuals with developmental disabilities, along with their families and advocates have struggled to achieve for over 40 years. Home and Community Based Waiver funding is the primary source of funding for individuals with developmental disabilities and families in achieving these goals.

Therefore, it is imperative to ensure that the Developmental Disabilities Home and Community Based Waiver funding source continues to be dedicated to furthering these values and goals. It is in this spirit that we submit these comments. In doing so, we highlight the beliefs and values we are collectively guided by with regard to community-based living, review legal standards, and highlight the characteristics that should be required in living arrangements that are supported with public funding via Medicaid Home and Community Based Waiver services for individuals with developmental disabilities.

In summary, while individuals with developmental disabilities have the right to choose where they live, it is the position of NACDD, AUCD, and NDRN that state and federal funds, including Developmental Disabilities Home and Community Based Waiver funds, should not support segregated living arrangements where all or nearly all of the residents are people with disabilities. Rather these funds should support living arrangements that "promote self-determination, independence, productivity, and integration and inclusion in all facets of community life" as set forth in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and consistent with requirements of the Americans with Disabilities Act and other legal requirements

## BELIEFS AND VALUES

In defining home and community characteristics, it is important to understand the values and beliefs that are fundamental to the standards for community living that CMS has stated. The DD Act provides an excellent context for understanding the basis for the community integration, choice, control and independence principles set forth in the CMS standards. The purpose of this act is "to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports and other forms of assistance that promote self-determination, independence, productivity and integration and inclusion in all facets of community life .."<sup>1</sup> The first finding of the DD Act is that "disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society."<sup>2</sup>

When read in its entirety, the intent of the DD Act is to recognize the competencies, capabilities and personal goals of individuals with developmental disabilities and to contribute to a system where individuals with developmental disabilities have the ability and opportunity to make personal decisions, exert control over their lives and participate in the same community activities that are available to individuals without disabilities. Inclusion and integration of individuals with developmental disabilities in the communities of our society, as well as individual choice and control of life decisions and daily living activities, are core intents of the DD Act and of the Medicaid Home and Community Based Waiver services.

The DD Act provides excellent definitions of these principles that can be used to guide your consideration. All definitions are used with respect to individuals with developmental disabilities.

- Inclusion: The term "inclusion" means "the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enables individuals with developmental disabilities to-
  - (A) have friendships and relationships with individuals and families of their own choice;
  - (B) live in homes close to community resources, with regular contact with individuals without disabilities in their communities;
  - (C) enjoy full access to and active participation in the same community activities and types of enjoyment as individuals without disabilities; and

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<sup>1</sup> P.L. 106-402, section 101 (b)

<sup>2</sup> P.L. 106-402, section 101 (a)

(D) take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.”<sup>3</sup>

- Integration: The term “integration” means “exercising the equal right of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals.”<sup>4</sup>
- Self-Determination Activities: The term “self-determination activities” means “activities that result in individuals with developmental disabilities, with appropriate assistance, having-
  - (A) the ability and opportunity to communicate and make personal decisions;
  - (B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;
  - (C) the authority to control resources to obtain needed services, supports, and other assistance;
  - (D) opportunities to participate in, and contribute to, their communities; and
  - (E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and play a role in the development of public policies that affect individuals with developmental disabilities.”<sup>5</sup>
- Individualized Supports: The term “individualized supports” means “supports that-
  - (A) enable an individual with a developmental disability to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life;
  - (B) are designed to-
    - (i) enable such individual to control such individual’s environment, permitting the most independent life possible;
    - (ii) prevent placement into a more restrictive living arrangement than is necessary; and
    - (iii) enable such individual to live, learn, work, and enjoy life in the community; and
  - (C) include-
    - (i) early intervention services;
    - (ii) respite care;
    - (iii) personal assistance services;
    - (iv) family support services;
    - (v) supported employment services;
    - (vi) support services for families headed by aging caregivers of individuals with developmental disabilities; and

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<sup>3</sup> P.L. 106-402, section 102 (15)

<sup>4</sup> P.L. 106-402, section 102 (17)

<sup>5</sup> P.L. 106-402, section 102 (27)

(vii) provision of rehabilitation technology and assistance technology, and assistive technology services.”<sup>6</sup>

While individuals with developmental disabilities have the right to choose where they live, public state and federal funds, including Developmental Disabilities Home and Community Based Waiver funds, should support living arrangements that “promote self-determination, independence, productivity, and integration and inclusion in all facets of community life” as set forth in the DD Act.

