

Keeping the Promise: Self Advocates Defining the Meaning of Community Living

Background

In June 2009, the Centers for Medicare and Medicaid Services (CMS) announced they would be publishing regulations defining the character of home and community-based settings. CMS acknowledged that, “some individuals who receive Home and Community Based Services in a residential setting managed or operated by a service provider have experienced a provider-centered and institution-like living arrangement, instead of a person-centered and home-like environment with the freedoms that should be characteristic of any home and community-based setting¹.” CMS stated that using such settings to provide “home and community based” services are contrary to the purpose of the 1915(c) waiver program.

The purpose of this paper is to provide CMS with a definition of "community" that captures the most vital elements of community life. In addition, we believe that these comments are important contributions to policy issues in the areas of housing, education, employment and transportation.

Introduction

Over the course of the last half century, the United States has made many important promises to its citizens with intellectual and developmental disabilities. These promises are found in the Developmental Disabilities Assistance and Bill of Rights Act, the Americans with Disabilities Act (ADA), the decisions of the Supreme Court and other federal courts, the Individuals with Disabilities Education Act (IDEA), the Rehabilitation Act of 1973, and other laws, rules, decisions, and findings. Those of us on the “receiving end” of the promises have taken our Nation’s commitments seriously. We expect that when our country guarantees “access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life” [as in the

¹ “Medicaid Program; Home and Community-Based Services (HCBS) Waivers; Center for Medicare and Medicaid Services. Advance notice of proposed rulemaking.” *Federal Register* 74 (June 22, 2009) Page 29453-29456

Developmental Disabilities Assistance and Bill of Rights Act] the promise will be kept. We believe that when our country recognizes “the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers and enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society (as in the Rehabilitation Act of 1973 as amended, 29U.S.C.794), that we will indeed be in control of own lives.

When taken together these promises made to citizens with developmental disabilities establish a clear national purpose:

- Increasing self-determination and personal control in decisions affecting people with developmental disabilities and their families
- Providing opportunities for people with developmental disabilities to live and participate in their own communities
- Improving quality of life for individuals and families as they define it for themselves
- Supporting families as the most important and permanent unit of development, protection, and lifelong assistance to persons with developmental disabilities
- Investing in each individual’s developmental potential and capacity to contribute in age-related roles as productive and respected community members
- Ensuring access to sufficient, high-quality health and social supports to protect each person’s health, safety, rights, and well-being
- Moving people with developmental disabilities out of poverty by significantly increasing opportunities for real work with real pay

Together these points outline a national commitment to integrated and respected community living for people with developmental disabilities. We know this national commitment can only be achieved with assistance from service and support provider agencies that are committed to and capable of delivering on these collective promises. Because these agencies are funded through the Medicaid program, the Centers for Medicare and Medicaid Services (CMS) and associated state program agencies are

responsible for the quality of service and support delivery. CMS's direction is central to setting standards and expectations for service providers.

Yet, despite this promise, many individuals who receive home and community based services do not experience genuine community settings or lifestyles. Many individuals are subjected to segregation, loss of control, lack of support, restrictions, no meaningful access to community and other challenges. Over time supporters of segregated, secluded, discriminatory or even exploitive models of care and support have adopted rhetorically the language of person-centered planning, insisting that its principles are at work in their program plans. Increasingly this has become a defense for practices that actually contradict the goals of individualized supports. Too much emphasis is being placed on the Person-Centered Planning rather than the measure of its outcomes. Did planning result in the individual having more control and choice in their life? Part of the problem is that often the choices being offered are from a profoundly limited menu.

Outcomes from self-directed lives must be the measures of success. Is the person enjoying a healthier and more satisfying life on their terms? Who is in charge? Does the individual have more control and choice? Is their participation in community genuine and meaningful? Are their relationships authentic?

To address these problems, the Autistic Self Advocacy Network (ASAN), Self-Advocates Becoming Empowered (SABE) and the National Youth Leadership Network convened a National Community Living Summit of self-advocates with developmental and intellectual disabilities. Twenty-five people attended the Summit. Immediately after the Summit, our team conducted 72 one-on-one interviews with our peers with developmental disabilities attending SABE's national self-advocacy conference. The Summit proceedings and interviews addressed three specific questions:

- What are three things that determine that a place or residential program is not part of the community?
- What are three things that determine that a place or program where a person gets residential services is truly in the community?

