August 18, 2014

To whom it may concern:

Thank you for the opportunity to provide input on the Impact of Federal HCBS Rules on DADS 1915 (c) Waiver Programs. These comments are submitted on behalf of Disability Rights Texas, EveryChild, Inc., Texas Council for Developmental Disabilities and The Arc of Texas. The Department of Aging and Disability Services cultivates an inclusive environment in which stakeholders have ample opportunity to be involved in the development and modification of waiver program principles, rules, policies, procedures, and guidelines. As a result, many waiver features substantially meet expectations in the Federal HCBS Rule, but there is great variation in the degree to which each of the waiver's services comply. We would be remiss if we did not acknowledge that, until recently, we were unaware that the CLASS renewal triggered the assessment process for the other four waivers. Had we understood that, we would have engaged agency staff much sooner.

## HCBS Transition

The Texas Legislature has instructed state agencies on a number of occasions to make program modifications in the interest of moving the system toward more efficiency and uniformity. The resulting processes occurred in silos, which we agree was necessary in the initial phases. The Federal HCBS Rule gives the state the opportunity to comply with these directives more meaningfully and systematically improve all of the waivers by streamlining their rules and requirements through assessing and developing remediation plans across all of the waivers by topic/service through extensive stakeholder input for each waiver.

It is difficult to provide meaningful input given that stakeholders only have access to the high-level six page summary document that covers five waiver programs. The ideal process would include the perspective of people with disabilities, their families, providers, advocates *and* state staff. Although we are reluctant to recommend an **HCBS Settings Transition Workgroup**, it is necessary to get meaningful input to determine how close Texas programs come to full compliance.

Fortunately, Texas has the opportunity to assess and remediate the waivers in advance of the transition of long-term services and supports into managed care. For this reason, the STAR+Plus waiver and its accompanying rules, policies and procedures must be included in the purview of a broader HCBS Settings Transition Workgroup.

The state is set on a course that will lead to a single functional long-term services and supports system. An HCBS Settings Transition Workgroup should be required to recommend that the most meaningful features of each of the waivers, those that support community integration and independence, be expanded to each of the other waivers as part of each waiver's remediation in preparation for the consolidation anticipated in future years. Example: HCS and Texas Home Living program rules are written such that they clearly recognize that the provision of respite in institutional settings is not a best practice

and we believe the same logic should apply to the other waivers without regard for what the Federal HCBS Rule allows. It is okay for Texas to be better.

We appreciate the acknowledgement that the Deaf Blind with Multiple Disabilities waiver program requires substantial remediation and we look forward to being included in that process. We recommend that the remediation plan start by building on the good work that has been done in other programs.

## Person Centered Planning

When the CLASS waiver was developed, rules included Quality of Life Standards, similar to the HCS Principles, against which providers were held accountable. Over the years the language has been removed from the waiver and rules and de-emphasized. Although CLASS case managers and providers are required to receive training on person centered planning, it does not appear that providers are monitored and held accountable to the principles of person centered planning in the planning process. The Intellectual and Developmental Disability System Improvement Workgroup redesigned the HCS person directed planning (PDP) process based on best practices and with substantial stakeholder input that included self-advocates. The process was field-tested and all involved in the development of the process agreed that it should be expanded to other programs.

While we support expansion of HCS planning process, we also recognize that there are areas that need improvement. For example, although the HCS survey process ensures that the person is included in the PDP process and that PDP items are reflected in the implementation plan, there is no enforcement of the requirement that the person was involved in the development of the implementation plan. We can fix that.