## **THE LEGAL OBLIGATION TO PROVIDE SERVICES IN THE LEAST RESTRICTIVE SETTING**

CMS standards require that programs should optimize participant independence and community integration, promote initiative and choice in daily living, and facilitate full access to community services. Accordingly, public funds should be used to support living arrangements that are consistent with these values and beliefs.

The guiding principle of the U.S. Supreme Court’s landmark 1999 decision in *Olmstead v. L.C.*<sup>7</sup> is the inherent right of an individual to be free from unnecessary segregation from the general public. The Court made the legal and social imperative for deinstitutionalization clear: unnecessary institutionalization is a form of discrimination under Title II of the Americans with Disabilities Act (ADA).<sup>8</sup>

The ADA expressly states that, “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”<sup>9</sup> Through its *Olmstead* decision, the United States Supreme Court applied the ADA to state operated publicly-funded institutions and explained that, “segregation perpetuates unwarranted assumptions that institutionalized people are incapable or unworthy of participating in community life.” The Justices also concluded that, “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” The Court then reasoned that since people with disabilities should not have to give up the benefits of full participation in their communities in order to obtain needed medical services and supports, states should make reasonable accommodations under the ADA to ensure that Medicaid and other funds are used to provide the most integrated and inclusive settings appropriate for individuals with developmental disabilities.

In 2009, the U.S. District Court for the Eastern District of New York, also weighed in on the characteristics of a community based setting. In *Disability Advocates, Inc v. Patterson*, the Judge

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<sup>6</sup> P.L. 106-402, section 102 (16)

<sup>7</sup> *Olmstead v. L.C.*, 527 U.S. 581, 119 S.Ct. 2176 (1999).

<sup>8</sup> *Id.*, 527 U.S. at 597.

<sup>9</sup> 42 U.S.C. § 12132.

was asked to determine whether adult care homes for individuals with mental illness in New York meet the definition of the “most integrated setting appropriate” as used in the Department of Justice (DOJ) regulations governing the ADA Title II 28 C.F.R. 35.130(d); 42 U.S.C. 12134; and the U.S. Supreme Court in *Olmstead*. The regulations define “most integrated setting appropriate” as “a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.” 28 C.F.R. Pt. 35, App. A at 452. New York argued that adult home residences for individuals with mental illness met this definition because they were: in the community; unlocked; and permitted residents the opportunity to interact with non-disabled people. The Judge rejected this argument, holding that the ADA does not require “an” opportunity for interaction with non-disabled people, but rather the maximum opportunity for such interactions. The Court considered the essential characteristics of institutions to be:

- the degree of control that people exercised over their own lives, for example: could they cook or plan their own meals, control their own budgets, decide when to eat and sleep, and host visitors in private at times of their choosing;
- the degree of individualization of the setting and services, for example, whether people could choose their own roommate and their own medical professionals; and
- whether residents had non-disabled friends, worked or volunteered with non-disabled people, and had opportunities for recreation with non-disabled people.<sup>10</sup>

The Rehabilitation Act mirrors the DD Act in its intent for inclusion and independence for individuals with disabilities. Specifically, the act states that “disability is a natural part of human experience and in no way diminishes the right of individuals to live independently; enjoy self-determination; make choices; contribute to society; pursue meaningful careers; and enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society.”<sup>11</sup>

Consistent with all these precedents, CMS recently denied a request from the state of Missouri to amend its 1915(c) MR/DDR Comprehensive Home and Community-Based Services waiver for increased transition of individuals into residential units clustered on the grounds of a large state-operated institution. In the letter dated August 2, 2010, CMS stated that the proposed waiver amendment proposal is not consistent with both statute and regulations as Missouri would not be providing services that permit individuals to avoid institutionalization.

