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Everyone Has a Voice

Self-Advocacy, Community Activism and One Woman's Story

By: Gerri Lee Nunn, Michelle Ainsworth, Laurel Benville and Dave Hingsburger

"I speak for those who can't."

"I am a voice for the voiceless."

"I advocate for those who can't advocate for themselves."

These comments appear fairly commonly in social media and within discussions within organizations which support people with intellectual disabilities, particularly in reference to people who have neither speech nor an organized communications system. Those who are non-traditional communicators or those who have very limited speech are usually the subject of 'I speak for' ... commentary.

Self-advocacy, however, suggests that the goal of direct support professionals is quite clear. The job is not to 'speak for' but to create situations wherein a person can speak for themselves. It might seem counterintuitive that someone who can't speak can speak for themselves, but that's not actually true.

Think about someone you know who doesn't use traditional communication, someone that in the bad old days we would have called 'non-verbal' or 'non-communicative.' Do you know their favourite foods? Do you know their favourite activities or music? Do you know how they like their tea? If you answered "yes" to any one of these, then the person is communicating; not only are they communicating, they are engaged in self-advocacy at the most primal level. It's important that this is recognized both as communication and as self-advocacy, as that's the beginning of understanding something: people need the dignity of the opportunity to speak for themselves.

To illustrate this point, we are going to tell you a story, from which we will give an example, and then we'll discuss briefly what this could mean, how we could transform service provision and our concept of self-advocacy.

Gerri Lee Nunn is a woman who receives support from a local agency tasked with providing support to people with intellectual disabilities. At the time that the events to be described occurred, she was not seen as an effective communicator or an effective advocate for herself with someone who didn't know her well. Everyone was to learn that these assumptions were both completely unfounded. Here's what happened.

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Gerri Lee's support staff received a call from the local theatre where she volunteers her time handing out programs and greeting people. She loves her job there and looks forward to it. One of the perks for volunteering – for all the volunteers – is getting to attend the evening's performance. Once before, because the show was popular, the accessible seating wasn't made available and the spot was sold. Gerri Lee was understandably upset as a result. The call was to indicate that again that seat had been sold and, as a result, Gerri Lee was asked not to come in to volunteer. It was thought that this would save everyone from upset.

Mistake! First Gerri Lee was really looking forward to the show; it was a band she liked. Second. Gerri Lee really likes volunteering and, regardless of the show, was looking forward to being there. It's a small community and Gerri Lee knows many of the people who attend the theatre, and she enjoys saying hello to them. It was a lose/lose situation for Gerri Lee.

The staff then began to talk about how to best advocate in this situation. They recognized that, while Gerri Lee had speech, mostly the speech was greeting 'phrases' and social 'phrases' that she had learned. Her spoken language wasn't really able to handle the complexities of discussion regarding inclusion and exclusion. So the question was, 'How to advocate in such a way to get results but without causing hurt feelings and damaged relationships?'

But then there was a realization about service provision: "Never do work for the person you support that belongs to them."

This belonged to Gerri Lee. It didn't belong to the staff or the agency. More than that, when agencies get involved, small discussions become big discussions, and things can lose their sense of proportion. So, how can self-advocacy be done with Gerri Lee's voice involved? How can she speak for herself when she can't actually speak for herself?

But ... "Never do work for the person you support that belongs to them."

When asked to think about it, the staff who supported Gerri Lee recognized that she was a very effective communicator and, ironically, the fact that they were so motivated to advocate for her was because she had advocated for herself to them about her upset concerning what happened with the cancelation of her attendance at the show, and the opportunity to volunteer that evening. So, she *can* advocate. So, she *had* advocated. Why not start there?

They, as staff, knew a lot about Gerri Lee's feelings about the volunteer job, about her experiences at the theatre, what she enjoyed and didn't enjoy, and how she felt the last time she wasn't allowed to attend a show she'd been looking for. We always say that, "Behaviour is communication," but what if we didn't say that, what if we believed that? What would happen then? Would it be possible to translate Gerri Lee's communication style? What if her behaviours, which communicated meaningfully, were put into the words that gave the behaviour meaning? What would happen then?