- What does Community Living really mean?

In attempting to answer these questions, we engaged both through our summit and through our interview team and interviewees a wide array of different backgrounds, experiences and identities reflective of the broad diversity of our great nation. Our participants came from across the country and from every age group. They differed not only in the types of disabilities and accommodations, but also in their languages, their incomes, their religious beliefs, their sexual orientations, their mode of communication, their races and ethnicities and every other manner of diversity. Some came from big cities, others small towns and rural areas. Some talked about having spent time in institutions - others had grown up in the community. Some have spent many years of their adult life in a sheltered workshop or day program – others are competitively employed. While we know that no effort can capture every aspect and facet of our wide and diverse community, we believe that this report and the process that led to it was broadly inclusive and captured many voices typically left out of these discussions. We assert the need to leave no voice behind and are proud of the diverse community this report represents.

From the answers to these questions, we found that over and over again people said that “community” was more than just a place, size or numbers. We found the definition of community living to be multi-dimensional with many different levels, layers and domains. Five particular “dimensions” stood out to us:

- physical size and structure;
- rights and self-determination;
- qualities and attitudes of providers;
- access to community life; and
- the meeting of support and access needs.

Our recommendations from the Summit and interviews are categorized into these five aspects of community living stated above. **To ensure that community integration is available to all people with disabilities regardless of where they live, we recommend applying these standards broadly to all community based services**

and settings, regardless of whether or not the building in which a person lives is owned by an agency, service provider, the person themselves or other third party entity. By these standards, we commit to hold those in power accountable to the promise made to us in the Americans with Disabilities Act, the Developmental Disabilities Assistance and Bill of Rights Act, the Rehabilitation Act, the Individuals with Disabilities Education Act and countless other pieces of legislation as well as regulations, proclamations and other public statements. Thus, we do declare that the following principles capture the meaning of living in the community:



Physical Structure and Size:

We are not in the community when we experience:

Segregation and Isolation: No matter the size, if services support segregation and isolation of people with intellectual and developmental disabilities from the community, it is not community. Segregation includes “locking” us away and is both wrong and dangerous, as it opens up the possibility of undetected abuse.

Policy Guideline: Gated communities, farmsteads, and clusters of group homes—even those that include both people with and without disabilities—are not in the community. When we live in those settings we become segregated from the general scope of community life. One summit participant noted that community must “integrate with people who don’t have disabilities, and this does not mean staff.”

Lack of Control: It is not community when a provider, licensing authority or the physical structure of a building takes away control from the people who live there. We must be free to come and go as we please. It is also a problem when we lack the ability to control the privacy of our own lives, by limiting our ability to lock the door of our rooms or our bathrooms or by forcing us to share a room with someone we don’t know or don’t desire to live with.

Policy Guideline: Homes in our community must reflect the personal style and preferences of the people who live there. We should have a key to our homes and be able to lock our bedrooms and bathrooms for privacy. We should not be forced to share a room with an unknown or undesired roommate. We should have the right to freely access and use kitchens, laundry rooms, and other social and domestic areas of the home.

Policy Guideline: People should have the freedom to choose whether to live in a rural, urban or suburban community. People should have reasonable access to places of commerce, recreation, and other aspects of community life.

Large Size: A large congregate care facility is not a home in the community. If a half dozen or more people live in a provider-owned group home, it is almost never controlled by the people who live there.

Policy Guideline: A home should not be considered “in the community” if more than four unrelated people live there.

Policy Guideline: We should live in apartments, houses, condominiums, trailers, etc. located in rural, urban, or suburban communities with typical public resources such as shops, houses of worship, places to work, and accessible transportation systems. We have the right to live in a safe community among people with and without disabilities.



Rights and Self Determination

We are restricted from experiencing community life by:

Rules: When we have to do what we are told and staff watch our every move. When we don't get to make rules where we live.

Lack of voice: When opportunities for typical life activities are strictly limited to what the provider will allow, not our own preferences.

No ability to see friends or family: When we experience limits on our freedom of association. When we are restricted and at times punished for expressing our sexuality. There is a lack of freedom to come and go. When we feel like we are being locked in.

No say: When we feel disempowered (due to restrictions on freedom and strong self-advocacy).

No choices: When we have no or limited choices. People make decision for us - limiting choices about where to live, food, clothing, health care, and spending money.