It is imperative that these gains not be reversed. We urge CMS to adopt strong requirements that prevent the use of Developmental Disabilities Home and Community Based Waiver funds for living arrangements that are not consistent with the values and goals in the DD Act as well as with the ADA, the *Olmstead* decision and the Rehabilitation Act, and to protect the continued use of these funds for true integrated community living.

## **RESEARCH DEMONSTRATES THE BENEFIT OF COMMUNITY LIVING**

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<sup>10</sup> *DAI v. Paterson*, 2009 U.S. Dist. LEXIS 80975 at 114-115

<sup>11</sup> P.L. 93-112, section 2 (a)

In addition to these legal and social goals, adherence to these standards of community living furthers the public interest by promoting the wellbeing of those served.<sup>12</sup>

A study of the results of the 1994 closing of North Princeton Developmental Center in New Jersey, published by the American Association on Mental Retardation in 2005, compared people who moved from institutional settings to people with similar service and support needs who remained in institutions.<sup>13</sup> The study produced “convincing evidence” that the multi-cognitive scores of people who remained in institutional settings significantly decreased from 1994-2001. The study also concluded that those who moved to community settings demonstrated significant increases in self-care skills over time. The authors concluded, “If we had focused solely on movers ... we would have missed one of the most salient findings of this evaluation, namely, the significant loss by stayers in their multi-cognitive competencies, particularly in the areas of social skills...”<sup>14</sup>

Similarly, a survey of guardians of people who moved from institutional settings to the community in Wisconsin led researchers to conclude that the vast majority of guardians felt that the transition to the community led to equal or enhanced satisfaction with their loved one’s living arrangements and overall happiness.<sup>15</sup>

Finally, a review of the literature concluded:

“The studies reviewed here demonstrate strongly and consistently that people who move from institutions to community settings have experiences that help them to improve their adaptive behavior skills. The studies suggest that community

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<sup>12</sup> It should be noted that institutional living is not solely bound by CMS’ or other definitions of institutions and that features of institutions are also found in places currently referred to as community settings. More specifically, people living in congregate settings of seven or more residents are more likely to report loneliness, less frequent satisfaction with their home, lower levels of community participation, etc. See Lakin, K.C., Doljanac, R., Byun, S., Stancliffe, R., Taub, S., Chiri, G., (2008) Choice-making among Medicaid Home and Community-Based Services recipients and ICF/MR residents in six states. *American Journal on Mental Retardation*, 113(5), 325-341.

<sup>13</sup> “Longitudinal Changes in Adaptive Behavior of Movers and Stayers;” Lerman, P., Apgar, D., Jordan, T. *Mental Retardation Journal*, American Association on Mental Retardation. February 2005, pp. 25-42. The study compared adaptive behaviors of individuals who lived in the North Princeton Developmental Center. The study assessed 150 movers and 150 stayers and looked at longitudinal changes. Movers and stayers were matched according to age, gender, cognition, social-emotional functioning, self-care, mobility, and challenging behaviors.

<sup>14</sup> Id.

<sup>15</sup> *Northern Wisconsin Center (NWC) Relocation Survey – March 27, 2006, prepared by APS Healthcare, Inc. for The Wisconsin Department of Health and Family Services (DHFS), Division of Disability and Elder Services (DDES).* See also Larson, S. A., & Lakin, K. C. (eds.). (1989). Deinstitutionalization of persons with mental retardation: Behavioral outcomes. *Journal of the Association for Persons with Severe Handicaps*, 14(4), 324-332. Updated in Kim, S., Larson, S., and Lakin, K.C. (2001) Behavioral outcomes of deinstitutionalization of people with intellectual disabilities. A review of U.S. studies conducted between 1980 and 1999, *Journal of Intellectual and Developmental Disabilities*, 26(1), 35-50.

experiences increasingly provide people with environments and interventions that reduce challenging behavior.”<sup>16</sup>

The potential for an enhanced quality of life and skill improvements for people who move to community settings, and the risk that those remaining unnecessarily in institutions may experience a loss of skills provides further impetus to support people with developmental disabilities in appropriate community settings.

