# Appendix A:

## Community Living Advisory Group Recommendation

# Community Living Advisory Group

Waiver Simplification Subcommittee

Co-chairs: Tim Cortez and Marijo Rymer

## Recommendation from the Waiver Simplification Subcommittee

### A. Change Rationale/Problem Definition:

Background:

Currently Colorado has two Home and Community Based (HCBS) Medicaid Waivers for adults with Intellectual/Developmental Disabilities. The HCBS Developmental Disabilities (DD) waiver provides comprehensive residential habilitative services and the HCBS Supported Living Services (SLS) Waiver provides a range of services that do not include residential support or 24 hour supervision. The intensity, level and degree of supervision for services under both waivers are determined by the needs and preferences of the individual based on the Supports Intensity Scale (SIS) Assessment.

Colorado has established annual allocation limits under the SLS waiver (referred to as Service Plan Authorization Limits--SPALs.) In the DD Comprehensive waiver, there is no limit on access to 24-7 residential supervision although there are some limits on specific services available to persons who receive DD Waiver benefits.

The SIS was originally intended as a guide to help adults with IDD, their families and case managers design service/support plans that meet individual needs and preferences; In Colorado, the SIS has been used primarily to determine the level of funding available for persons utilizing the waivers.

Community-Centered Boards (CCBs) are currently the single point of entry for the DD and SLS waivers. CCBs determine eligibility for services; administer the SIS; work with clients and their families to develop an annual service plan and provide ongoing case management. Many agencies, including most CCBs, also provide services and supports for the two adult waivers.

Neither waiver for adults with IDD offers self-direction opportunities. The Consumer Directed Attendant Services and Supports (CDASS) option for Health Maintenance, Personal Care Services, and Homemaker Services has not been extended to these waivers.

In Colorado, like most states, the HCBS DD (residential) waiver was first used to ensure that persons transitioning from state operated institutional settings could move into community based living environments. Most people in Colorado who receive benefits under the DD Waiver live in small group homes, apartments or host homes. Some live with onsite staff support in homes or apartments with three or fewer residents with IDD. A few are able to live in their own homes with full time supervision and support while some live in family homes and use the Family Caregiver service delivery option to access supports and services.

The SLS wavier was designed to provide less intense levels of support for individuals who preferred or required non-residential services. People receiving SLS benefits often live in the family home or in their own homes. There are many instances where the lack of DD waiver resources has limited the choices available to people resulting in situations wherein DD waiver eligible persons can only access the SLS waiver which, in turn, places an extraordinary and often impossible burden on natural support systems.

States establish caps on the number of people that can be served in any HCBS Medicaid waiver. In CO, as in most states, the demand for these resources exceeds the cap and long waiting lists are the result. Families can place the names of their children on a wait list for either/both the DD and SLS waiver when the child turns 14 in hopes that a resource will be available when the child reaches adulthood and is no longer eligible for services through Special Education, Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) or one of the HCBS Children's waivers. Additionally, people who receive SLS waiver services can remain on the DD waiver wait list.

Problem:

- Because of the long waiting lists in CO, when either a DD or SLS resource becomes available, most individuals accept the resource that is offered—regardless of whether the services available in that waiver address their individual needs and preferences. Consequently, there are some individuals who may have preferred to live quasi-independently who accepted the DD residential waiver because other support options were not available and there are many people receiving services through the SLS wavier who require much more intense services than the wavier was designed to provide.

- Additionally, over the past few decades, individuals with IDD and their families have made it clear that they wish to have greater control and flexibility over the types of services and supports that they obtain. The early community based system created care-taking environments in the community that offered far greater choice and freedom than that provided in institutions but the underlying principle of "care-taking" still characterized most HCBS Medicaid waivers for persons with IDD.

- Today, most people with IDD prefer to live as independently as possible and the service delivery system is evolving from "taking care of" people to providing the supports they need to maximize their skills and meet their preferences. Technology will continue to make independent living a possibility for many more people with IDD.

- Another factor that should be considered in re-design of waivers for persons with IDD is that the average lifespan of individuals with IDD has increased dramatically. In the

1960s, for example, the average longevity of people with Down syndrome was around 31 years; in 1993 the mean was 56 and for all people with IDD, the mean was 66; for the general population the mean was 70. Today, people with IDD, in most cases, can expect to live a typical life span of 75+ years. (Braddock—2013)

When the HCBS waivers were first introduced for people with IDD, life spans were considerably shorter and, consequently, the service delivery system did not have to react to the natural changes that occur as adolescents move toward adulthood and into middle and old age. The needs and desires of people with IDD change over time as do the needs and desires of everyone else. Likewise the needs and abilities of other people who support individuals with IDD (e.g. families and friends) also change over time—as do the lives of those who provide support for the general population.

Nationally, more than 25% of persons who provide primary support for a person with IDD are over the age of 60. (2013—Braddock)

- Clearly one of the most important issues that must be addressed in waiver re-design is the need to ensure that persons with IDD have as much control and direction as possible over the types and intensity of supports as well as the methods of delivery. Some families and individuals with IDD prefer and have the resources and skills to design and direct very complex service plans and to hire and monitor support staff. Others would prefer to delegate some or all of those responsibilities to outside agencies. People with IDD and their families prefer to decide with whom they live and by whom support is provided even if they choose to obtain those services through an agency of their choice.

As a result of all these factors and Colorado's restrictions on service delivery options such as self-determination and self-direction for people with IDD, the demand for a wide array of services that promote independence with optimal choice for adults will continue to grow at the same time that the demand for full support options including a choice of residential services will increase.

In short—the current system is both inflexible and outdated; the service delivery models and reimbursement structures are overly restrictive; the CO Waivers do not provide options for self-direction, and individual choice is limited.

## B. Recommendation and anticipated outcomes

The Waiver Simplification (WS) Subcommittee recommends that the CO Department of Human Services, Division for Developmental Disabilities with the CO Department of Healthcare Policy and Financing convene a work group to begin the process of exploring the advantages, disadvantages and fiscal implications of a re-designed HCBS Medicaid waiver to support eligible adults with IDD.

- The work group should be convened no later than Oct. 1, 2013 and should be small enough to be effective but large enough to represent persons currently served in the adult system as well as the families of younger persons with IDD who will enter the system in the next decade.

- Additionally, the WS Subcommittee recommends that the Departments in conjunction with the Work Group be charged with ensuring that the needs and preferences of persons currently receiving services in the DD or SLS waiver are thoroughly explored and addressed.

- The WS Subcommittee recommends that the work group explore a re-designed waiver for adults with IDD that will include flexible service definitions and easy access to enable participants to access services and supports when and where needed based on individual needs and preferences. The new waiver should ensure that participants can readily adjust and make changes in services as needs and preferences change.

- The WS Subcommittee proposes that a re-designed waiver for adults with IDD incorporates these principles:

    - Freedom of choice over living arrangements, social, community, and recreational opportunities
    - Individual authority over supports and services
    - Support for individuals to organize resources in ways that are meaningful to them
    - Health and safety assurances
    - Opportunities for community contributions
    - Responsible use of public dollars

## C. How does the Recommendation address the goals of Triple Aim?

a. Improved Consumer Experience: People with IDD and their families have long noted that the current CO HCBS Waiver services for people with IDD are too complex, rigid, and not responsive to individual needs and circumstances. A single adult waiver for persons with IDD must be designed to allow individuals to access the services they need and prefer throughout their lives as their situations change. With options for self-directed services in most all areas of waiver provisions, persons with IDD will have greater control and influence over the services and supports they receive.

b. Improved Health and Social Integration: With greater flexibility and enhanced responsiveness, individual service plans can be readily modified to accommodate changes in health, family, and social conditions. Greater individual control over the types of services provided as well as the direction of service providers will allow for enhanced social integration.

c. <u>Fiscal Responsibility:</u> A flexible HCBS Medicaid waiver for adults with IDD will allow individuals to move among less and more intensive levels of support based on individual needs and conditions. The goal of a potential new waiver is to ensure that public funds support the services that people need when they need them with ready access as individual situations merit.

## D. Type of action required (e.g., administrative, regulatory, statutory)

The implementation of a new HCBS Medicaid waiver will require statutory change as well as changes to Colorado rules. Initial administrative action to convene the work group is required.

## E. Likely fiscal impact

The fiscal impact is not known at this time. The WS Subcommittee acknowledges that the current levels of funding for HCBS Waivers for persons with IDD are clearly insufficient to meet the needs of those who are eligible for services.

## F. HCPF/DHS-DDD comment

The DHS-DDD agrees with the WS Subcommittee's Recommendation to begin the formal process to explore the advantages, disadvantages and fiscal implications of a new re-designed HCBS Medicaid waiver to support eligible adults with IDD.
This formal process should start through the convening of a waiver re-design work group.

