

Service, Support and Success

The Direct Support Workers Newsletter

Voice:

Avoiding the Temptation to Silence, Promoting the Need to Listen



By: Colleen Orrick

Recently my husband went to a conference. He brought back a satchel full of papers from the conference and on the front of the satchel was printed "Our Voice." We often hear reference to "voice" when talking about people making their views, wishes and perspectives known. My husband's satchel and our chat about his conference got me thinking about "voice."

We know the power of voice. Barak Obama said: "One voice can change a room, and if one voice can change a room, then it can change a city, and if it can change a city, it can change a state, and if it change a state, it can change a nation, and if it can change a nation, it can change the world. Your voice can change the world."

So we see that voice is powerful.

But also voice can be small and unique, W. H. Auden said simply: "All I have is a voice."

What do we mean when we speak of voice in these contexts? Whose voice are they talking about? Why is voice important to consider when we are providing direct support to people with disabilities? Do they have voices with the power that can change a room and thereby change their world? Has their voice been recognized as uniquely their own?

What is Voice?

Voice is one of those words that can have many meanings. Physically we can refer to the voice box, larynx, or the sounds that people make. This gives us some clues about what voice is. It is more than sound and not necessarily sound. People who do not make sound can still have a voice in that they can still communicate. They can communicate with or without using symbols. For example, they can use sign language. ASL uses symbols but is silent. It still represents voice in that the person is expressing their thoughts, ideas and feelings. Some people communicate without using symbols at all. Their body language, facial expressions and gestures communicate tonnes. We can conclude that voice is not about sound or the use of symbols to communicate. **It is not about language, but it is about communication.**

If we look a little deeper, the idea of voice in this context must also involve someone who listens. Remember that old Zen riddle: if a tree falls in a forest and no one is there to hear it, does it make a sound? In the case of voice, the kind of voice that we are looking at, someone who hears that voice is

essential. In my experience, people with disabilities do a lot of communicating, but not a lot of it gets really listened to. So in the spirit of the riddle, **can one have a voice if no one is truly listening?** I would answer no, they do not have a voice in the sense that I am using the term until someone is really listening and responding.

Voice in this conception involves **people telling their own stories for a purpose** while others listen and really hear what the person is telling them. Have you ever played that telephone game that kids sometimes play? You know, where the first person whispers something to the next person and then that person whispers it to the next person and so on and so on. By the time it gets to the end of the line and the last person says it out loud, the message is totally, and usually hilariously, garbled. This game nicely illustrates why it is important for people to hear the original voice that told the story. Once other voices take it up, it tends to get garbled.

In the context of a helping relationship, we have to recognize that there are **many voices claiming legitimacy**: the lawmakers, the Ministry and their agents, the agency management, our direct manager, our co-workers, the person's family and even their friends. In terms of the support that people with disabilities receive from us, all these competing voices have their places.

However, if our support is to be truly about helping people to have control in their own lives, then the **primary voice** directing the support we give must be that of the person receiving our support. Often, in human services, all these competing voices tend to drown out the voice of the person with a disability who is at the centre of the service. Sometimes their voice is not even sought or is just plain ignored. It is important to realize that, when we ignore the voices of the people we are supposed to be supporting, then our support is very likely to be oppressive or even abusive. In this chorus of voices that we must listen to, the voice of the person we are supporting must be the primary voice that we hear.

This leads us to another aspect of voice – that the voice of the person is **a legitimate and recognized participant in a dialogue**. For our purposes, I will call this the “dialogue of support.” Good support is like a conversation that takes place between the support worker and the person they support. It is a conversation that involves mutual respect and dignity, collaboration and solidarity.

My experience is that the voice most often missing from this conversation or dialogue is the voice of the person who is being supported. Sometimes that voice is seen as the least important or least knowledgeable. And yet, who knows more about what a person needs than that person themselves?

Make no mistake; this aspect of voice is about power. We can easily use a power imbalance in our helping relationships to drown out the voice of the person we are supporting. If a person's autonomy is to be preserved and respected, then so must be their voice. Having this kind of voice helps to empower people, it helps them to have control in their own lives. It helps our support to be emancipatory rather than oppressive or abusive.

When we recognize the voice of the people we support as the primary voice in our support dialogue, our support is truly directed by the people we support, their voice has an impact on what we do, their voice guides us as we support them.

Voice can be individual as in “my voice” or “your voice.” **It can also be collective** as in “our voice,” as on my husband's satchel. Collective voices are those of people who have common interests and/or life experiences purposely coming together and contributing their perspective as a group to a dialogue.

While it is most often the individual voice of the person we support that support workers listen to, we must be aware of the collective voices of people with disabilities also. This means listening to the voices of disabilities groups and organizations and being familiar with publications endorsed by people with disabilities.

It is also important for support workers to be attuned to disability rights and disability pride because they can have an impact on the person we support and on society as a whole as attitudes change.

What Helps Us to Hear a Person's Voice?