## **EMERGING OPTIONS FOR LIVING ARRANGEMENTS**

Over time, numerous options for a continuum of living arrangements for individuals with developmental disabilities have and will continue to emerge across the United States. These options have been developed in response to a variety of issues, concerns, and desires, including but not limited to the following:

- The historic lack of services in the community to appropriately support individuals with developmental disabilities to live self-directed, participatory lives in the community;
- The desire of families for safety and continuity of care;
- The desire of individuals with developmental disabilities to socialize and/or live with others;
- The desire of individuals with developmental disabilities to be seen as equal participants in all that society has to offer; and
- The tightening economy that makes congregate service provision more appealing for service providers.

Now is, therefore, the opportune time to provide a framework for determining options that will and will not support Medicaid Home and Community Based Waiver standards for community living.

Below is an outline of some emerging living arrangement options and whether each option is consistent and/or inconsistent with the beliefs and values that are intrinsic to the DD Act, the legal requirements of the ADA and the *Olmstead* decision, and the CMS articulated standards of community living.

It is essential to understand that if a setting has even one aspect that is inconsistent with the values of the DD Act and CMS standards for community living, the setting is not integrated and should not be supported as such.

### **Options for Living Independently:**

Contrary to popular belief, individuals with developmental disabilities are able to live in their own homes. Supports are offered in various forms and make living independently possible.

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<sup>16</sup> Larson & Lakin, *Id.*

Emerging Independent Living options include the following:

- A variety of approaches are being used to support individuals with developmental disabilities with all levels of needs to live independently in the community.
  - One option is for the person providing the care and supervision to live next door or in the proximity of the individual with developmental disabilities.
  - Another option is paying a neighbor to provide emergency support to an individual with developmental disabilities as needed.
- Individuals with developmental disabilities live in apartments among other members of the community. They receive individualized assistance and have access to multiple activities that support their growing independence and active involvement in community activities. In this approach a community is prepared for the integration of individuals with developmental disabilities. Specifically, the community and the specific settings to be frequented by the individuals with developmental disabilities are educated about these individuals to provide a foundation for acceptance and support.
- Public/private partnerships are being developed to increase the supply of affordable and accessible housing available for individuals with developmental disabilities and to prepare and facilitate availability of rental and/or home ownership for individuals with developmental disabilities. Services are purchased separately as needed to provide the necessary support.

How Options for Living Independently Are Consistent with DD Act Beliefs and Values:

- Individuals with developmental disabilities have the opportunity to live independently, with choices and controls over their daily life activities.
- Individuals with developmental disabilities are living where they have regular contact with individuals without disabilities and the opportunity to develop friendships and relationships with a wide range of individuals and families of their choice.
- Individuals with developmental disabilities are living where they can take advantage of opportunities for participating in community activities. Such opportunities can be facilitated by the proximity of generic and natural supports, such as individuals with developmental disabilities living on the public bus route or with access to public transportation for individuals with disabilities, or living in proximity or with access to employment opportunities, places of worship, socialization, recreation, shopping, volunteering and civic engagement.
- Services and supports are individualized based on the particular needs of the individual with developmental disabilities and promote self-determination, independence, productivity, integration and inclusion.
- Individuals with developmental disabilities have a choice of all the providers and staff available in the community.
- Other individuals in the community have regular contact with the individuals with developmental disabilities who can observe and report potential abuse.

### **Individualized Shared Living Options:**

While many individuals with developmental disabilities live with their own families, there are also approaches where individuals with developmental disabilities live with roommates or in the private home of an individual or family who provides the individual with developmental disabilities with support, guidance and supervision.

#### **Emerging Individualized Shared Living Options:**

- There are approaches that emphasize the long term sharing of lives and forming caring households and close personal relationships between an individual with developmental disabilities and supportive persons.
- There are also approaches where the person providing care and supervision lives with the individual with developmental disabilities (with or without additional roommates with developmental disabilities). Each person in the apartment/home has his or her own lease, making the apartment the home of the individual with developmental disabilities, instead of the individual with developmental disabilities living in the caretaker's home as is the case with foster homes.