The DHS-DDD supports this recommendation because it addresses the Department's Triple Aim goals. Additionally it aligns with the principles of self-determination, self-direction, person-centered service planning and delivery with a re-designed waiver that is flexible, easy to navigate and provides choice and control to people receiving the supports. Because the fiscal impact is not yet known, much work will need to be done in the re-design process to analyze projected fiscal impact to ensure fiscal responsibility and a financially sustainable service delivery system.

Submitted to the CO Community Living Advisory Group
On behalf of the CO Waiver Simplification Subcommittee

August 19, 2013

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# Appendix B:

Community Living Advisory Group Life Domains

# DEFINITIONS – LIFE DOMAINS

When considering the array of long-term services and supports that might be made available to individuals on Medicaid, supporting individuals to maximize their potential in each life domain is essential. The life domains specifically identified by the Waiver Simplification Subcommittee include Community Integration, Living Arrangements and Health and Safety. If a life plan is used to set goals in each of the life domains and to identify needed supports and services, the person should have the opportunity to provide routine feedback to ensure that the life plan is being implemented according to the individual's wishes. Every effort should be made to ensure that the choices of those with communication difficulties are honored.

It should be recognized that barriers exist in maximizing the choice in each domain. Regulatory barriers exist that restrict someone's ability to live their lives. The culture of the system, particularly if it is risk-adverse, may pose unnecessary limits on choice. Services and supports to secure health and safety may be restricted because of regulatory and financial considerations. It is important therefore to recognize these barriers and to the extent possible minimize impediment on choice in each life domain area. The Waiver Simplification Subcommittee is charged with recommending an array of long-term services and supports to the Community Living Advisory Group. Each service will have a definition. Each definitions should be constructed so as to minimize restrictions on an individual to live life while supporting health and safety.

The following definitions of the Life Domains are meant to serve as a guide to selecting and defining the services and supports that might support a person in attaining individual goals in each area. The examples listed for each domain or barriers that might exist are not meant to be an exhaustive list. These lists are meant to provide a sense of what might be included within a particular domain or what might be an impediment.

## COMMUNITY INTEGRATION

Individuals have the same opportunity to live in the community just like people without disabilities. They have choices for how they spend their time, with whom they spend their time and how they contribute to the community.

**With whom does the person want to spend time?**

- People who share similar interests: hobbies, job, church/synagogue,
- Own family
- Host family
- Friends from work, church, school, neighborhood, peers
- People who support the person
- Prefers to be alone most of the time

**How does the person want to spend his or her time?**

- Volunteering
- Job
- Adult learning opportunities
- Sports—recreation

- Church/synagogue
- Community activities: visiting museums, local attractions, coffee shops, restaurants, malls,
- Dating
- Listening to music, watching TV, movies,
- Hobbies
- Participate in groups or spend time alone
- School events (e.g. access to prom) and after school activities (e.g. sports, clubs, drama, etc.)
- Group activities and camps
- Hanging out with friends

**How can the people who support the person help him or her be a part of my community?**

- Providers should help identify interests and abilities
- Choices should be respected—including the choice to be alone or not to have community relationships
- As interests change, activities should also change
- Expectations should be higher than status quo
- Age, nature of disability should be considered
- Accessibility and transportation needs to considered
- Technological connections should be provided
- Social skill building opportunities should be made available
- Integrated/unified teams and activities
- Professionals should coordinate services and supports across settings (home/school)
- Peer mentorship services should be available in the community and at school

**How can the person contribute to his or her community?**

- Voluntarism
- Supported employment in a real job
- Customized employment
- Employment
- Shopping
- Worshipping
- Involvement in community organizations, clubs or political activism
- Supporting neighbors
- Fundraising for worthy causes
- Choice to not contribute to the community
- Training and ongoing support to manage money and resources under my control
- School to adult transition process needs strengthening

- Providers and case managers should offer opportunities to explore/test options
- Schools in rural areas could be key players for community engagement
- Definition of community contribution is different for different people

## LIVING ARRANGEMENTS

With access to the services and supports needed to live safely and comfortably, individuals have choices with whom they want to live and where they want to live.

**With whom? Choices:**

- Live in one's own home
- Live alone or with a roommate/companion of choice
- Live in group setting (Assisted Living, Group Home)
- Live with own family or not
- Live with a family other than one's own (Adult Foster Care, Host Home)
- Live with a spouse or other domestic partner
- Live with pets or not

### Considerations for Children

- Live with other family members by expanding definition of family to maintain waiver services
- Include child voice in decision (Best interest, least restrictive, least intrusive)
- Preserve family
- Live in voluntary/temporary placement setting

**Where? Choices:**

- Type of neighborhood—rural, urban, suburban, quiet, busy
- Setting with access to caregivers
- Setting with access to jobs or volunteer activities or church/synagogue
- Home owned or leased by the individual (co-signing OK)
- Home owned by an agency

**What is needed to live comfortably and safely?**

- Accessibility—ADA/FHA compliant
- Affordability
- Privacy when desired
- Independent living skills training
- Assistive technology
- Monitoring technology
- Adequate supports for the whole family, including ongoing planned respite, and crisis respite.
- Nutrition, physical activity

**Barriers re: living arrangements that need to be addressed:**

- Health and safety regulations that allow for as much independence as possible
- Control and choice over in-home supports
- Transportation
- HUD vouchers should be controlled by the individual not by an agency
- Future planning as individual and family needs and situations change
- Regulations that restrict parent/family involvement/caretaking –co-parenting, e.g. restrictions on how much time an individual can be "out of placement"
- Difficulty accessing HUD information
- Difficulty with landlords and policy being sensitive to behavioral issues

## HEALTH AND SAFETY

Individuals access the service and supports necessary to address their needs, to live successfully in the community and to mitigate any risks for institutionalization, avoidable acute conditions and incidents of abuse, neglect and exploitation.

**What supports are needed to live safely in the community?**

- Access to mental health services and supports
- Access to long-term services and supports
- Access to health and dental care
- Access to transportation
- Access to planned therapeutic respite. Temporary out of home options that don't jeopardize waiver eligibility/enrollment

**Things to consider regarding health and safe:**

- Honor risk-taking choices
- Services and supports should be based on need not diagnosis
- Gaps in access to acute health care, dental, and psychological/behavioral services
- Provider preferences/conveniences should be identified and not imposed on individuals in service without knowledge and agreement
- Needs to be a balance between choice and risk
- Levels of risk are affected by many issues and all should be considered in services/plan development:
    - Culture
    - Age
    - Family of origin
    - Health conditions
    - Socialization history
- Peer mentorship helpful in negotiating risk and choice
- Support economic security for the individual
- Flexibility of paid supports to adjust with the acuity of behavioral needs

## Considerations for Children across Life Domains

Embrace/incorporate values of Early Intervention and Family Support Services Program

- Focus is on helping parents and families meet the needs of their children
- Help parents and other family members learn ways to support and promote the child’s development within their own family activities and community life.
- The definition of “parents” and “families” are used to mean anyone who is in charge of the care and well-being of a child. These can be legal guardians, single parents, grandparents, surrogate parents, foster parents, or other family members. CES limits eligibility to children living with a.) With biological, adoptive parent(s), or legal guardian
- Services must be responsive to the needs of the entire family unit
- Focus is on reducing the added stress on families as a result of supporting a family member with a developmental disability in the home (financial, emotional, and physical).
- Family support is needed throughout the lifespan of the individual who has a disability.
- Services must be flexible enough to accommodate unique needs of families as they evolve over time.
- Services should be comprehensive and coordinated across settings as well as the numerous agencies likely to provide resources, supports, or services to families. Foster collaboration and cooperation with all agencies providing services and supports to children and their families

# Appendix C:

Community Living Advisory Group Waiver Simplification Subcommittee: Services and Supports Worksheet

# Waiver Simplification Services and Supports Worksheet

Waiver Simplification is focused on changing the design and delivery of home and community-based services (HCBS) to support person-centered access to long-term services and supports (LTSS) based on choice and individual needs and not solely on diagnosis or disability.  Waiver simplification will maximize choice and flexibility to the extent possible so that people receive the services they need when and where they need them in the home or the community.