Policy Guideline: We must have a right to privacy. We must be able to have time to ourselves and have a private space with a door that can be locked against intrusion by staff or housemates.

Policy Guideline: We must have rights of freedom of mobility, choice, and association. Staff cannot set rules about: a) where we go and when, b) when and what we eat or drink, and c) who may be invited into our home and at what time.

People are empowered to live in the community by:

Choice: We have choices about where and with whom we live, how to spend our time, what to buy, what to eat and drink, where to go, how to have fun, what to wear, where to work, who to chill with, who we date and marry. We are supported to make our own medical and sexual decisions. We choose who will give us advice.

Policy Guidelines: Meals are not brought in from a central location designed only to prepare food for people with disabilities. We have the right to choose what to eat, when to eat and where to eat. When eating at home, meals are prepared in a kitchen unless food is ordered from a restaurant or another location available to both individuals with and without disabilities. We can choose to make our own meals and use the kitchen when and how we want to.

Risk: We are supported to take risks, even if others don't approve. It is not a big deal when one of us makes a mistake. We get support to carry out a plan even when a provider does not agree with the decision being made. Service providers support us to get non-biased information when making decisions.

Policy Guidelines: We should receive value-neutral support (if requested) to make decisions about employment, spending money, diet, entertainment, travel, clothing, recreation, friendship, sexuality, relationships, medical decisions, and other relevant parts of community life. We may reject this support and choose to make a different decision; we may choose not to receive this support if we do not desire it.

Policy Guideline: We, as persons with disabilities, are required to follow one set of laws (the same as for other U.S. citizens and residents). We live free of rules established to control people with disabilities.

Qualities and Attitudes of Providers

Attitudes and qualities of providers which limit our opportunity to be a part of the community include:

Group Treatment: Agencies that operate programs of congregate care and group treatment that diminish our opportunities for a life and daily routines of our own choosing.

Power Difference: Agencies that create power differences between those providing services and those receiving service so that we are controlled, disrespected and denied a chance for self-determination.

Denial of Choice: Agencies that do not take the time or have the skill to listen for and identify our personal goals and preferred lifestyles. Agencies that are not committed or able to give us the chance to do the things and to be with the people that are most important to us.

Lack of Respect: Agencies that fail to teach their employees of the value of each person and the ability of each person to communicate his or her desires. Agencies that fail to teach their support staff to respond to us in a respectful, age-appropriate and helpful manner.

Branding: Agencies that draw attention to themselves at the cost of the persons they support by branding their homes, their vehicles, and their activities.

Dual Loyalty: Agencies that communicate to support providers that they are working for the agency first and for us, the people they support, second.

Attitudes and qualities of providers which enhance people's opportunity to be a part of the community include:

Respect: Agencies that teach respect for each individual they support as an important person by listening, learning and responding in ways that honor us as individuals and increase our control over our own lives

Uniqueness: Agencies that teach and help support providers to know and respond in age-appropriate ways to each of us as a unique person with unique interests, preferences, needs and goals- not as a person defined by our disabilities.

Independence: Agencies that teach and expect support providers to truly support us to be more independent rather than to do things for us.

Choice: Agencies that measure how they are doing in responding to our preferences and desires for life as a community member and make changes as needed.

Equality: Agencies that respect us as having and deserving real homes that are respected in the same ways as the homes of everyone else in the community.

Person-Centered Culture: Agencies that fosters personalized services through a person-centered culture of respect for both support receivers and support providers, including value-based training, low staff turnover and choice of support providers.

Freedom from Fear: Agencies that provide us with an environment in which we can live safely and without fear of harm, neglect, or exploitation from others, including from support providers, other program participants, or others in the community.

Policy Guideline: Those of us receiving services must have control over hiring, firing, and supervising staff. This supports our right to self-determination, balances the staff/consumer relationship, and makes clear that our needs determine the type of support provided.

Policy Guideline: Staff working to support us as persons with disabilities in the community must be trained about our rights, including the right to self-determination, and how to support our exercising choice and control in our own lives. There must be trained staff to support us in our home, to work, and to participate in the life of our local community.



Access to Community:

Community living is not:

Segregation: If we are forced to literally live outside a community, it cannot be a community living setting. If we live on the outskirts of town, and lack access to the mainstream of community life, we are effectively segregated.

