HCBS Setting Rules: How to Advocate for Truly Integrated Community Settings

A companion resource to:

The Medicaid Home and Community Based Services Settings Rules: What You Should Know!

Home and Community Based Services Rules Q&A: Settings Presumed to be Institutional & the Heightened Scrutiny Process

Created by the HCBS Advocacy Coalition   January 2016

Contents

Introduction & the Importance of Advocacy

The process for states to come into compliance with the new Medicaid home and community based services (HCBS) settings rules is ongoing, and involvement from advocates remains important. The HCBS rules require all HCBS settings (residential and non-residential) provide participants with the full benefits of community living and the same degree of access to their communities as individuals not receiving HCBS.[1] The HCBS rules provide an important opportunity to move state systems towards services that support full inclusion and integration into the community. To learn more about the new rules and what is happening in your state, see The Medicaid Home and Community Based Services Rules: What You Should Know, www.hcbsadvocacy.org, and www.Medicaid/gov/HCBS.[2]

All states have submitted their initial plans for coming into compliance, known as statewide transition plans (STPs). In response to the original STPs, the Centers for Medicare & Medicaid Services (CMS) sent letters to all states, notifying them of the additional work and next steps required for approval of their STP. In early 2016, many states are likely to announce a formal public comment period on "amended" STPs.[3] Among other updated subjects, revised STPs will provide information on the crucial step of assessing every setting where services are delivered for compliance with the rules. States must seek public comment on both their proposed *process* for assessing every HCBS setting's compliance with the rule, as well as on their *results* of setting

---

[1] In March 2014, final Home and Community Based Services (HCBS) regulations become effective that set forth new requirements for several Medicaid authorities under which states provide HCBS. The rules enhance the quality of HCBS and provide additional protections to HCBS participants The rule can be downloaded at: https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider

[2] The Q&A can be found among other helpful resources on hcbsadvocacy.org under "National Resources."

[3] These expected plans will "amend" the initial draft plans that all states submitted to CMS in the Spring of 2015. The amendments are intended to be responsive to individual comments that CMS sent to each state identifying parts of the plan that were insufficient and needed to be fixed. A link to these CMS letters to states can be downloaded at: http://medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/statewide-transition-plans.html

assessments. States must also seek public comment if they choose to submit settings that are "presumptively institutional" through the heightened scrutiny process and the state must provide to the public the evidence that the settings overcome the institutional presumption and meet the other HCBS settings requirements. For more information, refer to Home and Community Based Services Rules Q&A: Settings Presumed to be Institutional & the Heightened Scrutiny Process.[4]

Importance of Advocacy

The extent to which the HCBS settings rules are a catalyst for positive change will depend on the strength of each state's transition plan and the ability of stakeholders and advocates to influence the plan and monitor its implementation. The next several months are an important time to become involved in advocacy efforts. It is when important decisions will be finalized and the parameters of state plans will be set. CMS has stressed the importance of public comments and that they are looking closely at state outreach and response to public comments. Advocates voices matter!

Input from advocates and HCBS participants is critical so that states implement the settings rules in ways that ensure HCBS participants receive the benefits of, and are full included, in the broader community. States must accurately identify the settings with issues, issues such as an isolated location or a home operated like an institution. Advocates and HCBS participants have important information about the settings in the system, including settings that do not comply with the rules or are institutional in nature. Therefore, participation in the settings assessment process, particularly commenting on setting assessment results, is critical for advocates looking to advance community integration.

Advocacy is necessary now, so that when states publish amended transition plans, HCBS participants and stakeholders have their own setting specific information to inform their comments.

---

[4] Available on hcbsadvocacy.org under "National Resources."

HCBS Advocacy Steps You Can Take

9 Advocacy Steps To Advance HCBS

The following are steps advocates should take to use the HCBS settings rule to advocate for integrated community settings:

1. Start evaluating HCBS settings in your states' system as early as possible; do not wait for the public comment period!

2. Create a list of settings where HCBS participants receive services – residential, day programs and work.

3. Gather and analyze information about the settings on your list.

4. Identify institution-like settings and those that require heightened scrutiny.

5. Share your setting specific information with the state.

6. Analyze your state's setting assessment results.

7. Prepare and submit your comments on the state's revised statewide transition plan (STP).

8. Encourage other advocacy groups, HCBS participants and their families, and individuals you work with to engage in public input.