**Considerations for waiver services:**

- How does the service support the person's life choices?
- How does the service support caregivers and providers?
- What activities are included or covered through the service (ADL and IADL assistance, health and wellness, plan development, education, coaching, problem-solving, intervention to de-escalate crises, access to community resources, etc.)
- What activities/benefits are excluded?
- Will the service or support be needed by a specific population or multiple populations?
- Where is the service available (home, community, onsite at provider agency, offsite, etc.)?
- How the service is delivered (face-to-face, telephone, video conference, group, family, etc.)
- Who can provide the service, *i.e.,* provider and staff qualifications?
- What are the limits on the amount, scope or duration of the service?

| Service | Description | Life Domains | Target Population |
|---|---|---|---|
| **Personal Support , Homemaker services and Health Maintenance** | **Support in the community and at home including supportive supervision when needed (DDRD) for activities of daily living including: eating , dressing, grooming, hygiene, and walking/transferring; Instrumental Activities of Daily Living including: daily planning, decision-making, problem-solving, money management, transportation management, shopping, meal preparation, communication devices and techniques, homemaker and home maintenance services and support, service animal care/maintenance; and support to maintain health and wellness:**<br>• Support is either supervision of the completion of the task, doing the task, assistance with a task, instruction for the person to complete the task, or a combination of supports based on the individual's informed choice | ☒Community Integration<br>☒Health & Safety<br>☒Living Arrangements | ☒Elderly<br>☒People with Disabilities<br>☒People with IDD<br>☒People with Mental Illness<br>☒Children with Special Needs<br>☒People with Brain Injuries |

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| **Personal Coach** | **Support to develop goals and explore options to achieve goals (long or short term) related to life domains:**<br>- Identification of goals and aspirations<br>- The service should be available at entry into programs and intermittently as identified in the person-centered plan<br>- Person receiving services should have options to choose his/her personal coach and direct the process<br>- Support experiential learning<br>- Support for exploration of housing options for those moving from one setting to another | ☒Community Integration<br>☒Health & Safety<br>☒Living Arrangements | ☒Elderly<br>☒People with Disabilities<br>☒People with IDD<br>☒People with Mental Illness<br>☒Children with Special Needs<br>☒People with Brain Injuries |
| **Respite** | - **Respite support provided on a short-term basis including emergency services because of the absence or need for relief of persons who normally provide support to the person.**<br>- **Therapeutic Respite:**<br>  ○ Support provided on a short-term basis for:<br>    ▪ Assessment and treatment formulation<br>    ▪ Symptom monitoring<br>    ▪ Emergency support<br>    ▪ Hospital diversion<br>    ▪ Step-down support from any institutional setting<br>    ▪ Family support and education | ☒Community Integration<br>☒Health & Safety<br>☒Living Arrangements | ☒Elderly<br>☒People with Disabilities<br>☒People with IDD<br>☒People with Mental Illness<br>☒Children with Special Needs<br>☒People with Brain Injuries |
| **Home Modifications** | **Physical adaptations to a private residence necessary to support sensory/physical/behavioral health and welfare and enable greater independence in the home.** | ☒Community Integration<br>☒Health & Safety<br>☒Living Arrangements | ☒Elderly<br>☒People with Disabilities<br>☒People with IDD<br>☒People with Mental Illness<br>☒Children with Special Needs<br>☒People with Brain Injuries |

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| **Assistive Technology** | **Assistive Technology:**<br>• An item, piece of equipment, or system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve the ability to live as independently as desired.<br>**Assistive Technology Services:**<br>• Support that directly assists a participant in the selection, acquisition, or use of an assistive technology device, including:<br>o The evaluation of the assistive technology needs of a participant including usage outside the home—e.g. need for weatherproofed equipment<br>o Services consisting of purchasing, leasing, or otherwise providing for the acquisition of assistive technology for participants<br>o Services consisting of selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing assistive technology devices<br>o Coordination and use of necessary therapies, interventions, or services with assistive technology devices<br>o Training or technical assistance related to the assistive technology use for the participant or support network, including providers | ☒Community Integration<br>☒Health & Safety<br>☒Living Arrangements | ☒Elderly<br>☒People with Disabilities<br>☒People with IDD<br>☒People with Mental Illness<br>☒Children with Special Needs<br>☒People with Brain Injuries |

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| **Behavioral Supports** | Supports that assist the participant with behaviors that limit and impair everyday functioning. Behavioral supports assist the participant in developing, maintaining, improving, or restoring, to the maximum extent possible, the ability to participate meaningfully in the community and meet personal goals.<br>**Services**<br>• **Behavioral Consultation:**<br>Development and implementation of behavioral support plans and behavioral interventions necessary for the individual to acquire or maintain appropriate adaptive behaviors, interactions with others and behavioral self-management. Intervention modalities shall relate to an identified behavioral need of the individual and are monitored for outcomes and integration into all services and supports.<br>• **Behavioral Plan Assessment:**<br>Observations, environmental assessments, interviews of direct staff, functional behavioral analysis and assessment, evaluations and completion of a written assessment document.<br>• **Individual/Group Counseling:**<br>Psychotherapeutic or psych educational intervention for the individual to acquire or maintain appropriate adaptive behaviors, interactions with others and behavioral self-management, to positively impact the individual's behavior or functioning.<br>• **Behavioral Line Services:**<br>Implementation of the behavioral support plan, under the supervision and oversight of a Behavioral Consultant for acute, short term intervention to | ☒Community Integration<br>☒Health & Safety<br>☒Living Arrangements | ☒Elderly<br>☒People with Disabilities<br>☒People with IDD<br>☒People with Mental Illness<br>☒Children with Special Needs<br>☒People with Brain Injuries |

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| | address an identified behavior of an individual that puts the individual's health and safety and/or the safety of others at risk. | | |
| **Transportation** | **Non-Medical Transportation:**<br>• Service offered in order to enable waiver participants to gain access to waiver and other community services, activities and resources.<br>• Transportation services may include access to public transportation, training on the use of public transportation, the direct provision of transportation, or a combination of services based on the individual's informed choice<br><br>**Vehicle Modification:**<br>• Adaptations or alterations to an automobile that is the person's primary means of transportation that are necessary in order to accommodate the special needs of the person and enable the person to integrate more fully into the community and to ensure the health, welfare and safety of the participant. The following are specifically excluded:<br>○ Adaptations or improvements to the vehicle that are of general utility, and are not of direct medical or remedial benefit to the individual;<br>○ Purchase or lease of a vehicle; and<br>○ Regularly scheduled upkeep and maintenance of a vehicle except upkeep and maintenance of the modifications | ☒Community Integration<br>☒Health & Safety<br>☒Living Arrangements | ☒Elderly<br>☒People with Disabilities<br>☒People with IDD<br>☒People with Mental Illness<br>☒Children with Special Needs<br>☒People with Brain Injuries |
| **Community and Personal Engagement** | **Support to develop and implement goals and aspirations for employment, volunteer work, civic involvement, relationships, self-advocacy, training, and education. Services should be based on the individual's choice, including social media and other online opportunities.** | ☒Community Integration<br>☒Health & Safety<br>☒Living Arrangements | ☒Elderly<br>☒People with Disabilities<br>☒People with IDD<br>☒People with Mental Illness<br>☒Children with Special Needs<br>☒People with Brain Injuries |

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| | **Social engagement:**<br>• Activities that promote interaction with friends and companions of choice including:<br>• Teaching and modeling of social skills, communication, group interaction and collaboration<br>**Habilitation Services:**<br>• Services designed to assist the person in acquiring, retaining and improving self-help, socialization and, adaptive skills necessary for community living including:<br>○ teaching and modeling of social skills, communication, group interaction and collaboration.<br>○ Educational supports for complaints, grievances, appeals<br>○ Support for integrated & meaningful training and informed choice for community involvement including volunteering, self-advocacy, education options and other choices defined by the individual<br>**Supported Employment/Vocational Services:**<br>• Support for integrated & meaningful education and informed choice related to school transition planning (applicable populations)<br>• Support for meaningful job skill development and integrated education for employment, both hard (having the knowledge to do a technical defined task) and soft (not required a specified technical skill or physical task skills, including generic work (social) skills and job specific skills.<br>• Support for integrated services available through DVR and other work training options. | | |

# Appendix D:

Centers for Medicare and Medicaid Services Summary of Key Provisions of the HCBS Settings Final Rule

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop S2-26-12
Baltimore, Maryland 21244-1850

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES
CENTER FOR MEDICAID & CHIP SERVICES

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January 10, 2014

# Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule

## *(CMS 2249-F/2296-F)*

This final rule establishes requirements for the qualities of settings that are eligible for reimbursement for the Medicaid home and community-based services (HCBS) provided under sections 1915(c), 1915(i) and 1915(k) of the Medicaid statute. Over the past five years, CMS has engaged in ongoing discussions with stakeholders, states and federal partners about the qualities of community-based settings that distinguish them from institutional settings. As part of this stakeholder engagement, CMS issued an Advanced Notice of Proposed Rule Making (ANPRM) and various proposed rules relating to home and community-based services authorized by different sections of the Medicaid law, including 1915(c) HCBS waivers, 1915(i) State Plan HCBS and 1915(k) Community First Choice State Plans. CMS' definition of home and community-based settings has benefited from and evolved as a result of this stakeholder engagement.