Lack of Transportation: When we lack accessible, affordable transportation, we are kept out of our communities. It is important for us to have access to navigational aids so we can find bus stops, as well as access to training on how to use public transit. Segregated transportation (for example, a bus that is run by a disability provider agency just for people with disabilities) is not what we want. We must have access to transportation on a basis that is consistent with individuals without disabilities. In rural areas or other places with poor access to public transit, it is important that additional measures be taken to ensure we as people with disabilities are not isolated and thus left more vulnerable to abuse and being left out of community.

Policy Guideline: Those of us receiving home and community-based services must have access to accessible, affordable transportation.

Denial of Choice in Relationships: We should be able to spend time with who we want. All of our relationships should be respected. Services and supports should accommodate our relationships, not the other way around. Absolute rules like unreasonable sleep time restrictions or not being allowed in each other's rooms do not respect our right to be with other persons. We also believe some regulations must be changed. We should not be prevented from marrying because of guardianship, Medicaid, or Social Security rules.

Policy Guideline: We should not be forced to surrender our right to associate with who we want and when we want to communicate as a pre-condition for receiving services. In addition, changes to Medicaid, Social Security, and state guardianship laws should

ensure that people with disabilities have the right to marry and live with whom we choose.

Employment:

Whether we work in sheltered workshops, enclaves, or day habilitation centers, vocational segregation of us from people without disabilities does not count as community living. It is not gainful employment if we do not have the opportunity to make money at the same levels as other people who work in our community. We lose an important aspect of community life if we spend our time only around people with disabilities, in day habilitation centers, and are not able to be included in our broader communities.

Policy Guideline: We must have opportunities to work in jobs as part of the general work force, among people who do not have disabilities. Opportunities for earning wages and benefits should be the same as everyone else. CMS funding should be used for supported employment and not be used for sheltered workshops or settings paying sub-minimum wage for people with disabilities. CMS community funding should not be used for any segregated settings, including day habilitation centers. Anything that segregates us from our communities is not community.

Community living is:

Choice and Agency: We can do what we want when we want to do it, instead of having to decide as a big group of people and move together. This does not mean being alone in our independence, but exercising our self-determination.

Full Citizenship. We should be able to contribute fully to the community. This should include voting and participating in civic organizations.

Making a contribution. We believe in reciprocity (two-way relationships), to be able to pay forward society's support. For example, if friends drive us somewhere, we might watch their kids in return. We should have the opportunity to volunteer and participate in civic life like everyone else.

Knowing What is Going On in the Community We want to know what events and activities are happening. We want support to understand information about important community issues to make good decisions and have opinions.

Access to Community Resources. If we have a problem, we want to know where to go in the community to help us with solutions. Libraries, service systems, governments, and churches should be accessible sources of information and support for us.

Being a Part of a Neighborhood. We should live in a neighborhood where we can connect with community members who live next door. We would like to be treated like neighbors, and have the opportunity to work to make the neighborhood a better place.

Policy Guideline: State laws that prevent voting by people under guardianship must be amended to honor a person's right to vote.

Policy Guideline: Rules must not exist that restrict relationships between us as people with disabilities and our neighbors in the community. Visiting with neighbors should be routine and unobstructed by rules about privacy or liability.



Support and Access Needs:

Community living is not:

Aversives, Restraint, and Seclusion: When we are subjected to aversives, restraints, or seclusion, we are excluded from the community by abusive, inhumane violations of our rights that are sanctioned and tolerated by those in power.

Lack of Control: If we don't have control over our own personal belongings, money, or personal space, we are not in the community.

Policy Guideline: We must have the ability to hire, fire, train, and evaluate our staff without restriction or limitation—including no limitations set through options approved by an agency.

Policy Guideline: Typically systems do not separate housing from the services received by a person who needs support 24 hours a day. This creates a situation where we are not truly in charge of the place where we live. CMS must address the issue of separating housing and supports. Changing providers should not require us to leave the homes where we desire to live.

Community living is:

Control: We are in charge of our lives, which includes directing our services.

Communication: A fundamental aspect of community participation is the ability to communicate. Individuals must have access to needed augmentative and alternative communication (AAC) support, including the assessment, education, technology, and support systems needed to make aided communication meaningful.

