



Input on Home and Community Based Standards (HCBS) State Planning Process



Submitted by: North Carolina Council on Developmental Disabilities
www.nccdd.org
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The North Carolina Council on Developmental Disabilities (NCCDD) offers the following input to the North Carolina Department of Health and Human Services on the development of the CMS Home and Community Based Standards (HCBS) State Plan.

About NCCDD

The NCCDD works to advance opportunities and services for the estimated 177,000 persons with intellectual and developmental disabilities (I/DD) in North Carolina. Our grant awards and advocacy, across the state, support systems change efforts that are guided by the core values (integration, productivity, inclusion, independence and self-determination) set out in the Developmental Disabilities Bill of Rights and Assistance Act (P.L. 106-402). The Council consists of 40 members who are appointed by our Governor, with 60 percent of our membership comprised of persons with I/DD or a family member. Other members include representatives from the North Carolina General Assembly, our state service delivery agencies, non-profit and other professional groups.

Survey Methodology

Members of the North Carolina Council on Developmental Disabilities were asked general questions about home-like settings, having choice within their living situation, who they felt comfortable talking to about their living situations, and elements of the NC Innovations Waiver in group settings that needed improvement. These interviews were conducted via internet survey and telephone interviews.

All 25 Council members who were self-advocates and family members participated in the survey. NCCDD staff members also participated. The survey response rate was 80% with 20 completed surveys.

While only one respondent currently received Innovations Waiver services and resided in a group home setting, other Council Members have lived in group settings in the past and responded based on their personal experience and those of their peers. Three members were family members of individuals receiving Innovations Waiver services and residing in a group home setting. The remaining respondents were advocates who have knowledge of individual experiences and/or policy related to group environments.

The following report outlines the input provided by the NCCDD. Responses are provided in their own words.

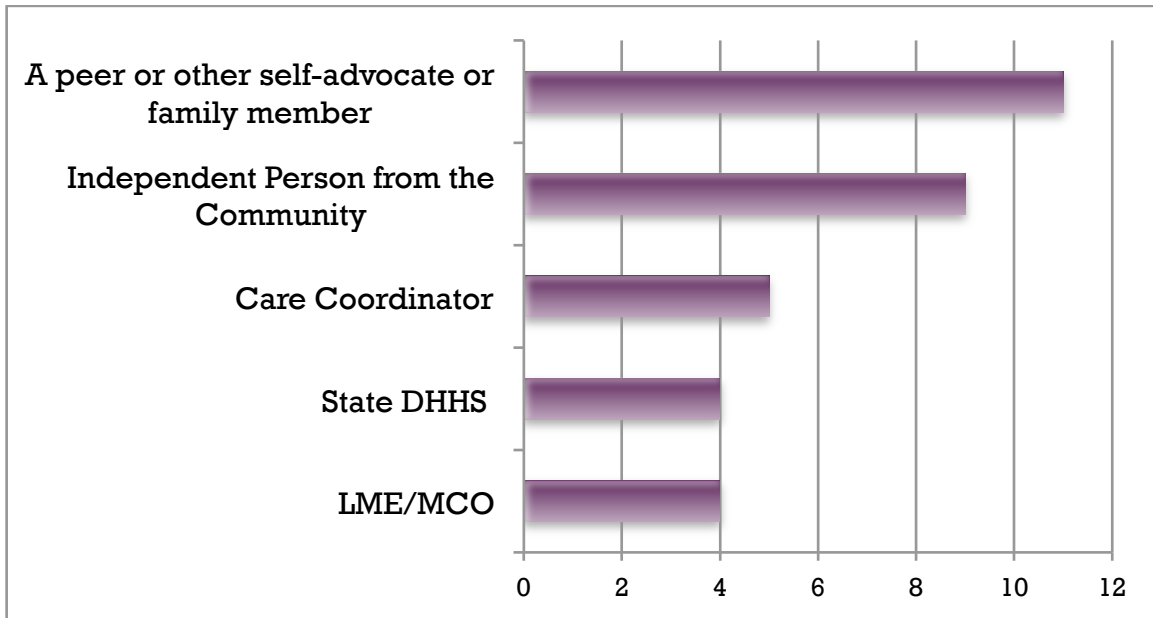
+ HCBS Settings: NCCDD Survey Summary

Question 1: How could you make your current living situation more "home-like"?