9. Submit to CMS your list of settings and critique of state setting assessments.

Pg. 04

Step 1. Start Evaluating Settings Early. Don't Wait for Public Comment Period!

Step 1. Start Evaluating Settings Early. Don't Wait for Public Comment Period!

The assessment of states' HCBS settings should be an ongoing process for advocates, just like it is for the states. Although a state may only have a formal public comment period after it has completed the setting assessment process, advocates should actively gather information well in advance of this comment period. This allows advocates to provide the state information throughout its assessment process, which can help ensure the assessment process is accurate and impact assessment results.

Gathering information on HCBS settings will likely take some time. Not only do many states have a large number and range of types of settings in their system, but there may be delays in gather information from other advocates, participants or providers, or getting responses to public record requests.

Preparing well in advance allows advocates to use the comment period to compare the information they have gathered with the state's assessment, produce detailed, specific comments, and organize other advocates and HCBS participants to comment too.

Step 2. Create a List of Settings where HCBS Participants Receive Services

To get started, create a list of HCBS settings from which you can identify settings that do not meet the HCBS requirements or are institutional in nature, including settings that isolate. Not all settings where HCBS participants receive services may be Medicaid funded. However, if the source of funding is not clear, it is easier to include the setting on the list and allow the state to respond that the setting is not HCBS funded. Below are some possible sources of information about setting types and locations, as well as ways you can use the sources to identify problems with the settings:

- **State HCBS waiver documents, such as approved applications or amendments, and State plan documents.** The "Services" section of these documents should identify the types of providers who can provide the covered service. This list of settings can act as your starting universe of settings to consider.

- **Provider listings for individual types of HCBS.** This could include listings used by participants to look for residential or day service options. You may be able to access this information on a state website or through a public records request. As with any public records request, it helps expedite the response when you narrow the request to focus on the information you really need, such as identifying specific provider types you are requesting.

- **Provider websites.** Sometimes larger providers have listings of their different setting sites. If there is a concern about the way a particular provider operates their settings, this could be a good source of information. Provider websites may also help you identify settings that are concerning due to their physical proximity to one another, which can promote institutional characteristics within the settings. For example, is one of the "selling points" of a residential setting that it is convenient to the provider's day program or other services?

- **Provider trade organizations.** There are state and national trade organizations for many provider types. If you are concerned about providers of a certain service in your state, such as sheltered workshops, facility-based day programs or residential campuses or gated residential

communities, it may be useful to look at these trade organizations to identify providers of those services from their membership lists.

- **Managed care organizations.** Managed care organizations (MCO) have provider networks, so they should have listings of types of providers. As part of the MCO provider approval process, the MCO may also have complaints or other relevant information about the provider.

- **Licensure listings.** Because such listings are by type of license, these can be particularly helpful if you have identified features of certain settings based on their licensure requirements. For instance, if the licensure requirements permit activities disallowed by the HCBS rules, such as limited visiting hours. Alternatively, the licensure requirements may be silent on certain requirements in the HCBS rule, such as participant choice and control over daily life activities, and you may know that such settings lack these required features of a community based setting.

- **Licensure reviews, surveys or inspections.** Annual reviews or inspections of settings or findings of violations will likely provide information about the nature of the setting. This information should be available from the licensure agency or whichever agency is responsible for such surveys and inspections.

- **List of 14(c) certificate holders and Community Rehabilitation Programs.**[5]

  Certificates under 14(c) allow the payment of subminimum wage to workers with disabilities.[6] The listing of 14(c) certificate holders should help in identifying segregated day programs that operate as sheltered workshops, where participants ability to interact with people without disabilities and

---

[5] U.S Dep't of Labor, http://www.dol.gov/whd/specialemployment/BusinessCertList.htm; http://www.dol.gov/whd/specialemployment/CRPlist.htm.
[6] See 29 U.S.C. § 214 and Department of Labor Factsheet http://www.dol.gov/whd/regs/compliance/whdfs39.pdf.

access to the broader community may be limited.[7] These certificate holders should be looked at closely.

