

Beyond Tokenism National Study
Report on Focus Group
Self Advocates Becoming Empowered
St. Paul, Minnesota
May 31, 2012

Introduction

The purpose of the Beyond Tokenism National Study is to identify the best practices currently being used throughout the United States and elsewhere to effectively include people with developmental disabilities with high and complex support needs in participating in policy-making, advocacy, and community activities of disability policy-making bodies. The Study is funded by the Michigan Developmental Disabilities Council and is intended to enhance the capacity of the Council to more fully include people with high and complex support needs in all of its activities.

Over the past decade, policy-makers have begun to include people with developmental disabilities on boards, policy-making bodies and all of their organizational activities (Caldwell, 2009). At the same time, researchers have begun to involve people with developmental disabilities directly in research through action research projects where the people with disabilities are active agents in the research rather than simply subjects to be acted upon (Beresford, 2003; Heller, 1996, 1995). More recently researchers have begun to ask people with developmental disabilities their opinions directly through individual surveys and focus groups (Llewellyn, 2009). Surveys have been found to have serious methodological problems with respondents from marginalized groups often answering what they think the researcher wants to hear, referred to as acquiescence, or answering most questions with the last option provided, recency (Finley 2002, 2001). Focus groups have been found to overcome these limitations and to be an especially effective method to include individuals and groups that have been previously excluded such as ethnic minorities, young people, old people and particularly people with disabilities (Kass, 2001).

In order to obtain a wider perspective of people with high and complex support needs being included in DD Council activities, a focus group was held with the Board of Directors of Self-Advocates Becoming Empowered (SABE), the national self-advocacy association. The focus group was held May 31, 2012, in St. Paul, Minnesota following a regular board meeting. Thirteen board members participated from ten states including Texas, Georgia, New York, New Mexico, Arkansas, Vermont, California, Minnesota, Oklahoma and Utah. Two thirds of the

participants were considered to have high and complex support needs and the balance had moderate support needs

Six of the 13 participants had participated in a Focus Group previously. All of the participants had extensive experience and involvement with Developmental Disabilities Councils, Protection and Advocacy organizations and University Centers for Excellence in Developmental Disabilities as well as other disability groups. The majority of the participants had served on multiple councils, boards, committees and task forces with the average being 3.6. The focus group lasted two hours and included eighteen questions.

Process of the Focus Group

The Focus Group was facilitated by the Beyond Tokenism Study Project Director who has extensive experience conducting research with people with developmental disabilities including focus groups, surveys and directed interviews. The facilitator began the Focus Group by explaining the purpose of the group. A consent form was read aloud to all the participants explaining the voluntary participation and confidentiality of the information. Everyone agreed to participate and signed the consent form (see attached form).

Content of the Focus Group

Question 1: Why do you serve on Boards or committees?

“I think that they don’t understand a lot of times why people with disabilities need to be on boards – they don’t think we can do it. We want to show people what we can do.”

“I like to be on boards or committees to help make changes, let your voice be heard and helping in making decisions in laws or policies.”

“I’d like to do this so that our voices can be heard and that they actually hear from someone that lives with a disability instead of just reading about it. Some people don’t even interact or even talk to people with disabilities and they are making decisions on things.”

“I think the reason why it is important to serve on these boards, because when decisions are made about lives, we should be at the table whenever decisions are made about us, we should be at the table. And, also, it’s just to watch where everything is going.”

Question 2: How do you get in these groups, how do you have some say on things?

“Participate or volunteering in some of the committees – be active.”

“If you are chair of a committee, they will listen to what you have to say. Other people that are working with you can make things happen in whatever Council you’re on.”

Question 3: How many people have been officers of the boards and how did you get to be an officer?

“You put your name on list and have them vote for you.

“You’ve got to prove yourself.” If they put you in as Chair, you’ve got to really prove that you can handle and do it.”

“The other thing is to have a campaign letter – that’s what I did when I ran for Vice President. I did a campaign letter.”