The people whose voices are most likely to be missing are the people who communicate in unique ways. If you are committed to supporting people in empowering ways, then you need to hear those voices. Here are some tips about how to hear the voices of people who communicate in unique ways:

1. Empathy is critical. Keep an open mind and an open heart. Be prepared to let go of any presuppositions or biases about this person and let them show you who they are. Be open to the ways this person is experiencing life. Be open to this person's feelings. Learn this person's non-verbal cues. As you get to know them you will begin to hear their voice, that is, you will begin to understand what they are communicating to you.
2. Believe that this person has something interesting and important to communicate. Believe that they are a legitimate participant in the dialogue, not only the dialogue of support, but all the other social dialogues in which people engage. This person has a place in the dialogues of relationships and communities. As their support worker, it may be your job to assist them to participate in these dialogues. To do this effectively, you have to believe that they have important contributions to make.
3. Be willing to reframe the person's behaviour as communication, especially behaviour that is interpreted as frustrating or annoying. What is this person trying to communicate? I know that, when people are not listening to me, I can become kind of frustrating and annoying (or so they tell me), why wouldn't a person with a disability?
4. Take the time, whatever time it takes, to hear the person's voice. Work through feelings of discomfort. For example, when there are long periods of silence, recognize them as necessary to the person's communication style and relax through the feeling that you have to fill that silence.

Try this experiment with a friend –when you are in a conversation with them, silently count to 5 before responding to them and then, the next time it is your turn to respond, silently count to 10 before responding. You will be amazed at how quickly people get uncomfortable. Yet periods of silence can be important aspects of a person's communication. There may be other aspects of a person's communications that make you uncomfortable, be willing to work through that discomfort, firm in the belief that the person has something important to communicate.

5. Communicate in ways that make it easy for this person to respond to you. Use closed questions so that the person can indicate 'yes' or 'no.' Present choices in short lists so the person can indicate one or the other choice easily. Pay attention to silences and repetitions, they can point to significant themes in a person's communications. If the person uses augmentative or alternative communication devices, it is your job to take whatever time is necessary to communicate in that manner with them.

How We Silence People's Voices:

1. We silence people by ignoring some aspects of communication such as their silence. I think of my brother, Gerry, who had Down Syndrome and was a man of few words. If I asked him to help with a household chore he would often remain silent. Knowing him I knew that his silence usually meant one of two things – he had not understood me or his answer was no.

I also knew him well enough to know that if he was silent after an invitation to dry the dishes it was because the answer was no. I would then continue the conversation in a very sisterly way until he was in the kitchen with a tea towel in hand. Sisters can do that. The point here is that it was important for me to understand his silence as communication and to understand what it meant.

2. We silence people with shame, stigma, and dehumanizing services. When people are in human services that are disrespectful and abusive, they are fearful and less likely to speak up. Historically what we have done to the brave souls who have spoken up is to isolate them, restrain them or drug them. Faced with this environment, it is no surprise that people are silenced.
3. We silence people by deeply wounding them. Once people are deeply wounded as the result of rejection, ridicule and abuse, even when they are in a more respectful and humanizing environment, they may be reluctant to communicate. It may take a lifetime (or more) to restore enough trust for true communication to take place.

It is our job to work at addressing this wounding and building trust, however long it takes. One outcome that we hope for is that we will hear the genuine voice of this person. When we do hear that voice, we respond with respect and acceptance.

4. We silence people when we are overly clinical and don't ask people who love them to tell us about them. Think about the file your doctor or dentist keeps on you. What if that was how people got to know you, by reading that file? How would that impact what they hear when you communicate with them? It would certainly introduce many biases.

Now think about how they would understand you if they had got some introduction to you from your mother, life partner or best friend. How about if they gathered all this information, but kept an open mind and let you tell them about yourself in whatever ways you are able to do that? They might be able to hear your voice without trudging through a swamp of bias and misinformation.

5. We silence the voices of people with disabilities by speaking about them and for them and thereby denying them control of their own story and the opportunity to speak for themselves. As much as possible, people need to be speaking for themselves. No matter how unique their voice is, it needs to be the one people hear. As a support worker, your job is to assist the person to use their voice, not to be their voice.

Why is it Important to Hear the Voices of People With Disabilities?

1. This should be the primary voice that directs the support we give to people. We cannot support people effectively unless we know who they are and what they want.
2. It humanizes people; they become more than a disability, more than a “client,” more than my “job.” We get to know them as a human being. This one is a little bit circular because, in order to hear that voice, we have to believe that this person is important. And it is important to hear that voice because it makes the person more human to us as we get to know them. Once we get to know people, it is more likely that we will respect their right to control their own life and less likely that we will harm them.
3. This is the primary voice of advocacy. If there is to be social change, then it is through the voices of people with disabilities that it will happen. I think of the brave women who started the class action law suits in Ontario. It is their stories, their voices that stand for justice for all the people who suffered in those institutions. Social change will come through the individual voices of people with disabilities and it will come through the collective voices of people with disabilities, through organizations that are run by and for people with disabilities.
4. This is the primary voice of the history of people with disabilities. This history must be in the voices of people with disabilities, it is their history. It cannot be effectively told in any other voice. It is also part of the history of our society. It is a history that we desperately need to know and to own. We need the heroes in this history and we need the lessons of this history if we are to grow as a society.
5. This is a voice that belongs with all the other wonderful voices that make up our society. Without the voice of people with disabilities, both their individual voices and their collective voices, our society is incomplete. It is like a song with parts of the harmony missing.

Conclusion

Voice is a critical part of supporting people with disabilities. We have to understand what a voice is. It is more than the physical sound that people make. It is more than language. It is communication in whatever form that takes.

We have to have some strategies for hearing the voices of the people we support and for making their voice the primary voice that directs the support we give. We have to understand how we silence people's voices so that we can avoid doing those things to people and so that we can help people to find their voices that have been silenced. We have to embrace the importance of hearing and responding to the voices of people with disabilities both in our practice as direct care professionals and as a society. We need all the voices to be truly whole.

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