## Settings Assessment

We do not agree that all existing settings where HCS waiver services are delivered can be considered in compliance with the HCBS settings regulations because we are not confident that they can be adequately assessed without asking waiver participants. It is essential that the assessment of these settings include the perspective of the people living under the current state regulations. Unfortunately, anecdotal evidence suggests that the intent of the program structure and rules may not always be evident to program participants. Program participants report having bedtimes and being forced to go to day habilitation programs not of their choosing despite the fact that state staff report that the intent of program rules is not to default people into day habilitation settings at all and that choice of day habilitation settings, if desired, is required. What's more, providers report that it is their *right* to move people based on a "business decision" rather than the desire of the person making the move. It would be good to know the extent to which the participant experience differs from the intent of rule language in order to make improvements. Please find a way to solicit and integrate waiver participant perspectives into this process. Focus groups and participant surveys are being used by other states and may be a good way to achieve an inclusive process.

The Federal HCBS Rule provides Texas with the opportunity to truly assess and make improvements to waiver programs so that waiver participants will be integrated in and have support for full access to services in the greater community, including opportunities

to seek employment and work in competitive integrated settings, to control personal resources, and to engage in community life in the same way as people who are not waiver participants. Certainly the fact that more than 25% of HCS waiver participants have no right to personal spending should specifically be addressed somewhere in future documents.

## Day Habilitation Redesign

Although no guidance has been received on non-residential settings, all agree that there is major work to be done. We believe that sheltered workshops and provider-owned and/or controlled day service settings, as currently operated, should be presumed to be settings that isolate individuals receiving HCBS from the broader community. Let's take this opportunity to make the most of community-based integrated employment and community based integrated non-work. There is no need to wait for CMS guidance, especially because the Sunset Advisory Commission adopted a management action that would require DADS to create an advisory committee to address the redesign of day habilitation programs, including appropriate funding for services; reimbursable settings and services; staffing ratio requirements; safety requirements; and other required standards. In addition to community-based waiver providers, day habilitation facility owners, and advocates, we recommend an additional modification that the committee should include a substantial number of persons who use or have used day habilitation services.

## Future Services Provided in Institutional Settings

The Sunset Advisory Commission recommends that State Supported Living Centers have the authority to be paid to provide services to community based waiver participants. The HCBS Settings Transition Workgroup should study and make recommendations about whether and how this can be implemented in light of the Federal HCBS Settings Rule.

## Other Areas to Improve

We don't want to lose the unique features provided in some of the waivers and understand that there will continue to be variability in the services offered to individuals based on demonstrated needs. The provision of respite in MDCP, orientation and mobility and intervener services in DBMD, habilitation and specialized therapies in CLASS, and transition assistance available in some of the waivers are integral to supporting community integration and independence. We don't want to lose those, but there may be others who could benefit from such services. There are also waiver services that are meaningful and should be available to people in all of the waivers like supported employment and employment assistance.

Other areas where the rules need to be addressed or strengthened include:

- Visitability standards;
- unimpeded, private, and uncensored communication and visitation with persons of the program participant's choice;
- access to the religious services of one's choosing;

- co-location and spacing requirements that discriminate against persons with disabilities;
- self-advocacy and peer supports;
- rules that encourage the development or maintenance of maximum self-reliance and independence with a goal of self-sufficiency;
- limiting the use of assisted living facilities (ALFs) and, if continued in DBMD and STAR+Plus, program rules that prevent the isolation of individuals in "institution-like" settings;
- access to certain consumer directed services in group home and host home settings;
- service limits that limit access to the greater community or cause risk of institutionalization;
- a community living options information process that encourages the most integrated settings and includes ongoing information to people in group homes and host homes, not just for those in institutions; and
- uniform mandatory participation (program termination) requirements without sufficient due process protections.

These are all issues that need to be addressed regardless of the service delivery model especially in light of the system transition.

Again, because of our inclusion in the variety of stakeholder input opportunities provided by DADS, we are confident that the state is in pretty good shape in a lot of areas. But let's not miss an opportunity to improve our system and make it the best that it can be. It is hoped that the attached input will be integrated into future transition plan documents.