In this final rule, CMS is moving away from defining home and community-based settings by "what they are not," and toward defining them by the nature and quality of individuals' experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics. The changes related to clarification of home and community-based settings will maximize the opportunities for participants in HCBS programs to have access to the benefits of community living and to receive services in the most integrated setting and will effectuate the law's intention for Medicaid HCBS to provide alternatives to services provided in institutions.

### *Overview of the Settings Provision*

The final rule requires that all home and community-based settings meet certain qualifications. These include:

- The setting is integrated in and supports full access to the greater community;
- Is selected by the individual from among setting options;
- Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;
- Optimizes autonomy and independence in making life choices; and
- Facilitates choice regarding services and who provides them.

The final rule also includes additional requirements for provider-owned or controlled home and community-based residential settings. These requirements include:

- The individual has a lease or other legally enforceable agreement providing similar protections;

- The individual has privacy in their unit including lockable doors, choice of roommates and freedom to furnish or decorate the unit;
- The individual controls his/her own schedule including access to food at any time;
- The individual can have visitors at any time; and
- The setting is physically accessible.

Any modification to these additional requirements for provider-owned home and community-based residential settings must be supported by a specific assessed need and justified in the person-centered service plan.

The final rule excludes certain settings as permissible settings for the provision of Medicaid home and community-based services. These excluded settings include nursing facilities, institutions for mental disease, intermediate care facilities for individuals with intellectual disabilities, and hospitals. Other Medicaid funding authorities support services provided in these institutional settings.

The final rule identifies other settings that are presumed to have institutional qualities, and do not meet the threshold for Medicaid HCBS. These settings include those in a publicly or privately-owned facility that provides inpatient treatment; on the grounds of, or immediately adjacent to, a public institution; or that have the effect of isolating individuals receiving Medicaid-funded HCBS from the broader community of individuals not receiving Medicaid-funded HCBS. If states seek to include such settings in Medicaid HCBS programs, a determination will be made through heightened scrutiny, based on information presented by the state demonstrating that the setting is home and community-based and does not have the qualities of an institution. This process is intended to be transparent and includes input and information from the public. CMS will be issuing future guidance describing the process for the review of settings subject to heightened scrutiny through either the transition plan process (for settings already in states' HCBS programs) or the HCBS waiver review processes (for settings states seek to add to their HCBS programs).

The final rule includes a transitional process for states to ensure that their waivers and state plans meet the HCBS settings requirements. New 1915(c) waivers or 1915(i) state plans must meet the new requirements to be approved. For currently approved 1915(c) waivers and 1915(i) state plans, states must evaluate the settings currently in their 1915(c) waivers and 1915(i) state plan programs and, if there are settings that do not fully meet the final regulation's home and community-based settings requirements, work with CMS to develop a plan to bring their program into compliance. The public will have an opportunity to provide input on states' transition plans. CMS expects states to transition to the new settings requirements in as brief a period as possible and to demonstrate substantial progress during any transition period. CMS will afford states a maximum of a one year period to submit a transition plan for compliance with the home and community-based settings requirements of the final rule, and CMS may approve transition plans for a period of up to five years, as supported by individual states' circumstances, to effectuate full compliance.

States submitting a 1915(c) waiver renewal or waiver amendment within the first year of the effective date of the rule may need to develop a transition plan to ensure that specific waiver or state plan meets the settings requirements. Within 120 days of the submission of that 1915(c) waiver renewal or waiver amendment, the state needs to submit a plan that lays out timeframes and benchmarks for developing a transition plan for all the state's approved 1915(c) waiver and 1915(i) HCBS state plan programs. CMS will work closely with states as they consider how to best implement these provisions and will be issuing future guidance on requirements for transition plans.

### *Changes in the Final Rule*

The final rule clarifies several major areas of confusion and concern expressed by some commenters and stakeholders engaged throughout the processes of rulemaking regarding the requirements for home and community-based settings. While CMS' responses to the specific comments are contained in the preamble to the final rule, below is a summary of the areas of the rule that received the most feedback and the changes in the final rule that address those comments:

- **Disability specific complex**. The proposed rule included "disability specific complex" in the list of settings presumed not to be home and community-based settings. Comments on the proposed rules suggested that the phrase "disability specific complex" had multiple meanings, and the continued use of the phrase could have unintended adverse impacts on affordable housing options. To avoid those consequences, CMS eliminated the use of the phrase from the final rule. The final rule includes the following language on other settings: "any other setting that has the effect of discouraging integration of individuals from the broader community…"

- **Rebuttable presumption**. The proposed rule indicated that CMS would exercise a "rebuttable presumption" that certain settings are not home and community-based. CMS has removed this phrase from the final rule and clarified in the final rule that certain settings are presumed to have institutional characteristics and will be subjected to heightened scrutiny if states seek to include these settings in their HCBS programs. The rule allows the state to present evidence to CMS that the setting is actually home and community-based in nature and does not have the qualities of an institution. CMS will consider input from stakeholders, as well as its own reviews, in applying heightened scrutiny. This process will require the state to solicit public input.

- **Choice of provider in provider owned or controlled settings.** The final rule clarifies that when an individual chooses to receive home and community-based services in a provider owned or controlled setting where the provider is paid a single rate to provide a bundle of services, the individual is choosing that provider, and cannot choose an alternative provider, to deliver all services that are included in the bundled rate. For any services that are not included in the bundled rate, the individual may choose any qualified provider, including the provider who controls or owns the setting if the provider offers the service separate from the bundle. For example, if a residential program provides habilitation connected with daily living and on-site supervision under a bundled rate, an individual is choosing the residential provider for those two services when he or she chooses the residence. The individual has free choice of providers for any other services in his or her service plan, such as employment services and other community supports.

- **Private rooms and roommate choice**. The final rule clarifies that states, as opposed to individual providers, have the responsibility for ensuring that individuals have options available for both private and shared residential units within HCBS programs. The rule further clarifies that an individual's needs, preferences and resources are relevant to his/her options for shared versus private residential units. Provider owned or operated residential settings will be responsible to facilitate individuals having choice regarding roommate selection within a residential setting.

- **Application of home and community-based settings requirements to non-residential settings.** CMS has clarified that the rule applies to all settings where HCBS are delivered, not just to residential settings. CMS will be providing additional information about how states should apply the standards to non-residential settings, such as day program and pre-vocational training settings.

# Appendix E:

## Centers for Medicare and Medicaid Services Guidance on Home and Community-Based Settings Requirements (Revised January 2015)

# Appendix C-5: Home and Community-Based Settings Requirements

## Overview

Since April, 2008, CMS has engaged in ongoing discussions with stakeholders, states and federal partners about the qualities of community-based settings that distinguish them from institutional settings. As part of this stakeholder engagement, CMS issued a 1915(c) Waiver Advanced Notice of Proposed Rule Making (ANPRM) and various proposed rules relating to home and community-based services authorized by different sections of the Medicaid law, including 1915(c) HCBS waivers, 1915(i) State Plan HCBS and 1915(k) Community First Choice State Plans. CMS' definition of home and community-based settings has benefited from and evolved as a result of this stakeholder engagement.

In final rules published on January 16, 2014, CMS moved away from defining home and community-based settings by "what they are not," and toward defining them by the nature and quality of individuals' experiences. The home and community-based setting provisions in the final rules established a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics. The purpose of the home and community-based settings requirements is to maximize the opportunities for participants in HCBS programs to have access to the benefits of community living and to receive services in the most integrated setting. The requirements effectuate the law's intention for Medicaid HCBS to provide alternatives to services provided in institutions. States' implementation of these requirements will contribute significantly to the quality and experience of participants in Medicaid HCBS waiver programs and will further expand their opportunities for meaningful community integration in support of the goals of the Americans with Disabilities Act and the Supreme Court's decision in *Olmstead v. L.C.*

## Instructions

This section was added to the waiver application for states to document state compliance with the final regulations published on January 16, 2014 regarding the home and community-based (HCB) settings requirements at 42 CFR 441.301(c)(4)-(5). In this section, states are to describe the settings where waiver participants reside, where waiver services are provided, and how these settings meet the HCB setting requirements at 42 CFR 441.301(c)(4)-(5). States must also specify how the state Medicaid agency determined that the settings meet the HCB settings requirements at the time of submission to CMS, as well as how the state will ensure that all settings will continue to meet the HCB settings requirements in the future. This section includes a large text field (allows up to 60,000 characters), to ensure ample space for the state's response.