#### **How Individualized Shared Living Options Are Consistent with DD Act Beliefs and Values:**

- Individuals with developmental disabilities have the opportunity to live independently with choices and controls over their daily life activities.
- Individuals with developmental disabilities are living where they can have regular contact with individuals without disabilities, and thus have the opportunity to develop friendships and relationships with a wide range of individuals and families of their choice.
- Individuals with developmental disabilities are living where they can take advantage of opportunities for participating in community activities.
- Services and supports are individualized based on the particular needs of the individual with developmental disabilities and promote self-determination, independence, productivity, integration and inclusion.
- The personal care provider is the non-relative family with whom the individual with developmental disabilities lives. Individuals with developmental disabilities have a choice of all other providers and staff available in the community.
- Other individuals in the community have regular contact with individuals with developmental disabilities and can observe and report potential abuse.

### **Intentional Communities/Co-Operative Communities:**

These communities contain homes, apartments and possibly other housing options that are clustered and designed for the purpose of meeting the unique needs of different populations or are unified by a common purpose and a fostering of mutual neighborhood support.

Whether these communities provide living opportunities that are integrated and otherwise consistent with DD Act beliefs and values and other legal requirements depends on how each situation is structured. In any case, a community should never be considered integrated based on

only a token number of non-disabled people residing among a high percentage of individuals with disabilities.

#### Emerging Intentional/Co-Operative Communities:

- Clustering of housing and services to address more than one target population, such as individuals with developmental disabilities and individuals who are aging, or individuals with developmental disabilities and college students. Common areas for sharing social activities and dining can be offered.
- Intentional Communities/Co-operatives focus on developing mutual neighborhood support and communities where members share their lives, and encourage interactions between its members. Some of these communities specifically seek to provide homes and a community for people with and without disabilities. Avenues for developing natural supports through relationships and support for one another are provided.

#### How Intentional/Co-Operative Communities Can Be Consistent with DD Act Beliefs and Values:

- Individuals with developmental disabilities have regular social connections with other individuals.
- There is an opportunity for bringing together and sharing community supports and services for individuals with developmental disabilities.
- Individuals with developmental disability are living where they can have regular contact with individuals without disabilities, and thus have the opportunity to develop friendships and relationships with a wider range of individuals and families of their choice.
- Individuals with developmental disabilities are living where they can take advantage of opportunities for participating in the community activities made available to the population of individuals without disabilities.

#### How Intentional/Co-Operative Communities Are Inconsistent with DD Act Beliefs and Values:

- The choices and controls that individuals with developmental disabilities have over their daily life activities may still be limited by the requirements/rules imposed by the community organizing entity and to opportunities provided by the community organizing entity, depending on the population of individuals without developmental disabilities (i.e., aging individuals).

#### Clustered Housing Options:

Clustered Housing Communities are where residences, whether homes, apartments, group homes and/or other types of licensed residences (such as Assisted Living Facilities) are clustered/grouped together in some form to provide for a community. These Cluster Housing options are designed to meet the needs of individuals with developmental disabilities in congregate settings. These communities are intended to provide safety, opportunities for socializing with other individuals with developmental disabilities, and sense of belonging to a community.

The main concern is that in these settings, there is little or no integration with people without disabilities. Even in those clustered housing communities that are open to others, it is generally the case that only a very small percentage of the residents are individuals without developmental disabilities.

Emerging Clustered Housing Options Include the Following:

- Small clustered housing arrangements where a small number of group homes are grouped together sharing common areas for social activities and dining.
- Large cluster housing arrangements offering campus style living where there are multiple housing units (all one type or mixed) and a wide range of services offered on the grounds.
- A clustering of apartments/homes for individuals with disabilities with no common services on site. Any supervision or personal care services are provided by organizations outside the cluster housing settings.
- A clustering of “condominium” units within one building, in which each individual owns his/her bedroom “unit” and has shared ownership of common areas for social activities and dining.