- **HUD website.** Some states have 811 projects, which are often disability-specific housing. HUD's website maintains an inventory by state of HUD-funded housing that identifies 811-funded settings and how many of the units are targeted to people with disabilities. Some, but not all 811 housing is targeted to a specific type of disability, and those that are may deserve a closer look at residents' experiences in those settings. The placement of the housing may also trigger closer scrutiny for other nearby settings. For example, if the housing is close to a day program, congregate residential facilities, or institutions, it could indicate that it is a setting that isolates residents from the broader community.

- **County/city tax information.** The tax information available online from local governments can provide useful information about properties owned by the same corporation (from property owner search); proximity of properties to one another, particularly if properties are contiguous (through property maps); whether property is located in a residential or industrial zone (from property maps and zoning layers); and other information.

- **Google Maps and Google Earth.** Google Maps can provide information, including a street view of a setting, from which you can gather information relevant to rule compliance, such as size, proximity to other settings where multiple people with disabilities live, and proximity to community resources (i.e., is the setting in town, walkable to transportation, close to possible employment). Google Earth provides access to good satellite imagery and additional information, and importantly, allows you to make a map on which you can plot the different types of settings. Such a map may allow you to more easily see the relationship of settings to one another and give you a better idea about geographic isolation that may contribute to the isolated nature of a setting.

---

[7] For examples of how these settings can segregated individuals from the community, see, for example, Department of Justice letters finding the states of Oregon and Rhode Island in violation of the Americans with Disabilities Act because of their over-reliance on segregated sheltered workshops, available at www.ada.gov/Olmstead; *see also* National Disability Rights Network, Segregated and Exploited: the Failure of the Disability System to Provide Quality Work (Jan. 2011), http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Segregated-and-Exploited.pdf.

Step 3. Gather and Analyze Information about the Settings on Your List

STPs are required to identify the types of settings that provide HCBS, but in many states this is a fairly general listing. Advocates may not be able to evaluate or gather information about every setting, but likely will but know the types of settings that are most likely to have the biggest concerns or issues with complying with the HCBS settings rules. Advocates may not have information about every setting, but gathering meaningful information about several different examples of problematic settings for each type of setting will help show the state how those settings function for the participants, how the settings need to change to meet the HCBS rules, or that they will not be able to meet those rules.

In gathering information, look for evidence that the settings have characteristics that isolate individuals from the community, as well as settings that are in or on the grounds of institutional settings. If you find such settings, be detailed and specific about the characteristics that support these findings. Use the CMS "Exploratory questions for settings" (both residential and non-residential) and other CMS guidance as a guide for what to details to include.[8] As much as possible, this information should include evidence about:

- How an individual experiences the setting
- The specifics of the setting

How an individual experiences the setting

To the extent possible, gather information about the experiences of individuals in these settings and how these experiences compare to the requirements of the HCBS rules. This would certainly include any information directly from

---

[8] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf.

participants, their families, advocates with direct knowledge and similar individuals. It could also include information from former or current staff. Advocates may also find usable information in reports from monitoring efforts or even from licensure reviews. Working with other advocacy organizations, especially self-advocacy groups, is critical because bringing everyone together to mine for information about settings will be much more effective than individual groups trying to gather this type of information.

The specifics of the setting

This should include information about how the setting currently does, or does not meet the HCBS requirements. Consider points such as:

- Does the setting offer of a range of services on-site, such as medical, financial, independent living and other services? Such "in-house or onsite" services often limit autonomy and options, "independence in life choices," and individual choice in who provides services and supports, as required by the rules.[9]

- Does the setting have a policy that visitors must be pre-approved and have an appointment or only visit during "house hours"? This violates the requirement that "[i]ndividuals are able to have visitors of their choosing at any time."[10]

- Does the geographic location of the setting lead to isolation from the broader community? Is the setting close to other settings that serve individuals with similar disabilities? Settings that are all owned/operated by the same provider indicate a high likelihood that there is operational interrelatedness among the settings. Such settings may create an isolated enclave or campus of people with disabilities that is very institutional in nature. Look for:
  - Shared transportation, such as a van for multiple units, which indicates a likelihood that community activities are likely very scheduled to

---

[9] 42 C.F.R. § 441.710(a)(1)(v); § 441.710(a)(1)(vi).
[10] 42 C.F.R. § 441.301(c)(4)(vi)(F).

accommodate the needs of the multiple units and which significantly impair choice of activity and the autonomy of the individuals.[11]

- o Shared dining or recreation facilities which would indicate operational connectivity between settings

- o Evidence that all the residents are employed at the same business or attend the same day program

- Is the primary purpose of the setting to deliver services, such as employment, to people with disabilities only?