Well, it brought about a letter that was from Gerri wherein staff only added an opening and a closing. Here it is:

We are requesting a meeting with [the] Theatre to discuss the recent exclusion of Gerri Lee from the Nylons. Here is a summary, and statement, regarding what happened:

Gerri Lee has volunteered at [the] theatre for a number of years. She has been a faithful volunteer and we believe contributes to the spirit and the mission of the theatre. We are asking to meet with you about the fact that Gerri Lee has been actively excluded from attending the next show that she was to volunteer at because the accessible seat has been removed in favour of a non-disabled patron. As you may know, Gerri Lee does not communicate well through traditional means, but she is an effective communicator in many ways. The following statement is created through our staff's interpretation of Gerri Lee's communication strategies:

Statement by Gerri Lee:

"I like volunteering at [the] theatre."

Gerri Lee communicates this very well by coming to the theatre, there is never any difficulty in motivating her to come to do her volunteer work and by the fact that she laughs, smiles and greets people when fulfilling her duties.

"Being a volunteer is important to me because I like the work and I like the social opportunities with other volunteers and with the people I know who attend the shows."

Gerri Lee has phrases that she uses to indicate that she knows someone, recognizes them and likes them. "Here comes trouble!" and "Hi ya gorgeous!" are two such phrases. Gerri Lee uses these when she is with the other volunteers and when she meets people she knows at the theatre. This volunteer work is an important aspect of Gerri Lee's social life.

"I look forward to attending the shows after I volunteer."

Gerri Lee communicates this very well by the anticipation she shows in attending the shows and by her reaction to the shows during the performance.

"There are some kinds of music I like more than others; I really like music like the Nylons perform."

Gerri Lee has heard a lot of different kinds of music and she reacts differently to different kinds of music; for example, she is not as fond of classical music as she is of more modern music. When it's music she likes, she dances in her chair and fist pumps to the music.

"I was looking forward to the show and getting geared up for the evening."

All week Gerri Lee has been listening to the [band's recordings] and showing excitement for the show. She will be very disappointed and will be expressing that disappointment to those around her that support her and love her. It's difficult for the family and support team to understand why Gerri Lee's obvious commitment to the theatre doesn't translate into her automatic inclusion.

"I don't like it when you exclude me."

This is not the first time that Gerri Lee has had to miss a show because the seating has been sold to non-disabled patrons. The last time this happened, Gerri Lee got quite angry and showed her disapproval clearly.

End of Statement

We would like to meet with you, and with Gerri Lee, to talk about what happened, and how this can be avoided in the future. We do not wish to speak for Gerri Lee but with Gerri Lee. It's important that the focus be on Gerri Lee and her relationship with [your] theatre and as a representative of the disability community who both wish to contribute and to be equal participants in the larger [community] and with the theatre in particular.

Okay, so here's what happened. From start to finish, including the writing of this article, Gerri Lee has been actively included and involved. When the meeting was set up, it was clear to everyone that Gerri Lee was the prime mover here, she was the advocate and staff were there to support her advocacy. They were not ...

"A voice for the voiceless."

"Speaking for those who can't."

They were allowing Gerri Lee to use the voice she had.

Now to the meeting:

The meeting was held at the theatre where Gerri Lee was able to express her concerns and anger over the situation. It was apparent that Gerri Lee was not pleased because, as soon as she saw [the theatre manager], she would not look at him, she was frowning, and she clearly said, "I'm mad at you!!" (Which she has never been observed saying before when she has been in contact with [him]). [The manager] read the letter and communicated directly with Gerri Lee. He apologized for this situation and told her that he was looking at this as a learning experience to ensure that the theatre staff and personnel do not exclude anyone. He was looking into creating an inclusion strategy in connection with the various booking agents that use the theatre. He told Gerri Lee how valuable she is and that she is an important part of the team.

Gerri Lee listened and it was evident that she felt her voice was heard because she was nodding when [he] was speaking. She slowly began to smile, and then it turned into a large beaming smile, and she then teased [the manager] like she used to.

What happened then?