Respectfully submitted,

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HCBS Settings High Level Transition Plan

## 1. HCBS settings exclude locations that have qualities of an institutional setting

**Home and Community-Based Services (HCS) and, where applicable, Texas Home Living (TxHmL) and CLASS**

We agree with the recognition that day habilitation (day hab) paid for through the HCS or other HCBS funding, such as TxHmL and CLASS, requires remediation. Texas transition plans for each HCBS program that pays for day habilitation should include strategies that move toward Employment First and Community-based Non-Work (CBNW) and away from the current facility-based day habilitation programs and sheltered employment. Texas day hab programs do not typically, but could, provide much more community engagement for participants if required and reimbursed. Please see the attached document that proposes review of and alternatives to facility-based day hab through person directed CBNW. It is important to note that CBNW should not diminish Texas' efforts related to "Employment First" and CBNW should never be a precondition to accessing vocational rehabilitation services, employment assistance or supported employment. It is important to note that Texas should also move from sheltered employment using sub-minimum wages to true employment and meaningful day activities that provide opportunities for person centered community engagement. It is not clear to what extent provision of day hab and sheltered employment and the funding are co-mingled. Paying for sheltered employment or any indirect expenses such as staff, sharing a building or immediately adjacent to a building, or transportation should not be allowed through HCBS funding.

Future worries regarding residential settings are based on leadership's openness (as expressed in SB 7, 83rd R, Texas Legislature) to consider adding more restrictive or congregate living arrangements in HCS at some future time. SB 7 Sec. 533.03551. FLEXIBLE, LOW-COST HOUSING OPTIONS says *"(a) To the extent permitted under federal law and regulations, the executive commissioner shall adopt or amend rules as necessary to allow for the development of additional housing supports for individuals with disabilities, including individuals with intellectual and developmental disabilities, in urban and rural areas, including:*

*(1) a selection of community-based housing options that comprise a continuum of integration, varying from most to least restrictive, that permits individuals to select the most integrated and least restrictive setting appropriate to the individual's needs and preferences;"*

We do not support adding additional congregate or otherwise more restrictive settings, including but not limited to, assisted living which is currently an approved living arrangement in DBMD (limited to 6 bed) and CBA/STAR+Plus (not limited to 6 bed). We do not support waivers of other disallowed institutional or institution-like residential settings in HCS, such as gated communities, farms, ranches or neighborhoods. Instead, we recommend expanding Community Living Options informing processes to include focus on non-group home housing opportunities and seeking additional subsidized

housing funds to support individuals in HCS, CLASS and other programs. We also recommend pursuing any necessary remedy to prevent local municipalities, home owners associations or other entities from excluding small group home settings in typical neighborhoods or individuals accessing an accessible, affordable apartment of their choosing in an integrated apartment community that serves individuals with and without disabilities.

## Community Living Assistance and Support Services (CLASS)

**Prevocational Services:** Please see the comments above regarding the use of day habilitation in the CLASS waiver as a prevocational service. Because day habilitation centers are allowable locations for CLASS prevocational services, remediation to comply with the HCBS rules will be needed.

**Person Centered Planning and Direction**: When the CLASS waiver was designed and implemented more than 20 years ago, the waiver required the development of a Person Centered Plan for each individual in the waiver. Over time the requirement changed into a simple requirement that initial training of DSA and CMA staff must include person centered planning. The amount, content and quality of the training appears to be open to interpretation. There is no longer a requirement that the Case Management Agency develop a person centered plan for each individual receiving services under the waiver and that the plan of care be developed based on the person centered plan. We strongly encourage DADS to incorporate and require person centered planning in the waiver.

**CLASS Individual Plan of Care:** The goal of the CLASS waiver is to support individuals with related conditions to achieve their desired lifestyles and to be valued members of the community. This goal comports with the HCBS settings rules and is the foundation of the CLASS waiver. In 2009 the CLASS waiver rules were amended to include language that directed the work of DADS Utilization Review. The new rule language required that each individual service be evaluated as to whether the service meets all of the following:

- protects the individual's health and welfare in the community;
- addresses the individual's related condition;
- not be available to the individual through any other source, including Medicaid state plan, other governmental programs, private insurance or the individual's natural supports;
- prevents the individual's admission to an institution;
- is the most appropriate type and amount to meet the individual's needs; and
- is cost effective.