+ HCBS Settings: NCCDD Survey Summary

Question 2: Who would you like to provide education about settings in which you could live in?



	Responses
LME/MCO	4
State DHHS	4
Care Coordinator	5
Independent Person from the Community	9
A peer or other self-advocate or family member	11
Other: Housing Specialist, Asset Development Coordinator, or Benefit Specialist	

+ HCBS Settings: NCCDD Survey Summary

Question 3: In your own words, what does "Choice" Mean?

Choice to live where he wants, with whom he wants, and choice with his lifestyle options, e.g., clothes, food, activities.

Choice mean I choose what I do versus what others determine what I am allowed to do. This also means that I have a protected voice in what happens in my life. Choice is not unlimited. It must be balanced with other important values, ensuring personal safety and protections, etc.

Being aware of as many reasonable options as possible, and being free to select the option that the person feels best suits him or her.

It means that there are options available...which is good since "one size does not fit all"

Choice means my son will decide where, when and how he wants to live his life with the support of staff that will honor his choices

You can make more than one decision. that you have rights to have input when you make a decision

Ensuring that people have ample, hands on experience when being provided with a choice. Choice is a learned skill and without ample support, experience and information, "choice" can be the cause of distress.

Choice is having right to decide, means to pay for options, ability to get around to different options, and support for options as needed

+ HCBS Settings: NCCDD Survey Summary

Question 4: Do you feel like the current Innovations Waiver allows you to have choices in the setting you live in? Choices about privacy, access to phone and email, visitors, and setting your own schedule?

Responses	
Yes	1
No	15

Please explain why not?

Low wages do lead to turnover and lack of qualified staff.

So many folks currently living in these situations talk about such small things they would like to do but can't because of the group home - having internet service in your room, making personal appointments

The Innovations Waiver now is very vague and up to interpretation of the LME/MCO's. ISSP's, PCP's can be written in away that all the I's are dotted and T's crossed so billing can take place. But there is not a focus on the outcome and quality of life that the plans are suppose to be providing to my son.

The provider or group home seems to make all the decisions. Too structured and one-sided. My friend can't use the telephone without permission. if she wants to make a call at 1:00 she can't because they won't let her use the phone. we can make choices on our own

There are too many rules and regulations that restrict options for people with significant disabilities (e.g. transportation and support not provided to see doctors unless you live in group home but then not enough pay to provide this individually) and not enough resources to pay for internet &/or tech devices/training/support. Since not enough individual support, then you cannot set own schedule. Also, many regulations about visitors causing limits

Current Innovations Waiver does not protect the consumers enough

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So many folks currently living in these situations talk about such small things they would like to do but can't because of the group home - having internet service in your room, being able to make personal appointments

I've seen restrictions on people's access to food, being able to set their own schedules, and having visitors (especially overnight visitors or visitors of the opposite sex).

Systems are not in place to allow for individual choices to be met

+ HCBS Settings: NCCDD Survey Summary

Question 5: Do you feel that your Person Directed Plan reflects your needs and preferences for your everyday living situation?

Responses	
Yes	4
No	12

Question 6: How could your service provider better understand your needs and preferences for everyday life?