How Clustered Housing Options Are Inconsistent with DD Act Beliefs and Values:

- Individuals with developmental disabilities are segregated from individuals without disabilities. Regular contact with individuals without developmental disabilities, and therefore, opportunities to develop friendships and relationships with a wide range of individuals and families of their choice, is limited to trips off-campus.
- Opportunities to participate in everyday integrated community activities are not naturally available. The addition of congregate services in the cluster housing setting, such as meals, sheltered workshops, and on-site employment, further reduce opportunities for contact with integrated community activities.
- The choices and controls that individuals with developmental disabilities have over their daily life activities and, therefore, their opportunity to live as independently as possible, are limited by the requirements/rules imposed by the provider and to opportunities offered by the provider.
- Although there may be some choice of providers and staff available in the community, providers will have invested in housing and on-site services in the cluster housing community, which may limit availability of community providers and staff. Such an investment in the housing and on-site services may necessitate individuals moving out of the cluster housing community if they wish to change providers.
- It would be inconsistent with DD Act Beliefs and Values for a community to be considered integrated based on only a token number of non-disabled people residing among a large majority of individuals with disabilities.

## **DEFINING WHAT IS AND IS NOT HOME AND COMMUNITY BASED LIVING ARRANGEMENTS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**

In defining community for individuals with developmental disabilities, it is important to exercise caution since each individual possesses their own sense of what community means to them based on familial and cultural values. However, based on the beliefs and values established in the DD Act, as well as requirements of the ADA, the *Olmstead* decision and the Rehabilitation Act, that recognize the basic civil right of all people to make choices about their living arrangements, relationships, and daily activities, it is possible to outline characteristics that are fundamental for any community.

While defining community for individuals with developmental disabilities may be challenging, individuals with developmental disabilities and their families know when they "achieve" a satisfactory life in the community. Sometimes it is easier to say what community isn't than what it is, but for each individual, there is an ideal that allows that individual to feel that they are a community member living a life of self-direction and participation. Although there may be barriers to taking advantage of or enjoying all of these fundamental characteristics, it becomes clear that the more community characteristics in which an individual can participate, the more the living arrangement is home and community based. In turn, the less community participation, the more likely the living arrangement is aligned with a congregate setting with the characteristics of institutional living.

It is our position that for living arrangements to be consistent with the beliefs and values of the DD Act, as well as with the requirements of the ADA, the *Olmstead* decision and the Rehabilitation Act, they must comply with each and every one of the following fundamental characteristics that allow people with developmental disabilities, like all members of the community, to:

### **1. Make choices about their daily lives**

What it is: Individuals with developmental disabilities must have access to options and make choices, such as where they live, work, or spend their day based on personal likes and dislikes. Decisions such as location of an individual's home, housemates, work activity, daily schedules, and personal choices such as clothing, friends, television programs, etc. must be specific to the person. Individuals with developmental disabilities must be supported to recognize that they can exercise their full rights and responsibilities as community citizens, volunteering time, assisting others, voting, etc.

What it isn't: The community would not be a system in which the state or provider agencies inform people where they will live, work or spend their day. People should not be offered housing arrangements that are only for people with disabilities, where all neighbors have disabilities and houses are clustered by provider or institution affiliation for the convenience of the provider or staff. People with disabilities, just like those without disabilities, should not expect to be told such things as with whom they will live, what they will eat, wear, watch on TV and when they will get up or go to bed.

### **2. Live in integrated settings where not all residents and neighbors have disabilities**

What it is: While disability is a natural part of life and many members of our society experience or will experience a disability, we do not expect all of our neighbors and household members to have a disability. While there will be variances in what becomes a normal expectation, people with disabilities should not have expectations of ratios higher than other members of their community.

What it isn't: People are only offered homes or living arrangements in settings where all or almost all of the residents have disabilities. These settings are often established for the convenience of the provider or funding system rather than the individual resident. Other choices may be diminished as well for the ease of management of the residence and staff.

### **3. Identify services and supports that are individualized to meet their needs**

What it is: People receive support to help identify, design and access the resources and services they need to have a quality life and participate in the community. Individualized services and supports promote self-determination, independence, participation, and inclusion in all aspects of community life. Naturally occurring services and systems are considered first before a specialized service is created and purchased. There is a conscious effort to adapt existing services so that people can participate alongside people who do not have disabilities. Individuals' wishes, needs, and desires are genuinely taken into consideration. Individuals are supported to make informed choices.