There is no requirement that the services listed on the IPC support the integration and inclusion of an individual into their community, or be person centered. We support the addition of language requiring that services be person directed and promote community integration.

**Quality of Life Standards**: The CLASS wavier was developed based on a set of quality of life standards. These standards were removed from the CLASS Provider Manual in 2012. We believe that the standards support integration and person directed services and

should not only be reincorporated into the provider manual, but become part of the rules and criteria against which services and providers are evaluated. Texas has a similar set of principles incorporated into the Home and Community-based Services (HCS) waiver.

**Out of Home Respite:** We understand that CMS has clarified that respite provided outside of the home can be provided in settings that would otherwise be precluded such as nursing facilities and intermediate care facilities and that CLASS allows for the provision of respite in both of these settings. Texas has prohibited the use of respite in an institutional setting in the HCS waiver. We believe a similar exclusion should be included in the CLASS waiver.

**Deaf Blind and Multiple Disabilities (DBMD)**

We agree with DADS that the Deaf Blind Multiple Disabilities program currently does not meet the standards established by CMS in the Medicaid HCBS rules. The waiver allows for services to be provided to individuals in assisted living facilities with up to 6 individuals in a home. We would like to work with the Department on the development of rules and implementation tools to bring the waiver into compliance. In addition, the DBMD waiver, like the CLASS waiver, needs to include the requirement that individuals are led through a person centered planning process which directs their plans of care. The waiver should also include a core set of community integration principles.

**Medically Dependent Children Program (MDCP)**

While MDCP does not pay for a residential service, the program would be more consistent with the HCBS guidelines if respite was not allowed to be provided in institutional settings, moving Texas toward more focus on community-based respite options across the waiver programs.

Related to day care settings, and considering the example provided by DADS that a day care program may be adjacent or in a hospital where the parent works, the standard should focus on whether the day care is integrated with individuals with and without disabilities. If that is established, then a person centered waiver of the location may be appropriate on a case by case basis.

## 2. Each individual's privacy is protected

Home and Community-Based Services (HCS)

Regarding lockable doors, they may be available now or soon, but residents have not been trained about this option, how to plan to use the option or whether to permit staff or others in the home to have a key. There should be an educational campaign regarding this and other aspects of the HCBS guidelines to empower self-advocates and their families to fully benefit from the new guidelines and engage in the 5 year transition process.

Choice of housemates in HCS residential settings is largely the exception and not the rule. Although providers have to be familiar with person directed approaches and fill out an implementation plan that reflects the person centered plan, the choice of housemates or roommates is much more provider driven and may not even be part of the discussion. Texas should increase focus and accountability regarding this and other choices through training and regulatory activities. Also, require that service planning address desired characteristics of staff support and housemates and hold providers accountable for following through, to the maximum extent possible, to support choice of housemates, roommates, and staff. Lastly, require the individual to sign and receive a copy of the provider's implementation plan and that the plan is updated during the plan year as appropriate.

Control of one's own schedule and activities, including access to food, is not common. Instead, staff convenience or the provider companies arbitrary "policies" take precedent over individualization, choice and control. Similar to the roommate issue above, much work needs to be done through service planning, implementation plan development and provider accountability. All key stakeholders should be made aware of these requirements as part of the first year of Texas' transition plan, including individuals in the HCBS programs, families and others involved in their lives. Also, it is more difficult to have access to the food of one's choosing when someone else, often staff within provider established menus, does the shopping and manages the food budget. We recommend that choice begin at the grocery store and not at the refrigerator or food pantry door. There are insufficient provider standards to support food choices, money management education or opportunities and schedules related to food or anything else. We recommend requiring access to a minimum personal spending amount for individuals so that food and other items can be purchased and that persons have independent access to those funds and training to manage those funds. Otherwise, each provider company has a policy and formula for room and board charges within DADS general rules, and individuals have very different amounts left for personal spending depending on which provider they choose. Furthermore, strict enforcement requiring disclosure of the current room and board agreements prior to enrollment with a provider should happen and individuals should be made aware of the room and board rules and agreements through an educational campaign. Also, service coordinators and providers need to understand appropriate, albeit limited, access to SNAP benefits and enable individuals they support to access those benefits which should both increase choice of food and increase access to funds for personal spending needs.