## Technical Guidance

The HCB setting requirements support home and community-based settings that serve as an alternative to institutional care and that take into account the quality of individuals' experiences. They require that all home and community-based settings meet certain qualifications, including, at a minimum:

- Is integrated in and supports full access to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS;

- Is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board;
- Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;
- Optimizes, but does not regiment, individual initiative, autonomy and independence in making life choices; including but not limited to, daily activities, physical environment, and with whom to interact;
- Facilitates choice regarding services and who provides them.

The regulation also includes additional requirements for provider-owned or controlled home and community-based residential settings. These requirements include ensuring:

- The individual has a lease or other legally enforceable agreement providing similar protections. The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the State, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.
- The individual has privacy in their sleeping or living unit including:
  - ➢ Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors.
  - ➢ Individuals sharing units have a choice of roommates in that setting.
  - ➢ Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.
- The individual has the freedom and support to control his/her own schedule and activities, including access to food at any time;
- The individual can have visitors of their choosing at any time; and
- The setting is physically accessible to the individual.

Any modification to these additional requirements for provider-owned home and community-based residential settings must be supported by a specific assessed need and justified with documentation in the person-centered service plan including the following:

- Identify a specific and individualized assessed need.

- Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
- Document less intrusive methods of meeting the need that have been tried but did not work.
- Include a clear description of the condition that is directly proportionate to the specific assessed need.
- Include regular collection and review of data to measure the ongoing effectiveness of the modification.
- Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
- Include the informed consent of the individual.
- Include an assurance that interventions and supports will cause no harm to the individual.

The regulations at 42 CFR 441.301(c)(5) excludes certain settings as permissible settings for the provision of Medicaid home and community-based services. These excluded settings include nursing facilities, institutions for mental disease, intermediate care facilities for individuals with intellectual disabilities, and hospitals. Other Medicaid funding authorities support services provided in these institutional settings.

The regulations 441.301(c)(5)(v) also identify other settings that are presumed to have institutional qualities, and do not meet the threshold for Medicaid HCBS. These settings include:

- any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment,
- any setting that is located in a building on the grounds of, or immediately adjacent to, a public institution, or
- any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.

If states seek to include such settings in a 1915(c) waiver, CMS will make a determination through heightened scrutiny, based on information presented by the state demonstrating that the setting is home and community-based and does not have the qualities of an institution. This process is intended to be transparent and therefore, must include input and information from the public.

### Settings that Isolate

Some settings have the effect of isolating individuals receiving HCBS from the broader community. Settings that have the following two characteristics alone might, but will not necessarily, meet the criteria for having the effect of isolating individuals:

- The setting is designed specifically for people with disabilities, and often even for people with a certain type of disability.
- The individuals in the setting are primarily or exclusively people with disabilities and on-site staff provides many services to them.

Settings that isolate people receiving HCBS from the broader community may have any of the following characteristics:

- The setting is designed to provide people with disabilities multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities.
- People in the setting have limited, if any, interaction with the broader community.
- Settings that use/authorize interventions/restrictions that are used in institutional settings or are deemed unacceptable in Medicaid institutional settings (e.g. seclusion).

The following is a non-exhaustive list of examples of residential settings that typically have the effect of isolating people receiving HCBS from the broader community:

- <u>Farmstead or disability-specific farm community:</u> These settings are often in rural areas on large parcels of land, with little ability to access the broader community outside the farm. Individuals who live at the farm typically interact primarily with people with disabilities and staff who work with those individuals. Individuals typically live in homes only with other people with disabilities and/or staff. Their neighbors are other individuals with disabilities or staff who work with those individuals. Daily activities are typically designed to take place on-site so that an individual generally does not leave the farm to access HCB services or participate in community activities. For example, these settings will often provide on-site a place to receive clinical (medical and/or behavioral health) services, day services, places to shop and attend church services, as well as social activities where individuals on the farm engage with others on the farm, all of whom are receiving Medicaid HCBS. While sometimes people from the broader community may come on-site, people from the farm do not go out into the broader community as part of their daily life. Thus, the setting does not facilitate individuals integrating into the greater community and has characteristics that isolate individuals receiving Medicaid HCBS from individuals not receiving Medicaid HCBS.
- <u>Gated/secured "community" for people with disabilities:</u> Gated communities typically consist primarily of people with disabilities and the staff that work with them. Often, these locations will provide residential, behavioral health, day services, social and recreational activities, and long term services and supports all within the gated community. Individuals receiving HCBS in this type of setting often do not leave the grounds of the gated community in order to access activities or services in the broader community. Thus, the setting typically does not afford individuals the opportunity to fully engage in community life and choose activities, services and providers that will optimize integration into the broader community.
- <u>Residential schools:</u> These settings incorporate both the educational program and the residential program in the same building or in buildings in close proximity to each other (e.g. two buildings side by side). Individuals do not travel into the broader community to live or to attend school. Individuals served in these settings typically interact only with other residents of the home and the residential and educational staff. Additional individuals with disabilities from the community at large may attend the educational program. Activities such as religious services may be held on-site as opposed to facilitating individuals attending places of worship in the community.

> These settings may be in urban areas as well as suburban and rural areas. Individuals experience in the broader community may be limited to large group activities on “bus field trips.” The setting therefore compromises the individual’s access to experience in the greater community at a level that isolates individuals receiving Medicaid HCBS from individuals not receiving Medicaid HCBS.

Multiple settings co-located and operationally related (i.e., operated and controlled by the same provider) that congregate a large number of people with disabilities together and provide for significant shared programming and staff, such that people’s ability to interact with the broader community is limited. Depending on the program design, this could include, for example, group homes on the grounds of a private ICF or numerous group homes co-located on a single site or close proximity (multiple units on the same street or a court, for example). In CMS’ experience, most Continuing Care Retirement Communities (CCRCs), which are designed to allow aging couples with different levels of need to remain together or close by, do not raise the same concerns around isolation as the examples above, particularly since CCRCs typically include residents who live independently in addition to those who receive HCBS.

More information regarding the home and community-based setting requirements is available on the CMS website at:

http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html

### CMS Review Criteria

The State’s description of settings where waiver participants reside and receive HCBS demonstrates how the state will ensure that all HCB setting requirements at 42 CFR 441.301(c)(4)-(5) will be met and includes:

- A list of the specific settings where individuals will reside;
- A list of the specific settings where individuals will receive services;
- The process that the state Medicaid agency used to assess and determine that all waiver settings meet the HCB settings requirements; and
- The process that the state Medicaid agency will use to ensure that all settings will continue to meet the HCB settings requirements in the future.

# Appendix F:

## United States Department of Health and Human Services Guidance on Person-Centered Planning and Self-Direction

June 6, 2014

TO: Heads of Operating Divisions
Heads of Staff Divisions

SUBJECT: Section 2402(a) of the Affordable Care Act – Guidance for Implementing Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs

Section 2402(a) of the Affordable Care Act requires the Secretary to ensure all states receiving federal funds develop service systems that are responsive to the needs and choices of beneficiaries receiving home and community-based long-term services (HCBS), maximize independence and self-direction, provide support coordination to assist with a community-supported life, and achieve a more consistent and coordinated approach to the administration of policies and procedures across public programs providing HCBS.

The attached guidance contains standards on person-centered planning and self-direction of HCBS that should be embedded in all HHS funded HCBS programs as appropriate. The guidance is consistent with the final rule from the Centers for Medicare & Medicaid Services on Medicaid HCBS and meets the requirement in section 2402(a) for a more consistent administration of policies and procedures across programs. This guidance is the Department's first step in implementing section 2402(a).

HHS agencies that administer HCBS programs are to apply these standards on person-centered planning and self-direction as you develop or revise regulations, policies and guidance, provide technical assistance, offer funding opportunities, or take other relevant actions. The agencies most directly affected by this guidance include:

- Administration for Community Living
- Centers for Medicare & Medicaid Services
- Health Resources and Services Administration
- Indian Health Service
- Substance Abuse and Mental Health Services Administration
- Administration for Children and Families

If your agency is not listed above, you are encouraged to review this guidance and consider how the programs you administer, including your research and demonstration programs, could be used to promote the use and further enhancement of person-centered planning and self-direction.

All HHS agencies are encouraged to share this guidance with relevant stakeholders, including funded agencies, contractors, advocacy groups, advisory councils, associations, and others who may have a role in the home and community-based system.

This guidance is not intended to supersede or otherwise conflict with existing regulations or guidance, nor does it provide a basis for enforceability on non-Departmental entities. Section 2402(a) does not prescribe a specific timeframe for achieving full implementation. However, it is expected the affected agencies will take active steps to implement this guidance.