What it isn't: People are placed in existing programs and projects. Their personal plans to help them access these programs are developed with little or no input from the individual. People are seldom offered options that all citizens enjoy with individualized adaptations that allow them to participate.

### **4. Fully participate in the community**

What it is: People participate in activities and events of their choice, based on their likes and interests alongside people who do not have disabilities. Staff discreetly supports people only as needed and requested. People with disabilities take advantage of naturally occurring supports. They use transportation systems that are available and used by all citizens. People expect to "go out" to access the services and supports they need.

What it isn't: People "visit" the community in groups organized for people with disabilities. They participate in community activities that are determined by others to be fun or appropriate without meaningful input from individuals with disabilities.

Everything is "special" to meet their needs. Transportation is provided by "the system" and only offered to those with disabilities. In some cases, all of the services and necessities are chosen by others with little or no input from the individual and brought into the residence so that people are never required to leave their home.

### **5. Develop relationships with people with and without disabilities and with whom they have a wide range of interests**

What it is: People develop interdependent friendships and relationships with people who do not have disabilities as well as those who have disabilities. They have friends and caring relationships other than support staff and family members. People feel loved and appreciated for who they are.

What it isn't: People should not have to seek permission or stay within "rules" to talk with or call a friend. When people with developmental disabilities live in segregated settings

they generally have no opportunity to develop relationships with people who do not have disabilities or who are not paid staff.

## **6. Make choices about providers and staff**

What it is: People with developmental disabilities have the right to choose and hire their provider agency and staff. They have input into the hiring and managing of their staff. They receive assistance in dealing with staff problems and training on managing staff. Staff members understand that they work for the individuals and that the home belongs to the individual. Staff members allow personal space and privacy and respect the desires of the individual.

What it isn't: Staff members are assigned to people based on availability and scheduling. If there is a disagreement or complaint from the individual regarding the staff person, the individual must accept responsibility and change or an agency may refuse to provide further support. Staff feels that they are in charge of the people they serve, and they determine activities, make decisions and decide how support will be provided.

## **7. Feel that they are reasonably safe**

What it is: People feel safe and are able to enjoy being out and about in their community without fear and with reasonable expectations that they will not be abused or mistreated while in the community. If they experience an uncomfortable situation or some type of abuse, they know how and to whom to report to and they feel confident that their concerns will be considered valid and will be addressed. People are empowered through education, training and support to safely navigate their community, to recognize, understand and prevent abuse and to engage in healthy reciprocal relationships.

What it isn't: People rely on paid staff or family members to observe abuse or neglect and report incidents because their input is not valid. People with disabilities have not been taught to say "stop" or "no" when strangers, family or trusted staff treat them inappropriately.

## **CONCLUSION**

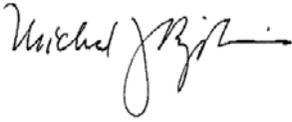
Congress and the United States Supreme Court have established a clear legal mandate that CMS and states must design and deliver federally funded services in a manner that does not unduly isolate or segregate individuals with developmental disabilities. Extensive empirical reports and scientific research further support this direction and provide ample evidence of the benefits of community living in settings that provide opportunities for self-direction and participation in all aspects of community life.

New approaches of living arrangements are emerging across the nation to support individuals with developmental disabilities for which Home and Community Based Waiver funds are being sought. While some of these living arrangements offer innovative options for supporting the inclusion and integration of individuals with developmental disabilities into our communities, there are models of living arrangements that challenge the fundamental values and goals set forth in the DD Act, as well as requirements of the Americans with Disabilities Act, the U.S. Supreme

Court *Olmstead* decision, and the core standards for community living articulated for the Home and Community Based Waiver.

Advocates have worked for over 40 years to shift the bias of federal and state funding from institutional settings to the community. It is imperative that these gains not be reversed. NACDD, AUCD and NDRN urge CMS to adopt strong requirements that prevent the use of Developmental Disabilities Home and Community Based Waiver funds for living arrangements that are not consistent with these values and goals and to protect the continued use of these funds for true community living.

Respectfully submitted,



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