Visitors of one's choosing at any time conflicts with some provider's practices and routines. We recommend that residential settings, during the 5 year transition, build capacity for visitability and that we identify this barrier and focus on it in the current transition plan. Not only should a person be able to find a living arrangement that is physically accessible, a person who does not use a wheelchair or other mobility device should be able to have a visitor who does. The city of Austin has visitability standards in place for new subsidized housing and those requirements for the ability for a visitor to get in the home and access at least one bathroom door would promote family and friends staying connected.

Physical accessibility is negatively impaired by the HCS lifetime cap of $7,500 for minor home modifications. HCS should be modified to increase the cap to at least $10,000 (similar to CLASS), recognizing both the increasing transition of individuals with physical disabilities from nursing facilities into HCS and the aging of person with developmental disabilities as a group in Texas. Secondly, the cap should not be a lifetime cap which limits choice of providers, moving out of one's childhood home into independent living arrangements, or changes in the type and costs of minor home modifications one needs and that may increase independence. Also, if a person's lifetime cap is used in a group home setting, they may not have an opportunity to move to another town or part of town without access to additional minor home modifications. This can be a barrier to choice, employment, furthering one's education or access to public transportation.

We recommend creating peer support for individuals with IDD by individuals with IDD, which will be a significant way to encourage more empowerment and choice in the DD HCBS programs. We suggest funding this program through Medicaid, similar to the Mental Health Peer Specialist service in Texas. Another option may be to build the service into the waivers similar to the support broker advocacy option that currently exists in certain waivers.

A related issue to choice is the role of service limits and utilization review in the HCS program. Although the Texas Legislature let service limits imposed on the HCS program in December 2011 expire in statue on August, 31, 2013, these limits are still part of the Utilization Review process in HCS. In addition, providers and service coordinators misunderstand and misspeak when explaining the substance of these limits, which services did/do and did not/do not have limits (nursing and behavior supports, for example) and how to justify the appropriate amount of services an individual needs to remain healthy, safe and integrated into the community. Due to these factors, group homes become the default for individuals who could be successful in more independent living arrangements and for children who could remain with their families. This is an urgent matter that requires immediate remediation and is inconsistent with true person centered approaches and promoting independence. In fact, these factors promote dependence and prevent de-institutionalization on an individual and systemic level. While there is an expression of the desire to successfully support individuals with complex medical or behavioral needs **in the community** and perhaps some related funding requests, the issues noted above could be partially addressed now through a stakeholder process not limited to the DADS/HHSC workgroup that is looking to create mini-institutions to address these needs.

## Texas Home Living Waiver (TxHmL)

1. Settings - See day habilitation comments above
2. Choice – TxHmL program may force a choice between employment and remaining eligible for the program by requiring eligibility based on a lower income level than most HCBS programs. TxHmL does not have the institutional income limit up to 300% SSI. Increasing the income limit would allow this lower cost program with an overall cost cap of $17,000 annually to serve individuals who could also work part time. Additionally, the program would be ideal for keeping children in families if, like the other programs, the parent's income was not counted.

References to person centered approaches above also apply to individuals in the TxHmL program. We are pleased that all services in TxHmL may be consumer or participant directed and encourage expansion of consumer directed options across the other HCBS services.