“Sometimes it’s just who you know!”

“I believe people need to have confidence in themselves to ask for when they need help. For example: I was one of the first ones to be on the Arc, US Board; also, The Arc of Nebraska. Every time we’d have a meeting, we would go over the board pack so that I was informed. I think that’s a big part of it.”

“It’s who you know – how do you get known by other people? A lot of times, if you can, you have to go to some of the national conferences where a lot of the professionals are at, and then get your name out there and you can talk about the training you’ve had, the presentations given, and get to know them that way.”

Question 4: What are some of the things the organizations have done to support your full participation?

“One of the things that they can do to help you is when you don’t understand something; you need to have the responsibility that you have to say that you don’t understand it. The responsibility they are to take their time to explain things to you.”

“They could introduce you to people or they could invite you to other meetings or other places that they go to and introduce you to new people.”

“My work did it for me – they provided me with an assistant to help me with computer stuff or whatever – scheduling things, and helped me when I go somewhere. They help me to be able to prepare and have the tools I need when I travel across the state to meet with families and things like that.”

“I have proper support – like when I come here, our Council helped pay for me to be here and to help me understand more. They pay the person to come down and

help me take notes and if I'd get lost or if I don't understand, they explain to me – this is what they're meaning or this is what they're doing. I'll ask is this proper or is this not proper, and they can tell me that this is proper and this is why.”

“I also think that the chairperson of that organization can set an example for others to follow by how they include or interact with people with disabilities on that board or committee. Set an example on how to interact with people with disabilities.”

“With me, I didn't have any type of support to help me understand stuff. I was, for the first time, on a committee and they were discussing stuff and I didn't know a couple of things, and I asked for help and they didn't listen to me. A couple days later, I went to someone at the Arc and I talked to him and said that this wasn't right, because there are two advocates on here and they have supporters – when I went in, I had no one. He said, well, you know when I'm there you will have a supporter too.

Question 5: How important is it to get to know each other?

“I think that can make or break you. If someone says that you don't have the confidence in yourself to begin with, then how people include you is going to give you confidence.”

“It helps just getting to know each other.”

“There could be an orientation on how to help or support someone. They can introduce you to other people or they could invite you to things after the meetings – dinner or something – go out and socialize with everybody else.”

“Most people get out of their comfort zone. The hardest thing for me was to get out of my comfort zone. I went and shook hands and that's not me. It brought up the fact that if I can do that, there are other things I can do.”

Question 6: What things help you to get out of your comfort zone? What are some things to help you to be better able to speak up?

“What I try to do at first is listen, you know, as to what is going on, and then look at the materials that I have given to me. You know they usually give you stuff or send you stuff. I let them know what form I needed and you know, pay attention to that. Because some of the boards and things have been hard at first, because if you don't know anyone or if you don't know what's going on, you know, you have to start somewhere. I was on a state committee on education and all they wanted people to do was go in and say yes to the materials that they had sent out.

So, I started asking questions and it's hard for some people to ask questions and it changed how they wanted people to do stuff."

Question 7: A lot of people have talked about being afraid to participate. How many people were afraid when they went to their first meeting? [Everyone raises their hand]. What happens when you are afraid and how do you overcome it?

"You just don't say anything. You think that if you say something, someone is going to take it wrong and then you have that thought in your head and it just stops you from saying anything."

"I am shy."

Question 8: What else can organizations do to more fully include your participation?

"Another thing is that people don't listen to us. They should try to understand what we're saying because there are people out there that did not understand about people having disabilities. The reasons why I'm saying this is because when I was growing up, there was nothing around for my Mom and I, you know, to get help. There was nothing. So, now, there is stuff out there, but, still, to this day, they still do not listen to what we have to say. Another reason I'm saying this is that there is a DD Council in my state that doesn't understand and they don't want to listen to what we have to say. Even the people who are at the Capitol; they don't want to listen to us."