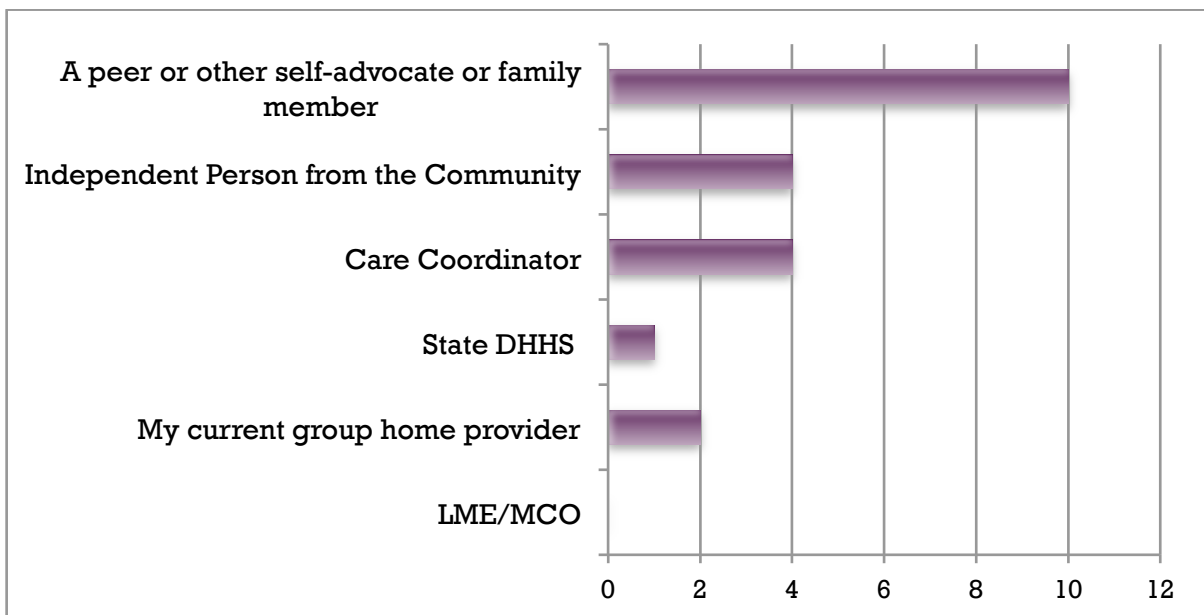
- ❖ No, because it is drawn up within limited parameters. You have to work with what you have and what you have is not enough.
- ❖ To use more than one type of assessment tools to understand my needs and preferences.
- ❖ Getting to know the person that the plan is written for.
- ❖ Need different types of questions that ask about daily life and schedules
- ❖ It is not that his team doesn't understand his needs it that lack of quality of staff and the overturn of staff, we really can't get a good start before we have to start over.
- ❖ Plan is long range goals and there is no place to talk about everyday life. Would need new or different questions to get these answers
- ❖ Basic needs are generally constant but life is constantly changing. We need the freedom to constantly change and evolve with life.
- ❖ By really listening to what I am saying and realizing that provided with the right supports, I can achieve anything
- ❖ Need proper back up staff support as everyday life affected by front line staff when sick, unable/unwilling to support, not fully trained on the individual's plan, etc

+ HCBS Settings: NCCDD Survey Summary

Question 7: If you needed to change things about your current living situation or things you do during the day, do you feel like there is someone you could talk to?

Responses	
Yes	11
No	5

Question 8: Who would you feel most comfortable speaking to about making changes in where you live or your daily schedule?



	Responses
LME/MCO	0
My current group home provider	2
State DHHS	1
Care Coordinator	4
Independent Person from the Community	4
A peer or other self-advocate or family member	10

❖ *I would be afraid of retaliation from my provider if I complained.*

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Summary

- Respondents support the changes in the HCBS standards that would offer individuals more choices in community living. The majority felt that choice was limited in the current waiver programs (Pg 5). Members offered suggestions for possible solutions.
 - Members offered their own definitions of “home-like” and “choice” (Pg 2 and 4)
 - Respondents did not feel that the Person Directed Plan reflected their needs and preferences in its current form. Suggestions for improvement were offered (Pg 6).
 - Many feel that they have someone to talk to if they wanted to make changes in their current living situation (Pg 7)
 - The majority of members would feel more comfortable receiving education talking with an independent person from the community or a peer self-advocate or other family member. (Pg 3 and 7)
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For more information, please contact:

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