**Community Living Assistance and Support Services (CLASS)**

Individuals in the CLASS program live in their own home/family home with the exception of those few individuals who receive Support Family Services and those who can potentially receive Continued Family Services. We support DADS remediation activities to further review the services for compliance with the CMS privacy rules. We ask that DADS and HHSC work together to develop a rate that adequately supports individuals who cannot live in their own home/family home to live in a Support Family instead of an institution. The service was added to the waiver in 2004, but to date only a very small number of individuals have been able to use the service due to the rate methodology and subsequent low rate.

We also believe that there are some adults in the CLASS waiver who might need an out of home setting and have no option other than to leave the waiver and reside in an institution. We therefore encourage DADS to explore the possibility of amending Support Family Services to allow access to individuals over the age of 18. We also encourage DADS and HHSC to work on a payment rate that

**Deaf Blind and Multiple Disabilities (DBMD)**

The DBMD waiver needs attention and work to ensure that compliance with the HCBS settings rules. §42.630 of the Texas Administrative Code which specifies the residential service requirements of the DBMD waiver need to be amended to ensure that each individual's privacy is protected.

**Medically Dependent Children Program (MDCP)**

Further review of the host home option as an allowable setting is needed to ensure compliance in the event the individual receives MDCP in a host home.

## 3. Barriers (modifications) to individual privacy must be addressed.

**Home and Community-Based Services (HCS) and Texas Home Living (TxHmL)**

As noted in section 2, protecting the privacy of individuals in HCS residential settings is largely the exception and not the rule.

The Federal HCBS rules require that any modification or restriction of a participant's rights and freedoms must be supported by a specific assessed need and be approved by the participant or LAR, who has the authority to restrict the specific right.

The rules then outline the steps that specific requirements that must be documented in the person-centered service plan, including:

- A specific assessed need which requires a modification or restriction of a specific right;
- Positive interventions and supports used prior to any modifications;
- Less intrusive methods of meeting the need that were tried but did not work;
- A clear description of the modification or restriction that is directly proportionate to the specific need;
- Regular collection and review of data to measure ongoing effectiveness of restricted right;
- Established time limits for periodic reviews to determine if the modification is still necessary or can be terminated;
- Informed consent of the individual; and
- An assurance that interventions and supports will cause no harm to the individual.

According to the assessment summary document HCS is in compliance with these requirements because of the service planning process and TAC §9.173 (b)(15)(19)(20) and (21), which requires the program provider to protect and promote specific rights of individuals including:

- To be free from the use of unauthorized restraints;
- To have a personalized IPC and implementation plan based on individualized assessments that meet the individual's needs and abilities and enhance that individual's strengths
- To help decide what the implementation plan will be; and
- To be informed as to the progress or lack of progress being made in the execution of the implementation plan.

However, these rules do not specifically address a participant's privacy rights or include the assurances and requirements of the Federal HCBS Rules. The current rules will need to be revised to comply with the new Federal regulations, however, the assessment summary does not address a process to evaluate and revise Texas Administrative Rules to align with the HCBS Setting requirements regulations.

To fully implement the Federal HCBS Setting rules, Texas will need to evaluate and revise applicable Texas Administrative Code (TAC) for compliance with these all requirements of the Federal HCBS Setting rules.

We suggest that DADS convene or utilize an existing stakeholder workgroup to:

- Examine each TAC section governing I/DD Medicaid Waiver programs or services; and
- Propose revised language to comply with HCBS Setting rule requirements.

## 4. Residential Settings to include a private unit option for individuals.

**Home and Community-Based Services (HCS) and Texas Home Living (TxHmL)**

The Federal HCBS rules require that residential settings include a private unit option for individuals that include integrated settings, selected by the individual from options, and ensure an individual's right to privacy, dignity and respect. These requirements must be evaluated at the program provider level where individuals receive services, not a high-level analysis of current TAC rules.