"You know I'm just thinking about the first question you asked your comfort level and how people get into their comfort level. So, I'm tying it into that question and summarize a little bit about what you are asking. Like first, you asked about your comfort level. Your comfort level does depend on how you feel in meetings. So, if someone is not comfortable in their group that can cause fear. Your fear kinda gets in the way of your speaking up. I forgot to answer the first questions about your comfort level. For me, I would say that if you know someone that is a part of that group, have your accommodations ahead of time, have that person help you. I think the more you can do that, that can help to overcome some of the fear you have. Because, sometimes what happens is that when you're not comfortable, it causes fear, and I think your comfort level depends on whether or not you feel if your accommodations are going to get met."

"I think also that you can help you when you are on a committee, like asking you later on if there is anything that you need help with, any other supports that you need, do you understand what's going on. You know, that kind of stuff helps

people get comfortable with a group. You know, making sure that people are okay- asking if they want to add something when things are out there and people are asking questions.”

“I also think that if you’re going to have a person with a disability to be on your board or committee is that you need to talk to them about what the accommodations are and the supports they need. For example: some people may not know how to read and making the material so that people can understand it and a lot of us don’t understand the words. Another thing that I think is helpful is that they color code the material, like green is money, blue is the minutes – I’m not sure if I’m telling it right, but just for an example.”

“Another way is to explain the “big words” and put it into our “readers”.

“You know they need to treat us like we’re human beings. It’s like they want to touch us, but they don’t dare because you’re going to break or you have a disability, is there anything I can do. They treat you like a baby. They should treat us like they would want to be treated.”

“What I was thinking of is have someone in there for people who cannot take notes right, to help take notes for other people.”

“We can ask if we can have someone take notes and if they ask why, say because you know I cannot take notes right.”

Question 9: How does it help you to have someone taking notes for you?

“I also think like when we’re in a meeting, it goes too fast for people. So things that you’re responsible for need to be written down. Also, it helps to remind you of things.”

For someone like me, that would be helping me to understand – that would be my minutes for me to know and to refresh.

“I think that it also helps to have more than one person taking notes on a board or committee because it makes you feel at ease if you have someone else to talk to and it’s also intimidating when you have all these professionals and you are the only one with a disability and trying to speak out for what you believe in and try and help them to understand.”

Question 10: Why is it important to have more than one self-advocate in the group?

“I think that it’s important because you want them to know that people are different and that you have different views. People are not all the same, just like people on this board are not all the same. All opinions count. That’s important to

let them know, because sometimes they will point out and say, you're different from other people, and you're to the point that the very first time you say something, it's different from what they want you to say and when you disagree with them – oh yeah, you're different alright. Then, you're starting trouble.”

“One thing that would be important is to put board content on CD's.”

“It not only helps me, it would help other board members so that they can get the information.”

Question 11: Some people talk about having the material two weeks in advance – why is that so important?

“The reasons that it's important, you'll actually be able to participate in the meeting and if we don't understand it, then how are we going to be able to participate in the meeting. So we need to have time to allow people to go over the material with us so that we can understand it and so that we can form opinions of how we feel about things.”

“I think that it's so important to be prepared ahead of time so that everyone, not only does it show that you're able to be prepared for a meeting but so are others.”

“Sometimes when they give you those board packets, they're so big, and not everything that's in there, you have to read. So what we did was put in a beginning page on the top of it that said you have to make a decision about this – you have to vote on this – and there's another page on top of the other thing that you don't have to vote on and says, this is just for your information to read later. So that you can pay attention to the important stuff that you have to be concerned about during the meeting, and the other stuff you can worry about later. That way, people can do that, and the color coding was done so that everyone could be on the page, along with pictures, so that people will know that this is the minutes – there's a picture of the recorder – and all of this is on that front page so they will now the difference.”