  - o Are the majority of people present in the settings (other than paid staff) people with disabilities? If there are people without disabilities in the setting, are they in different parts of the setting? For example, in an employment setting, do people with disabilities and those without disabilities work in segregated work areas in the same building?

- Is there meaningful participation in community events and activities in ordinary community venues (not owned, operated, or leased by HCBS providers) such as fitness facilities, community centers, recreation centers, libraries, community colleges, religious centers, etc.?

  - o Does this participation occur when these venues are open to the general public and include participants who are community members without disabilities and who are not paid staff of the provider?

- Do participants have routine and frequent opportunities, of their choosing, to access services available to the general public?

  - o Does the setting provide readily available support for getting to activities and opportunities?

  - o Are there restrictions on when or how often and individual may use such supports?

  - o Is there available staff who are properly trained who can help individuals access other services that can help them obtain and maintain competitive employment in integrated settings?

---

[11] Transportation should also meet the needs of the facility it serves. For instance, if a facility serves individuals who use wheelchairs, is the van accessible and does it have sufficient tie-downs to accommodate the individuals or do people need to stay behind due to transportation limitations.

- o Are the activities individually-planned and delivered or do they occur in groups?

- Does the type and range of available activities allow for a meaningful day that is comparable to individuals without disabilities of similar age? This could include educational, recreational, familiar, social, faith-based, volunteer experiences, and employment opportunities.

- Does the setting maximize an individual's opportunities for engaging in meaningful day activities outside the home?

- Does the setting facilitate contact and interactions with community members without disabilities?

  - o Does this occur outside the setting?

- Do the activities maximize independence (social, interpersonal and economic), autonomy, and self-direction?

- Does each individual in a setting have their own choices and flexible schedule (not group or facility based schedules)?[12]

---

[12] Although the questions in this section do not generally come from any guidance, they are intended to help identify institutional qualities in settings and other issues related to the rules.

Step 4. Identify Institution-like Settings & those that Require Heightened Scrutiny

There is no magic formula or key feature that identifies a setting as institutional or as a setting that needs to change to become sufficiently communitybased to meet the HCBS rules. Because the rules focus on the experience of the individual, the same type of setting, e.g., a 4-bed residential facility, could be institutional or community based depending on where it is, the policies in place, how it is run, and the opportunities of individuals who reside in that facility.

Although there is no simple test, there are some things advocates should do when thinking about how to identify possibly problematic settings:

- Review CMS guidance on heightened scrutiny, exploratory questions for residential and non-residential settings, and settings that isolate.[13] Although you may have read these pieces of guidance when they first came out, it is helpful to remind yourself of what CMS has said. It can also help you pick out pieces that you know you will want to cite to in your comments when you are highlighting ways a setting does not comply with what CMS has said is required or is an indicator of a non-community based setting.

- Brainstorm about possible settings that receive HCBS funding and that could be isolating based on location, size, or relationship to other institutional settings:

    o Settings on the campus of an ICF-ID/DD, nursing facility or other similarly institutional setting. This would include looking for both residential and non-residential settings connected to such facilities.

    o Settings on former institution grounds.

    o Large, congregate settings that specifically cater to people with disabilities, including assisted living, farmsteads, gated communities, apartment communities with additional services or amenities that are targeted to older adults or people with disabilities.

---

[13] Each of these documents can be download at: http://hcbsadvocacy.org/learn-about-the-new-rules/ .

- o Smaller facilities, such as group homes or more independent living situations, grouped in close proximity. For instance, multiple homes on the same street. Licensure listings can be helpful in identifying such settings based operators and location.

- o Co-location of day and residential settings.

- o Geographically isolated, segregated day settings that seem unlikely to provide much interaction with the community.

- o Large, congregate day settings comprised primarily or exclusively with people with disabilities and limit their choice of daily activities in the setting. Examples include sheltered workshops and some day habilitation programs.