The manager has been working on the changes needed. When asked, "Do you think having Gerri Lee give you her letter and being there to advocate for herself had more of an impact than if the [local agency] staff had done it on their own?" He responded quickly: "Without a shout of a doubt – it's about her, not about you or me. It's about her. Her voice was heard and, from that, I'm taking action at the theatre to ensure an inclusive environment. It's about inclusivity."

Summary

The idea of being another's voice is a seductive one but a dangerous one. It operates on the assumption that the only voice that matters is the spoken voice, and that other ways of 'speaking' or other ways of 'communicating' aren't valid and have no place in self-advocacy.

So maybe a couple of take away points:

- Look for ways to assist all those you support to engage in self-advocacy

- Recognize, honour and document all the ways that the people you support communicate
- Resist the urge to speak for someone, find ways for them to communicate and use their own voice
- Hold space for people with disabilities to use their own voice
- Never do work for the person you support that belongs to them

Gerri Lee's story is one that demonstrates that language is language is language. And of course, having the dignity to speak for yourself, in your own way, really, deeply matters. It did to Gerri Lee, it did to all the staff who support her, and it did to the theatre manager.

Even though it's called 'self-advocacy' when people with intellectual disabilities do it, it's important to remember that Gerri Lee's advocacy will end up benefiting all people with disabilities who live in her community. So, maybe today, we'll just call what Gerri Lee did what it was: "community activism."

About the Authors:

Gerri Lee Nunn

Gerri Lee enjoys connecting in her community in a variety of capacities. She enjoys connecting with people and loves sharing a laugh. Gerri agrees that she knows everybody in the small town of Huntsville, having lived there all her life.

Gerri Lee has volunteered for many venues throughout the years and has been volunteering at the local theatre for over five years, checking tickets, handing out programs and welcoming patrons. She shares that the theatre is her favourite place to volunteer. Gerri loves the social interaction and the concerts and musicals – she is a music lover. Gerri was asked to describe herself in one comment. She laughed and said, "Hi ya gorgeous!"

Michelle Ainsworth

Michelle Ainsworth has been working in the human services field for over 18 years. She is the Team Leader for the Supported Employment Program and a Coordinator of Community Development at Community Living Huntsville. She is passionate about community and has been an avid volunteer since she was 11 years old. She is also a radio host on Hunters Bay Radio, the founder of Muskoka Animal Rescue and Muskoka Vegetarian Association and wrote for a local community newspaper called "The Great North Arrow." Michelle was the recipient of the 2016 Muskoka YWCA Women of Distinction Awards for Social Activism and Community Development. Michelle is passionate about her career and making connections. She lives surrounded by nature in the Muskoka area with her partner, their son and companion animals.

Laurel Benville

Laurel has been working for Community Living Huntsville for ten years, most of the time in the Community Participation Program. Laurel finds her career rewarding and particularly enjoys connecting with people she supports and walking alongside them their life journey. Laurel lives in Kearney, just North of Huntsville on a peaceful river with her husband and mother.

Dave Hingsburger

Dave is the Director of Clinical and Educational Services for Vita Community Living Services and is a well-known speaker and writer on the topic of disability. He was so inspired by what happened through Gerri Lee's self-advocacy that he's looking at ways to incorporate what was learned into everyday practice.

With this issue, we have begun our 6th year of publication. We have also completed our first year of producing webinars based on the articles in partnership with The National Alliance for Direct Support Professionals. Both the journal articles and the webinars have broad international reach. Also last year, at the request of our readers, we became "The International Journal for Direct Support Professionals" which has had a strong positive reaction from our subscribers. When this project began, neither Angie nor I had any idea that it would grow so big, reach so far and make such a profound difference in how people with disabilities received service. With every single journal, we receive feedback from readers about how the article has changed the way they provide service or the way they care for themselves and the people they serve. We are strongly indebted to those who write for the journal and to our organizations Vita Community Living Services and Hands TheFamilyHelpNetwork.ca for their support of our time in producing the newsletter, as well as to The National Alliance for Direct Support Professionals for producing a webinar that anyone in the world can attend and, of course, to all of you for taking the time to read the newsletter, to share it with others, and to use it in ways that turn words and ideas into practice. So Happy New Year to all of you and welcome to another year of the 'webijournal.'

Answers to FAQ's about the journal

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