The Administration for Community Living will coordinate section 2402(a) activities within the Department as part of the work of the Community Living Council Strategic Plan. Sharon Lewis, my Senior Advisor for Disability Policy and Principal Deputy Administrator for Community Living, will chair an interagency team to oversee the implementation of this guidance and future section 2402(a) activities. I am asking the Heads of the agencies listed above and other interested Operating Divisions and Staff Divisions to let Sharon know who you want to represent you on this group. This interagency team will develop annual work plans (including a roll-out plan of this guidance to stakeholders), share lessons learned and best practices, and report to the Secretary on an annual basis on the progress being made in implementing section 2402(a). For your reference, a list of the members of the June 2010 workgroup that contributed to the development of this guidance is enclosed.

For questions regarding this guidance, please contact Shawn Terrell, Administration for Community Living at (202) 357-3517 or shawn.terrell@acl.hhs.gov .

Thank you for your support in implementing section 2402(a).

Kathleen Sebelius

Enclosures:

- HCBS Section 2402(a) Guidance
- Roster of June 2010 Section 2402(a) Workgroup

# Guidance to HHS Agencies for Implementing Principles of Section 2402(a) of the Affordable Care Act:

## Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs

## Introduction

The Patient Protection and Affordable Care Act (Pub. L. 111–148, enacted on March 23, 2010), amended by the Health Care and Education Reconciliation Act of 2010 (Pub. L. 111–152, enacted on March 30, 2010), collectively referred to as the Affordable Care Act (ACA), includes section 2402(a), entitled "Oversight and Assessment of the Administration of Home and Community-Based Services." This section requires promulgation of regulations by the Secretary of Health and Human Services (HHS) to ensure states develop community-based long-term services and supports (LTSS) systems designed to allocate resources and provide the necessary supports and coordination to be responsive to the person-centered needs and choices of older adults and people with disabilities in ways that maximize their independence and ability to engage in self-direction of their services, and achieve a more consistent and coordinated approach to the administration of policies and procedures across public programs.

LTSS are assistance with activities of daily living and instrumental activities of daily living provided to older people and adults with disabilities that cannot perform these activities on their own due to a physical, cognitive, or chronic health condition. LTSS may provide care, case management, and service coordination to people who live in their own home, a residential setting, a nursing facility, or other institutional setting. LTSS also include supports provided to family members and other unpaid caregivers. LTSS may be provided in institutional and community settings.

For purposes of this guidance, home and community-based services (HCBS) are services and supports that assist older adults and people with disabilities (including mental health and substance use disorders) to live with dignity and independence in community settings. HCBS complement medical and other traditional health services, and help people to maintain and improve health and quality of life in their chosen community setting. HCBS play an important role in healthcare integration efforts, including the evolution of health and medical homes, and care transitions.

This guidance is not intended to supersede or otherwise conflict with existing regulations or policies, or other guidance issued by HHS. Affected HHS operating and staff divisions are expected to take active steps to implement the guidance. HHS agencies should use it to develop or revise requirements and options, as appropriate, within programs that offer or impact policies related to HCBS. Specifically, the standards in this guidance should be used in future program regulations, program policies, funding opportunities, technical assistance contracts, grant opportunities, and other programs funding HCBS. The statute applies to all federal and state programs, including those "other than the state Medicaid program," as cited in section 2402(a) of the ACA. HHS staff performing duties such as contract monitoring and grant administration must have the knowledge and capacity to report on the implementation of this guidance to the Secretary upon request.

This initial guidance serves as an important first step in implementing section 2402(a) of the ACA. It outlines the standards for person-centered planning (PCP) and self-direction (SD) that should be reflected in all HHS programs that fund or provide HCBS.

## Background

Over the past forty years federal, state, local, and tribal governments have developed and financed HCBS for older adults and people with disabilities across the lifespan to promote community living, and to avert or minimize institutionalization.

The scope of HCBS offered under various federal and state programs is significant. For example, HCBS provided under Medicaid waiver and state plan authorities include programs authorized under section 1915(c) of the Social Security Act (the Act); newer programs under sections 1915(i), 1915(j) and the 1915(k) of the Act; and other HCBS that may be covered under the Medicaid State Plan such as home health and personal care. HCBS may also be offered in a managed care environment through for example, concurrent section 1915(b) and (c) Medicaid waivers or section 1115 demonstration projects. HCBS are often included in initiatives and demonstrations to improve care for Medicare-Medicaid dually eligible beneficiaries. In 2014 the Centers for Medicare & Medicaid Services (CMS) issued a related final regulation on HCBS and related guidance that outlines requirements for PCP and SD. Medicaid State plan home health, personal care, case management, and many rehabilitative services benefits are HCBS.

HCBS are also offered through block grant programs administered by the Substance Abuse and Mental Health Services Administration and grants from other HHS operating divisions including the Administration for Community Living (ACL), the Health Resources and Services Administration, and the Indian Health Service. The ACL and CMS are presently working with the U.S. Department of Veterans Affairs to expand the availability of HCBS for veterans. There are also many programs offered by states, territories, and the District of Columbia that provide HCBS using non-federal payment sources, or combined resources.

The number of HCBS programs and wide variation in services, eligibility rules, delivery systems, payers, and associated regulatory authorities create significant challenges for states and programs that have day-to-day responsibility for implementation.  This can result in administrative duplication; inconsistent policies; gaps in service adequacy; inconsistencies in plans of care; poor service quality; fraud, abuse, and mistakes; and other issues.

The impact of these differences among HCBS policies and practices on the people who need HCBS is significant. Individuals, families, and caregivers are often faced with navigating a confusing maze of policies and bureaucracies, which can impede access. System framework issues also contribute to fragmented services, duplicative efforts, people not receiving the services they need for which they are eligible, or individuals not having access to preferred services such as self-directed HCBS that maximize choice, control, and satisfaction.

This guidance will improve the efficient administration and consumer experience of programs at the state, federal, and community levels by aligning HCBS to standards for PCP and SD, and by enhancing the ability of HHS's oversight of PCP and SD.

## Approach to Implementation and the Development of Standards

In response to a 2010 request from the Secretary of HHS, the Office on Disability, now under the umbrella of the ACL, convened a workgroup on section 2402(a) implementation that included staff from the following agencies:

- Administration on Aging (now an ACL component)
- Administration on Intellectual and Developmental Disabilities (now an ACL component )
- Assistant Secretary for Planning and Evaluation
- Centers for Medicare & Medicaid Services
- Health Resources and Services Administration
- Indian Health Service
- Office for Civil Rights
- Substance Abuse and Mental Health Services Administration

The workgroup met regularly over the course of two years as members considered a range of options and strategies for implementing section 2402(a) of the ACA.  In addition to implementation strategies the workgroup discussed key focus areas including PCP, SD, workforce competency and adequacy, quality of life, and a definition for HCBS.  The workgroup developed concept papers, conducted interviews with subject matter experts, and engaged in outreach to key stakeholders including advocacy groups, state associations, people with disabilities and older adults, providers, and other federal departments and agencies.

A consensus emerged among members of the workgroup that the initial focus of internal HHS guidance should be on two areas, PCP and SD, as a first step toward implementing important provisions of section 2402(a) of the ACA in a manner that supports consistent application and availability across state and federal programs.

## Standards for Person-Centered Planning

### Overview of Person-Centered Planning

Underpinning successful HCBS is the importance of a complete and inclusive PCP process that addresses the person's array of HCBS needs in the context of personal goals, preferences, community and family supports, financial resources, and other areas important to the person. The process should result in the provision of appropriate services consistent with the efficient use of available resources.

To support the PCP process, some states are utilizing or developing a standardized comprehensive functional assessment process to determine eligibility for various programs through a "no wrong door" approach. Functional assessments are related to the PCP process, and must be undertaken using a person-centered approach. The functional assessment and the PCP should be used as a basis for service authorization, utilization review, budgeting, measuring goals and improving outcomes, and other purposes. However, the PCP process often results in quality-of-life goals that exceed the ability of any set of program-specific services and supports to fully meet them. Therefore, the PCP process must not be limited by program specific functional assessments. One of the functions of the PCP process is to help the person and the support team to develop innovative and non-traditional ways to meet the goals in the plan. The goals must not be restricted due to a lack of easily identified services or supports. Several initiatives in HHS support a standardized functional assessment process including the Balancing Incentive Program, (http://www.balancingincentiveprogram.org/), and the Aging and Disability Resource Centers (http://acl.gov/Programs/Integrated_Programs/ADRCs/Index.aspx).