- Identify any licensure or other features that could then be used to indicate similar types of settings. As discussed above, licensure information can be helpful in identifying institutional indicators such as size of a facility, staffing ratios, rights protections, or lack thereof. Once a type of setting has been identified as isolating or otherwise problematic, the licensure information can be used to identify similar settings and can also provide information on settings owned or operated by the same entity.

Step 5. Share your Setting Specific Information with the State

Once you have compiled your information, in collaboration with other groups, share that information with the state. Ideally you should share some of this information while the state is still conducting its own assessments. Sharing in advance of final results can help influence the state's process and highlight potential issue areas with settings and with the process itself. If your state has already made public some of its preliminary results, be sure to highlight where your findings differ from the states' findings.

Step 6. Analyze Your State's Setting Assessment Results

Once a state has completed the results of the settings assessment, it must release the information for public comment through an amended STP. The information you have already gathered should be very helpful in evaluating the states' assessment results. Remember, as you evaluate the results, keep in mind (and handy) the CMS guidance so you can easily note if there is something stated incorrectly in the results and/or where there is conflict between the guidance and state's statements. You can do the same with the information you have gathered on settings. In particular, look closely at the amount and specificity of the state's justifications for why each setting is not institutional or meets the characteristics of an HCBS setting. This information must be in the STP. CMS guidance lays out the type and specificity of evidence it expects, particularly if a setting is being submitted for heightened scrutiny.[14]

The follow are some questions you may want to ask as you go through the state's assessment results:

- Do the updated plan and assessment results appropriately categorize different types of settings?

- Are all of the settings included in the results that should be? Which settings are missing?

- Look for known settings and compare those results to previously gathered information to check whether the information in the state's assessment results is accurate.

- If the state is submitting any settings for a heightened scrutiny review:
  - Does the setting overcome the presumed institutional characteristics?

---

[14] Heightened scrutiny Q&A from CMS, June 2015:https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/home-and-community-based-setting-requirements.pdf

- o Is sufficient information provided that describes the experiences of individuals in the setting and proves the degree of community integration required by the rules? Is additional information necessary?
- o If the setting does not meet the criteria, gather together information that disproves the state's information and provide detailed comment.

- Identify in your comments any settings that are incorrectly categorized as compliant with the HCBS rules but should be categorized as "presumptively institutional".

- Identify in your comments settings that the state has not identified at all. This is particularly relevant for settings that should be identified as settings that isolate and therefore should be submitted for heightened scrutiny if the state wishes to continue their use. Many states do not have good processes for identifying these settings, so this is a key area for identifying problems and comment.

Step 7. Prepare and Submit Comments on the State's Revised STP

Commenting on setting assessment results will likely be different from the typical comments most advocates submit. The comments on settings should have a level of specificity that is not often necessary when commenting. Advocates should draw from the evidence they have gathered about the individual setting and the individual's experience to make a case for how the characteristics of that setting do or do not match the specific requirements of the HCBS rules. Including specific evidence in the comments should help force the state to be similarly specific in processing the information on the settings and in responding to the comments with reasons why, if the state makes no changes to the plan, the state did not alter its findings.

Advocates need sufficiently specific information from the state's assessment process to be able to identify the settings in question and then provide information. Personally identifiable information should not be available about individual participants. Also, specific information about an individual's experience that could potentially identify the individual or release inappropriate information about that individual, e.g., restrictions on their freedom due to a certain health condition that thus reveals the health condition, should be protected. However, this does not mean that the state can provide information about settings in such a way that is very general and thus does not give stakeholders sufficient information to understand how a setting has been assessed. The state must provide enough information to allow meaningful comment.[15]

---

[15] If advocates are concerned about including certain information in their comments about settings or the experience of individual participants, they can consider drafting a public version of their comments that removes overly identifying information and submit a more specific version to the state, citing freedom of information act requirements when requesting that pieces of the comments not be released publicly or be redacted, unless to CMS. The same is true if advocacy with the state is ineffective on settings and advocates write to CMS and include the specific comments. Advocates can cite to HHS FOIA regulations, 45 C.F.R. §5.67(c), to request that CMS protect personally identifying information found in the comments. (citing that "…addresses of individual beneficiaries of our programs" would often be a "clearly unwarranted invasion of personal privacy."