For example, individuals in group homes do not have consumer direction options, this is contrary to the HCBS settings rule that requires individuals receiving Medicaid HCBS to have independence in making life choices, including but not limited to daily activities, physical environment and with whom to interact." 42 CFR 441.301(iv).

Whether a specific setting actually complies with the HCBS settings rules requirements must be determined by assessing the individual provider program within each setting. This means that Texas must assess settings at the provider level, including surveying providers and people receiving services to determine if the programs are truly complying with the HCBS setting rules.

Texas should develop a survey for providers and people receiving services.

**Settings that are Provider Owned or Controlled**

Additionally, the HCBS rules include specific requirements for settings that are provider owned or controlled. These include that an individual has the same responsibilities and protections from eviction that tenants have under the landlord tenant law and that the state must ensure that a lease, residency agreement or other form of written agreement will be in place for each participant that provides protections that address eviction processes and appeals comparable to those provided under landlord tenant law.

This is not currently required by rule in Texas and should be addressed as Texas revises applicable Texas Administrative Code (TAC) rules for compliance with the Federal HCBS Setting rules.

**Community Living Assistance and Support Services (CLASS)**

Further review of support family services is needed to ensure compliance.

**Deaf Blind and Multiple Disabilities (DBMD)**

Further review of residential services is required and the previous comments about settings that are provider owned or controlled apply to the DBMD waiver as well.

**Medically Dependent Children Program (MDCP)**

Further review of the host home option as an allowable setting is needed to ensure compliance in the event the individual receives MDCP in a host home. In addition, over restrictive rules that may lead to program termination may not be consistent with best practices or rights, restrictions, dignity, respect, independence or other important rights.

For individuals at or near transition to adulthood, starting no later than age 14, significant efforts should be made to plan for additional autonomy, privacy and other issues key to living as an adult. Establishing person centered service planning for all and ensuring that individuals participate in their own planning would move the program in the right direction. Training on health literacy in order to participate in one's health care decisions is another tool for MDCP participants as well as other waiver participants. These issues should be reviewed with stakeholder input and part of the MDCP transition plan.

**Employment and Community-Based Non-Work Recommendations**

Possible Initiatives:

- Set goals and expand competitive and customized employment for individuals with disabilities.
- Set goals and expand Community Based Non-Work (CBNW) within day habilitation programs and through other funding sources such as safety net and home and community-based services or programs.
- Certify and regulate day habilitation programs through the Department of Aging and Disability Services regulatory division.

Community-based non-work (CBNW) refers to services focused on supporting people with disabilities to access community activities in settings where most people do not have disabilities. Often referred to as community integration or community participation, the definition specifies that individuals spend 50% or more of their time in integrated community settings rather than in segregated, congregate facility-based settings where most people have disabilities.

The information below is, in part, from a Data Note publication - Winsor, J. E. and Butterworth, J. (2012). Growth in community-based non-work. DataNote Series, Data Note 41. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
See additional Texas data using the link below, starting on page 321.
http://communityinclusion.github.io/book12/pdf/bluebook2012_final.pdf

Understanding the role of community-based non-work (CBNW) services is complex nationally, not just in Texas. While different data sources suggest different levels of investment, there is consistent evidence that CBNW services are being used more frequently. The number of states reporting that they provide CBNW services on the IDD Agency Survey grew from 18 in FY1996 to 30 in FY2010. Nationally, the reported participation in CBNW services has grown steadily for states that report it as a service, from 18.7% in FY1999 to 47% in FY2010. However, Texas lags behind.

CBNW services accounted for 57.7% of state IDD (Intellectual and Developmental Disability) agency expenditures for FY2010, for the 27 states that reported expenditures for this service. However, data collected directly from community rehabilitation providers (CRPs) on the 2010-2011 National Survey of Community Rehabilitation Providers

suggest a lower level of participation in CBNW, only 16.4% in 2010. Over time CRPs have also reported growth in CBNW, from 10% for the 2001-2002 CRP Survey to 16.4% in 2010 (Domin and Butterworth, 2012).