### Definition of Person-Centered Planning

Person-centered planning is a process directed by the person with LTSS needs. It may include a representative who the person has freely chosen, and/or who is authorized to make personal or health decisions for the person. PCP should also include family members, legal guardians, friends, caregivers, and others the person or his/her representative wishes to include. PCP should involve the individuals receiving services and supports to the maximum extent possible, even if the person has a legal representative. The PCP approach identifies the person's strengths, goals, preferences, needs (medical and HCBS), and desired outcomes. The role of agency workers (e.g., options counselors, support brokers, social workers and others) in the PCP process is to enable and assist people to identify and access a unique mix of paid and unpaid services to meet their needs, and provide support during planning. The person's goals and preferences in areas such as recreation, transportation, friendships, therapies, home, employment, family relationships, and treatments are part of a written plan that is consistent with the person's needs and desires.

Preferences may include, for example, the following concepts related to the person's experience and necessary supports:

- Family and friends

- Housing
- Employment
- Community integration
- Behavioral health
- Culture
- Social activities
- Recreation
- Vocational training
- Relationships
- Language and health literacy
- Other community living choices

PCP assists the person to construct and articulate a vision for the future, consider various paths, engage in decision-making and problem solving, monitor progress, and make needed adjustments to goals and HCBS in a timely manner. It highlights individual responsibility including taking appropriate risks (e.g. back-up staff, emergency planning). It also helps the team working with the individual to know the person better.

## Person-Centered Planning Process

PCP must be implemented in a manner that supports the person, makes him or her central to the process, and recognizes the person as the expert on goals and needs. In order for this to occur there are certain process elements, consistent with statutory or regulatory provisions. These include:

1. The person or representative must have control over who is included in the planning process, as well as the authority to request meetings and revise the plan (and any related budget) whenever necessary.
2. The process is timely and occurs at times and locations of convenience to the person, his/her representative, family members, and others.
3. Necessary information and support is provided to ensure the person and/or representative is central to the process, and understands the information. This includes the provision of auxiliary aids and services when needed for effective communication.
4. A strengths-based approach to identifying the positive attributes of the person must be used, including an assessment of the person's strengths and needs. The person should be able to choose the specific PCP format or tool used for the PCP.
5. Personal preferences must be used to develop goals, and to meet the person's HCBS needs.
6. The person's cultural preferences must be acknowledged in the PCP process, and policies/practices should be consistent with the HHS Office on Minority Health Standards National Standards on Culturally and Linguistically Appropriate Services (CLAS) http://www.minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15.

7. The PCP process must provide meaningful access to participants and/or their representatives with limited English proficiency (LEP), including low literacy materials and interpreters.
8. People under guardianship or other legal assignment of individual rights, or who are being considered as candidates for these arrangements, should have the opportunity in the PCP process to address any concerns.
9. There must be mechanisms for solving conflict or disagreement within the process, including clear conflict of interest guidelines.
10. People must be offered information on the full range of HCBS available to support achievement of personally identified goals.
11. The person or representative must be central in determining what available HCBS are appropriate and will be used.
12. The person must be able to choose between providers or provider entities - including the option of SD services - when choice is available.
13. The PCP must be reviewed at least every twelve months or sooner, when the person's functional needs change, circumstances change, quality of life goals change, or at the person's request. There must be a clear process for individuals to request updates. The accountable entity must respond to such requests in a timely manner that does not jeopardize the person's health and safety.
14. PCP should not be constrained by any pre-conceived limits on the person's ability to make choices.
15. Employment and housing in integrated settings must be explored, and planning should be consistent with the individual's goals and preferences, including where the individual resides, and who they live with.

## Elements of the Person-Centered Plan

The person-centered service plan must identify the services and supports that are necessary to meet the person's identified needs, preferences, and quality of life goals. To the extent that PCPs are consistent with statutory and regulatory provisions, the PCP must have the following attributes:

1. Reflect that the setting where the person resides is chosen by the individual. The chosen setting must be integrated in and support full access to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving HCBS.
2. The plan must be prepared in person-first singular language and be understandable by the person and/or representative.
3. In order to be strengths-based, the positive attributes of the person must be considered and documented at the beginning of the plan.
4. The plan must identify risks, while considering the person's right to assume some degree of personal risk, and include measures available to reduce risks or identify alternate ways to achieve personal goals.

5. Goals must be documented in the person's and/or representative's own words, with clarity regarding the amount, duration, and scope of HCBS that will be provided to assist the person. Goals will consider the quality of life concepts important to the person.
6. The plan must describe the services and supports that will be necessary and specify what HCBS are to be provided through various resources including natural supports, to meet the goals in the PCP.
7. The specific person or persons, and/or provider agency or other entity providing services and supports must be documented.
8. The plan must assure the health and safety of the person.
9. Non-paid supports and items needed to achieve the goals must be documented.
10. The plan must include the signatures of everyone with responsibility for its implementation including the person and/or representative, his or her case manager, the support broker/agent (where applicable), and a timeline for review. The plan should be discussed with family/friends/caregivers designated by the individual so that they fully understand it and their role(s).
11. Any effort to restrict the right of a person to realize preferences or goals must be justified by a specific and individualized assessed safety need and documented in the PCP. The following requirements must be documented in the PCP when a safety need warrants such a restriction:
    a. The specific and individualized assessed safety need.
    b. The positive interventions and supports used prior to any modifications or additions to the PCP regarding safety needs.
    c. Documentation of less intrusive methods of meeting the safety needs that have been tried, but were not successful.
    d. A clear description of the condition that is directly proportionate to the specific assessed safety need.
    e. A regular collection and review of data to measure the ongoing effectiveness of the safety modification.
    f. Established time limits for periodic reviews to determine if the safety modification is still necessary or can be terminated.
    g. Informed consent of the person to the proposed safety modification; and
    h. An assurance that the modification itself will not cause harm to the person.
12. The plan must identify the person(s) and/or entity responsible for monitoring its implementation.
13. The plan must identify needed services, and prevent unnecessary or inappropriate services and supports.
14. An emergency back-up plan must be documented that encompasses a range of circumstances (e.g. weather, housing, staff).
15. The plan must address elements of SD (e.g. fiscal intermediary, support broker/agent, alternative services) whenever a self-directed service delivery system is chosen.
16. All persons directly involved in the planning process must receive a copy of the plan or portion of the plan, as determined by the participant or representative.

### Person-Centered Planning Implementation

Implementing the person-centered plan requires monitoring progress to achieve identified goals, so that appropriate action is taken when necessary. This includes mechanisms to ensure all HCBS - paid and unpaid - are delivered, that the plan is reviewed according to the established timeline; there is a feedback mechanism for the person or representative to report on progress, issues and problems; and that changes can be made in an expedient manner. People receiving HCBS must be fully involved in the process to update their service plans based on their needs and preferences on an ongoing and regular basis, no less often than annually, based on the time the plan was created or last revisited.

Successful implementation for systems or accountable entities (e.g. state or local programs) requires policy, mission/vision statements, and operations documents at the federal, state, local, and person-level (for self-direction) aligned to incorporate PCP standards, and that staff involved in the PCP process have a consistent understanding of the process and implementation. In order for PCP principles to be fully realized leadership, administrative, and other staff are strongly encouraged to receive competency-based training in PCP. A process for monitoring PCP should be implemented at the federal, state, and local levels and incorporated as an integral component of quality improvement activities across HCBS programs.

For people using HCBS, this includes active engagement in the planning and service delivery process involving a number of support professionals. The person's input informs the quality of services and supports when he/she takes an active role in the PCP process by:

- Providing accurate information for eligibility and service planning.
- Actively identifying and engaging providers, case managers, family members, friends, direct support workers, support brokers, medical professionals, and others.
- Approving and signing only a plan that is developed and accepted by everyone involved.
- Participating fully after the approved plan is implemented (e.g., appearing timely for meetings and appointments, reviewing the plan regularly).
- Providing regular feedback on the HCBS provided.

## Standards for Self-Direction

### Overview of Self-Direction

Section 2402(a) of the ACA emphasizes the importance of allocating resources to enable people to maximize their independence including by employing LTSS providers directly, designing an individualized, self-directed, community supported life, and using an accurate, fair, and flexible system for individual budget determinations. This service delivery model is referred to as self-direction, participant-direction, consumer-direction, and cash and counseling. Although PCP must be at the center of planning for all individuals receiving HCBS, SD may not be desired, or may not be available, to those who seek or are receiving HCBS. Longstanding evidence from demonstrations and programs such as "Cash and Counseling" and CMS's "Independence Plus" program indicate better outcomes and cost savings result through the use of SD. The concept of

SD may also be integrated into the traditional service delivery system through a focus on gradual transfer of control and the provision of regular opportunities to make choices in many contexts and settings, permitting the person to experience self-directed opportunities absent an established self-directed service delivery system. These types of precursor activities may be useful for people who are not, for whatever reason, able to experience the full benefits of a self-directed service delivery model.