In commenting, advocates should also review the updated STP for its responsiveness to the issues CMS raised in its letter to the state about the initial STP (submitted to CMS in the spring of 2015). Many states will release an updated plan that is responsive to the CMIA letters from CMS, but does not yet include individual setting survey results. When these plans are released for public comment, advocates will want to determine if they are responsive to the improvements that CMS requested in their CMIA letter to the state.[16] This comment period may also be a good time to provide the state with any site-specific information you may have gathered. Providing the information to the state even before it has released its assessment results could help shape state officials thinking. In fact, many states are actively seeking information from stakeholders about settings and may welcome the information. Remember to include this information once again during the required formal comment process that must occur subsequent to the state releasing the assessment results.[17]

---

[16] If the state does not fully respond to the CMIA letter in the updated plan, comment to the state and include recommendations on how to comply if you have them. Many states were told to improve their settings assessment process, including the process to identify settings for heightened scrutiny. Therefore, many states should have more information in their plans on these processes.

[17] It is important to include all information in the formal comment process, even if provided to the state previously, because the rule requires that the state summarize and respond to comments received during the public comment process. Although it is helpful to provide information early on or as the state is working on a piece of transition, it is important to submit the comments formally so the state responds and if the state fails to act, advocates can follow up with CMS.

Step 8. Encourage Others to Share their Opinions Too!

Engage in outreach to inform interested stakeholders about the opportunity to comment on the state transition process. In this advocacy, the number of comments submitted is significant, so encourage other advocacy groups and individuals to submit their own comments rather than sign on to those of another groups. Encourage people receiving services and their family members to share their opinions! Every opinion matters!

Provide tools to help stakeholders understand the STP, the public comment process, and any other stakeholder input process the state may be using, such as a stakeholder transition committee. When possible, develop a sample template for commenting. As discussed above, comments are really important and can significantly affect settings across a state.

Get started early, gather relevant information, draft comments, and make it as easy as possible for others to do the same!

Step 9. Submit to CMS Your List of Settings & Critique of State Setting Assessments

While states must respond to public comment and submit their response to CMS, they only send a summary to CMS. After the state issues the transition plan with the response to comments, review how the state responded to your comments. If you think that they did not make sufficient changes and did not offer reasonable explanations as to why those changes were not made in their response to comments, you may consider sending your comments to CMS with the full list of specific settings identified. If you choose to send your comments to CMS, you should send them with a cover letter highlighting the areas that the state failed to respond to and the settings that most concern you.

Continued Advocacy

The implementation of the HCBS rules is a long-term process and will require advocacy throughout to ensure effective implementation. However, this does not mean that the advocacy must always be resource intensive; much of the work is more about monitoring the state process. Advocacy is important throughout the process, but especially in the STP and assessment process to make sure that the states have strong plans to follow. Also, the national organizations listed on this document are all working on HCBS implementation and are working collaboratively to assist state advocates in understanding the process, evaluating state plans and assessment processes, and crafting effective comments and plans for advocacy. State advocates may contact these organizations through emailing hcbsadvocacy@gmail.com and the organizations will coordinate to try to provide assistance.

HCBS Advocacy Coalition & Contact Information

These national organizations are all working on HCBS implementation and are working collaboratively to assist state advocates in understanding the process, evaluating state plans and assessment processes, crafting effective comments, and advocacy planning.

State advocates may contact these organizations by emailing hcbsadvocacy@gmail.com. You can also visit the coalition website: hcbsadvocacy.org.

The HCBS Advocacy Coalition is a voluntary association of the following organizations working together to advance state compliance with HCBS setting requirements:

- American Network of Community Options and Resources
- Association of People Supporting Employment First
- Association of University Centers on Disabilities
- Autistic Self Advocacy Network
- Bazelon Center for Mental Health Law
- Coalition to Promote Self-Determination
- Justice in Aging (formerly National Senior Citizens Law Center)
- Human Services Research Institute
- National Association of Councils on Developmental Disabilities
- National Consumer Voice for Quality Long Term Care
- National Council on Independent Living
- National Disability Rights Network
- National Down Syndrome Congress
- National Health Law Program
- TASH
- The Arc of the United States