One limitation is that CRP, such as the vocational services provided through the Department of Assistive and Rehabilitative Services and agency contractors, and IDD agency responses are not directly comparable, and may reflect differing approaches to reporting duplication of service. This disparity raises concerns about how state agencies are defining and categorizing services. There is currently a limited amount of data on the structure, activities, and outcomes of this service, and states, including Texas, have not established clear service expectations or quality-assurance strategies (Sulewski, Butterworth, & Gilmore, 2008; Sulewski, 2010).

While some states report service requirements for how much time CBNW participants spend in the community, it is possible that in some cases states have reclassified services from facility-based to community-based as the emphasis on community participation grows, even though substantial time is still spent in facility-based settings such as congregate day habilitation settings for Texans with IDD. The low daily reimbursement rate for Texas day habilitation services likely contributes significantly to this problem.

Individuals with IDD and other disabilities would benefit if Texas defined CBNW, collected and publically reported CBNW data, set benchmarks (similar to the 50% of the person's time as noted above) and promoted growth in CBNW across programs for. However, integrated employment should not decrease as a result of this effort. Benchmarks should also be set for growth in integrated employment for individuals with IDD and other disabilities. CBNW should not be treated as a prerequisite for employment assistance, supported employment or integrated employment. Each of these services must be options based on individualized, person directed service planning.

In addition, Texas state agencies should set goals for increasing integrated employment of individuals with disabilities.

Unfortunately, examining a subset of 11 states that were able to provide complete service data over the past four data-collection periods found that CBNW services have continued to grow, possibly at the expense of integrated employment (Table 1). The percentage of individuals receiving CBNW services increased from 41% in FY2007 to 45% in FY2010; however, there was not an increase in integrated employment participation in these states.

In Texas, there had been benchmarks for individuals with IDD that were achieved in the 1990s for certain programs that began to serve at least 50% of the individuals in the programs in integrated employment services. Once outcomes were achieved, the focus was dropped and the persons with IDD accessing employment services and being employed declined. Currently, Texas has new initiatives on employment that may be

able to correct this downward trend and more individuals may be working in integrated settings.

Benchmarks and goals can effectively drive outcomes for both employment and CBNW can clearly be identified for all Texans with disabilities. As the prevalence of CBNW services grows, additional research is needed on whether these services enhance or impede integrated employment outcomes in Texas, decrease the number and utilization of sheltered workshops and contribute to community participation in meaningful daytime activities for individuals with IDD and other disabilities.

Table [i]

| Year | Total Served | Integrated Employment | Facility-based Work | Facility-based Non-work | Community-based Non-work |
|---|---|---|---|---|---|
| 2007 | 134,890 | 20% (n=26,645) | 23% (n=30,929) | 22% (n= 29,079) | 41% (n= 54,733) |
| 2008 | 133,973 | 24% (n= 31,757) | 23% (n=31,255) | 21% (n=28,291) | 43% (n=57,533) |
| 2009 | 146,423 | 21% (n=31,331) | 21% (n=30,961) | 22% (n=32,080) | 40% (n=57,852) |
| 2010 | 147,603 | 21% (n=31,233) | 22% (n=33,176) | 22% (n=32,817) | 45% (n=66,360) |

Setting goals for increasing employment and CBNW, including but not limited to IDD day habilitation programs, must be accompanied with clear standards through certification and regulatory oversight that is conflict free and conducted as the direct responsibility of the regulatory state agency rather than through Home and Community-based Services (HCS) provider's oversight.

We urge consideration of these alternatives programmatic initiatives in appropriations, sunset reviews and other venues where community-based services or employment services are being discussed.

States were included in this analysis if they provided data on the number served in integrated employment, facility-based work, facility-based non-work, and community-based non-work services for all years between 2007 and 2010. The 11 states included were CO, IN, KS, MA, NC, NV, NY, SD, VA, WA, and WY.