Self-direction is a service delivery model where HCBS are planned, budgeted, and directly controlled by the person receiving services. Self-direction should involve the individuals receiving HCBS to the maximum extent possible and include family members, guardians, or other legal representatives as applicable. Through SD, the person can maximize independence and control over needed HCBS, including for example, choosing and discharging personal care staff. Often SD services are provided in the person's own home. SD typically involves a fiscal intermediary or financial management service, that performs tasks such as payroll processing and tax withholding. Many people who choose to self-direct also use the services of a support broker or agent, to assist them in managing the self-directed HCBS and associated tasks. Often family members and the HCBS consumer are trained as support brokers/agents, although they may not perform the associated tasks. People who self-direct their HCBS may have varying levels of control over a flexible budget, which is required to be sufficient to meet their needs appropriately in the community, and maintain health and safety.

The principles and processes described below are used to ensure consistent standards for SD across public programs. Program features that create the ideal environment for successful SD include:

- A common understanding of SD among case managers, direct service workers, support broker/agents, individuals and their families, any agency-based staff, and others.
- Consistent and effective implementation of the SD model structure and related functions such as support broker/agent, and financial management service/fiscal intermediary.
- The option to use a SD model is made available to all individuals who receive HCBS.
- Clear rules and procedures are established for people to manage their direct service workers (e.g., hiring and firing, staff responsibilities, conflict resolution, salary, supervision, scheduling, etc.).
- A budget process is in place that assures appropriate and timely HCBS are provided based on the person's needs as specified in the PCP. The team-based budget formulation and approval process is used to address the person's assessed individual needs (e.g. not associated with any particular residential setting, "one size fits all" rubric, or other arbitrary methodology disassociated from the individual); is flexible; permits for timely, straightforward modifications and adjustments; and maintains the person's health and safety in the community.

## Definition of Self-Direction

SD means a consumer-controlled method of selecting and using services and supports that allow the person maximum control over his or her HCBS including the amount, duration, and scope of services and supports as well as choice of provider(s). Often, in addition to the typical range of HCBS, self-directed delivery systems permit the person to purchase alternative goods and supports (where authorized by statute or regulation) that may not be available in traditional HCBS service delivery systems. Alternatively, some services available in traditional services delivery (e.g. respite care, day programs, criminal background checks, drug and alcohol screens, training) may not be available in a self-directed service delivery model. There are also various administrative arrangements that apply specifically to SD. For example, the person may act as the "employer of record" with the necessary supports to perform that function, and/or have a significant and meaningful role in the supervision of direct service worker(s). Some people may use a representative to direct their HCBS, and family members or legal guardians may have a role to assist people under guardianship, or un-emancipated minors. People who are self-directing their services should be given as much responsibility as they desire to hire, train, supervise, schedule, determine duties, and dismiss the providers or direct service workers whom they employ directly, or for whom they may share employment responsibilities with an agency. Many people use the services of a support broker or agent to assist them in these and other duties, with the support broker/agent included as distinct service in the person's PCP.

Payment of SD HCBS could be through the provision of vouchers, direct cash payments, or use of a fiscal agent or fiscal intermediary to assist in paying for services and making certain all necessary payroll functions, including the payment of taxes, are performed. Fiscal agents/intermediaries may also provide regular service and payment summaries to the person receiving HCBS, and issue payment to providers, direct service workers, and support brokers/agents through electronic or paper methods. In some self-directed models, fiscal agency fees are based on a monthly or utilization basis, and are included in the person's HCBS budget. Self-directed models exist in both traditional fee for service and managed care delivery systems.

## Required Elements of Self-Direction

HCBS programs that provide SD must incorporate the following elements, to the extent they are consistent with statutory and regulatory provisions:

1. SD service delivery models must meet the PCP standards described in this document.
2. SD, when offered within programs, should be available to all individuals regardless of age, disability, diagnosis, functional limitations, cognitive status, sex, sexual orientation, race, ethnicity, physical characteristics, national origin, religion, and other such factors.
3. When representatives are required, they must be freely chosen when circumstances permit.
4. HCBS consumers must have access to information and counseling and information on self-direction through a variety of sources as needed or desired, so they can make an informed decision when choosing a SD service delivery model.
5. Case managers and administrative staff should have training in SD. This includes training, for example, on recruitment and education of direct service workers, budget processing, how the PCP relates to the SD budget, needed alternative supports, housing search, etc.

6. When a person chooses SD, an assessment of the supports needed to be successful should be conducted. People who choose SD must have access, for example, to culturally-linguistically sensitive information, training in issues specific to self-direction, financial/fiscal management services, and support brokers/agents, to assist them in the successful management of their HCBS.
7. In addition, the following information and support should be provided:
    a. PCP and how it is applied through SD.
    b. Use of and access to the grievance process.
    c. Individual rights, including appeal rights.
    d. Reassessment and review schedules for PCP, budgeting, etc.
8. The SD PCP must specify the following:
    a. The HCBS the individual will be responsible for self-directing.
    b. The methods by which the person will plan, direct or control services, including whether authority will be exercised over the employment of service providers and/or authority over expenditures from the individualized budget.
    c. Appropriate risk management techniques that explicitly recognize the roles and sharing of responsibilities in SD, and assure the continued appropriateness of the PCP and budget based upon the resources and support needs of the person.
    d. The process for facilitating voluntary (and involuntary) transition from self-direction to a traditional service delivery model or other arrangement (e.g. institutional setting). There must be procedures to ensure the continuity of services during the transition from self-direction to other service delivery methods or provider types.
    e. Financial/fiscal management supports to be provided.
    f. Support broker/agent services, irrespective of payment method (fee for service, managed care). If there is no support broker/agent required or chosen, the person must have training in acting as his/her own support broker.
9. If the PCP includes the employer authority to select, manage, or dismiss providers, it must specify the authority to be exercised by the person, any limits to the authority, and the parties responsible for functions outside the authority of the person.
10. If the PCP includes budget authority (which identifies the dollar value of the HCBS under the control and direction of the person), the SD PCP must meet the following requirements:
    a. Outline the method(s) for calculating the dollar values and/or categories in the budget, based on reliable costs and service utilization.
    b. Define a flexible and easily accessible process for making timely adjustments in dollar values to reflect changes in the person's SD PCP, particularly to support health and safety.
    c. Provide for a regular procedure to evaluate expenditures under the budget, including those outlined in the SD PCP.
11. The SD planning process must be conducted in a manner and language understandable to the person and his/her representative(s). Individuals and/or their representatives must be provided with auxiliary aids and services if necessary for effective

communication.  The SD process must provide meaningful access to people and/or their representatives who have limited English proficiency.

12. SD program entities must explicitly outline and make transparent to all stakeholders enrollment requirements such as limitations based on geography, demographic factors, residential arrangements, etc.
13. People must have the flexibility to choose the needed services and supports that best meet their needs and preferences within the context of a PCP process that includes the development of an agreed upon, multi-lateral, and approved funding allocation/budget amount for the projected SD HCBS.
14. People must have the flexibility to choose how funds will be used based on the HCBS identified in the PCP, consistent with the requirements of the funding authority, in a transparent manner, including (where appropriate), the ability to move funds categorically as needed.
15. People must have the flexibility to expeditiously and seamlessly change their service plans and budget allocations, based on different needs and preferences, with an assurance of health and safety.
16. People must be able to choose their paid and unpaid direct care workers and/or medical support staff, may include family and friends based on administrative policies, so long as they meet agreed upon guidelines and qualifications for the position, and are willing to perform the duties.
17. People must be allowed to direct the training of their workers in a manner consistent with applicable program requirements, and receive financial support to accomplish critical training needs as appropriate and available.
18. People must be provided with opportunities to participate in defining quality, such as the determination of worker qualifications and training, personal goal setting, and performance measures.
19. People must be supported in taking risks associated with pursuing their goals. There must be a back-up plan for assumed risks, and for a variety of emergency situations.
20. People must have the opportunity, as identified in the PCP and budget, to allocate or set aside funds for emergency needs (e.g., more costly emergency back-up workers, alternative emergency housing) to the extent authorized by applicable law and regulations.
21. People must have the opportunity, as identified in their PCP and budget, to allocate or set aside funds for, and where authorized, specialized purchases made timely such as necessary home or vehicle modifications to support independence and avoid unnecessary institutionalization.
22. People who need assistance with decision-making and do not have an authorized representative must have the option to choose an informal representative to assist them in selecting or managing services and supports, and/or have a person authorized to make personal or health decisions for them. People must also have access to one-on-one assistance as needed or requested with selecting or changing their informal representative.
23. The finalized SD PCP must be signed by the person or his/her legal representative, and a written copy of the plan and budget should be provided to all relevant parties.