“I think that having an agenda prepared sometimes before a meeting is good because there may be topics that you have to pay attention to and then there are topics that you don't have to pay attention to, and I think in my experience when I have agendas ahead of time, we go over the agendas, I know at what point on the topics that I need to pay attention to so that if I have something to say about it.”

Question 12: Who helps you be prepared for a meeting?

“It has to be someone that you can trust.”

“I think it’s important to pick your own support person, because that’s a person you feel comfortable with; you know that person so that they know how to support you; they know how to help you to understand the materials that you’re going over and I think that helps a person to be able to go to a meeting feeling more prepared.”

“It’s like the people who you know. Like me, I have two people with the state Arc that will go over the agenda with me just to make sure that I understand what’s going on and for me being prepared in case I’m asked a question.”

“On the Council – what we did was to get all the self-advocates together and take about 10-15 minutes to discuss the agenda and what’s going to be discussed during the meeting. This way, if we had any questions we could ask – ok, I’m confused about this or I’m confused about that – or I don’t understand about this, and that really helps because you’re going in to a meeting more learned because you know what’s going on. That 10 minutes of support really does help.”

“It’s part of my job as self-advocate to provide support.”

Question 13: How many self-advocates should serve on a board?

“Depends on the size of the group.”

“I also think it depends if it’s like the DD Council or another organization other than a self-advocacy organization, because then the whole board should be.”

“Legally, I think it has to be 50%.”

“50% of people with disabilities or a family member.”

“It should be half and half. Everyone seems to agree that it should be more than one.”

“I would say in a large organization, at least 10, because when it comes to comes to voting and some of those kind of things, you have people that are strongly wanting something, most of the time if you only have 1 or 2, you are automatically out-voted, unless you can convince some other people to see it in the way that you’re talking.”

“Also, I think, if there is more than one person with a disability, they have to be from different parts of that state.”

“A lot of it has to do with diversity and there will probably never be that diversity.”

“Most of the time you get people from the rural areas and there are so many in cities, and outside of that, it’s hard to get to your meetings.”

Question 14: Let me come back to what we discussed a little earlier – influence and there was a lot of reaction on this – a lot of you feel that’s why you’re on these committees. How do you make a difference?

“Making your voice be heard”

“Speaking up.

“The passion of the issue.”

“Sometimes you just say what you’re feeling – sometimes you have to think if it affects you it affects other people.”

“ How it affects you makes a difference because we’re the only ones that can say that.”

“Asking you to be part of something other than being on a board.”

“ We don’t sugarcoat the information, we just tell it like it is.”

“Don’t be afraid to speak up for what you believe in.”

Question 15: What can the organization or the Council do to better help you?

“Make you look good – you don’t want to just look good, you want to be heard by a lot of these people”

“ Have someone from the Council be in our shoes and see how we feel.”

“I think they want you on there because if you turn them down, they get highly upset. I was asked to be on our DD Council and I said, I don’t want to be on it, I’d rather stay in the position that I’m on, because I would be able to tell you what’s good and what’s not good, what I like or don’t like. If I’m on a Council, I can’t do that, it changes the dynamics, I’d become one of you and not be able to tell you what to do.

“I think that whatever your position on a board is, you can help influence others – an officer can also help influence others.”

Question 16: How much influence do you feel you have being on these committees?

“It depends.”

“If I’m on it I’m going to have my influence whether they like it or not.”

“The National Council that I’m on now there are people with disabilities but come from different backgrounds and we all work toward the betterment of people with disabilities and our input counts and then we get to shape things for the President and the Congress. Actually the good thing is, we can tell them if they’re wrong about something. They’re asking for our advice.”

“In my experience, the amount of recommendations that you get by being on a committee and people telling you whether or not they like your opinions. How you serve on one board can lead you to becoming a member on another board.”

“Standing up for what you believe in – you may be rewarded, but it’s a dirty job.”

“You have to listen to people with disabilities – provide support for them – help them build their confidence so that they believe in themselves – so they will speak up for themselves.”

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