Policy Guideline: Those of us who experience challenges in spoken communication should be supported to try various methods of alternatives and augmentative communication (AAC). As new technology becomes available, we should have the opportunity to use it to communicate. Staff should keep trying to see what might work and support our opportunities to improve our ability to communicate with modes of AAC

that progressively vary in capability. Medicaid should pay for AAC devices, including AAC provided on “dual-use” devices and systems like iPhones or iPads.

Digital Inclusion: Telecommunications is a part of the modern community. While living in the community, we should have access to a phone, a computer, the Internet, necessary assistive technology devices and, if needed, digital literacy training to make long-distance and short-distance interpersonal communication meaningful. No limits should be set by staff on when and how we access these systems or what types of content we can access.

Policy Guideline: CMS funding should support us as persons receiving services to access the Internet and learn how to use online technologies.

Accessibility: Homes, transportation, and other aspects of community life and methods of support must be accessible—not just within the guidelines of physical access set by the ADA, but truly accessible to us as individuals living there. This means that our broader access needs are met—even if they are non-traditional.

Policy Guideline: Wherever possible, support should be provided in ways that maximizes our use of natural and peer supports in the community, not just paid staff and providers.

Policy Guideline: The goal of support and services should be to maximize our independence and empowerment. Respect the dignity of risk—avoid making suggestions that could take control of us in the context of providing support.



Conclusion

Self-Advocates Becoming Empowered (SABE), Autistic Self Advocacy Network (ASAN) and the National Youth Leadership Network (NYLN) want to acknowledge and thank Commissioner Sharon Lewis for asking us to present this information from the stand point of self-advocates which will show how decisions impact people's lives. This is in keeping with President Obama's charge to his administration. We have jointly presented indicators of what community is and what it is not. However, people don't need special skills or education to differentiate between "genuine community" and "community-like" settings or lifestyles. Genuine community means having real choice in assistance, friends, partners, supports and living circumstances. Genuine community happens in inclusive, diverse and mixed neighborhoods. Living in genuine community means making your own decisions and being an independent and self-sufficient citizen. Living in genuine community is enjoying all the same rights, privileges and responsibilities of every other citizen. In genuine community people have names not labels, live in neighborhoods not on campuses, make their own choices, and enjoy privacy and genuine relationships of equality.

To some people, these ideas may seem radical. Some people may say that they go too far. We disagree – it is only because of the low standards that have controlled the world of disability service-provision for too long are these ideas viewed as new or unusual. We believe that we should have the same rights and opportunities as anyone else. People with disabilities should be, and are by right, equal to people without disabilities. This simple but revolutionary idea is what has guided all of our recommendations and discussions. We refuse to settle for less any longer. We demand for ourselves and for our peers a community that places us in a position of equality to our neighbors. We reject the old models of "care" and "charity" for a world that is instead ruled by rights, interdependence and true community. By these principles, we make common cause and declare to a candid world a new chapter in the disability rights struggle.

Summit participants were of leaders from the Autistic Self Advocacy Network, the National Youth Leadership Network, Self-Advocates Becoming Empowered, and allies.

Autistic Self Advocacy Network

Elesia Ashkenazy
Noranne Cochrane
Paula C. Durbin-Westby
Andrea Joyce
Shawn Kirk
Savannah Logsdon
Ari Ne’eman
Scott Michael Robertson

Self-Advocates Becoming Empowered

Max Barrows
John Britton
Cathy Enfield
Chester Finn
Erin Johnson
Tia Nelis
Victor Robinson
Eric Treat
Joe Wrinkle

National Youth Leadership Network

Micah Fialka Feldman
Reed Hahne
Betsy Valnes

Allies

George Braddock
Lucinda Griffin
Charlie Lakin
Nancy Thaler
Karen Topper

Special Thanks to the Interview Team

Elesia Ashkenazy
George Braddock
Shawn Kirk
Savannah Logsdon
Ari Ne’eman
Nancy Thaler

Photos By: Shawn Kirk

This report was written by:

Max Barrows
George Braddock
Paula C. Durbin-Westby
Shawn Kirk
Charlie Lakin
Stacey Milbern
Ari Ne’eman
Scott Michael Robertson
Nancy Thaler
Karen Topper
Betsy Valnes
Nancy Ward
Betty Williams

Editing provided by:

Paula C. Durbin-Westby
Ari Ne’eman
Karen Topper