

## Rights, Respect and Tokenism: Challenges in Self-Advocacy

After having had many conversations about rights, respect and tokenism with many people with intellectual disabilities, a few of us decided to sit down and talk more about it. We talked about what we think people with intellectual disabilities are telling us about some of the important issues related to this idea of "self-advocacy." We gathered together over a few afternoons in the winter of 2010, and recorded our conversations. Those talks are here within this paper.

Long time activist in the developmental services sector Peter Park offered his home for the talks. Comfortably seated in his home, Peter leads these discussions, leaning forward with a focused look while sharing his views on the subject. Sitting beside Peter is his wife and fellow activist, Rhea Park. Rhea is also currently active in what is now known as the self-advocacy movement. Kim Rider typically sits across from Rhea: she is a support worker who facilitates supports for Rhea. Sue Hutton is a Masters of Social Work candidate at University of Toronto, who has worked in the developmental service sector for 20 years; she and Amanda Amorim, also a Social Work student in Toronto, round out the conversations.

What became clear in these conversations, and in those we have had with other self-advocates, is the importance of "respect," especially as it connects to rights, to the success of self-advocacy. And in all of these discussions around respect and rights, the issue of tokenism kept creeping in.

Respect is a topic that people seem to get passionate about, and this group certainly did. Peter, Rhea and Kim believe respect ties very closely with rights. The group discussed how if someone has their rights taken away, they are not being treated with respect. Everyone is worthy of, and deserving of, respect and of having their rights upheld. What was also made clear was the importance of self-advocacy to ensuring access to rights. When it comes to fighting for having one's rights upheld, Peter and Rhea Park have been knocking on doors (or knocking them down) for over three decades.

To help set the stage for our discussions, Peter talked about how the self-advocacy work all started for him. For Peter, the idea to get involved in the self-advocacy movement came when he was institutionalized (or, as he calls it, incarcerated) in the Oxford Regional Centre from age twenty to thirty-eight. Peter remembers being inspired by a magazine article about self-advocacy while he was in the institution. When Peter finally got out, David Baker, a human rights lawyer with ARCH Disability, arranged for Peter to meet Ken Nelson from People First, Alberta. Ken facilitated a People First group in Edmonton in the late 1970's. David also intro-

### Authors

Sue Hutton,  
Peter Park,  
Rhea Park,  
Kim Rider

### Correspondence

layiagirl@yahoo.com

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duced Peter to Elmer Peevers from North Bay, who had a similar advocacy group: People Advocating Rights. Ken encouraged people with disabilities to speak for themselves, rather than having a social worker speak for them. Peter saw that if he brought the issue of rights into the advocacy work of People First, that there was some real potential for change. Peter got out of the institution in February 1978, and started the Brantford People First group in May of that year. Peter didn't want anyone to be stripped of their rights again the way he had been in the institution. It was at that time that the principles of human rights came into the forefront of the advocacy work for Peter.

Thirty years later, Peter is still having conversations about the importance of human rights in the self-advocacy movement. Peter, Rhea, and others say the lack of respect for people with intellectual and developmental disabilities seems to continue to exist in the developmental services sector. Questions of rights and advocacy are entering conversations within the sector, but many self-advocates believe there may be a long road ahead before the sector really gets it right. If one takes a bit more time to listen, there are many stories to be heard, stories of rights being violated. At this point, we are not sure how many people are truly taking the time to really listen to the voice of the self-advocates.

Peter and Rhea discussed how what has been done to date feels to many self-advocates like little more than tokenism. We spent some time discussing the idea of "tokenism" in the developmental sector and the self-advocacy movement, and just what it is. There are times when each of the members of this group has witnessed or heard about what seems to be a misuse of the term "self-advocacy." For example, the group members talked about how some employees of agencies in the developmental services sector will ask a self-advocate to talk publicly about their service as a way of sharing information about the service with those new to it. But this is not always about seeking out the self-advocate's opinion. If one took the time to ask questions, one would learn that the "self-advocate" may not have even come up with the words. It may have been a marketing team that wrote something for them to say to promote the agency; something that made it look as if the self-advocate was involved, and as if they

endorsed the service. For Peter, Rhea and Kim, this is not true self-advocacy, but tokenism.

It seemed to us that when people want to advocate for something, they choose what they want to advocate for, and it's typically something that is very important to them. They will then choose just how they want to advocate with the group that is the focus of their concern. Many different agencies in the developmental services sector have taken up the cause of self-advocacy and have tried to incorporate it into their services in various ways. But it is the experience of this group that this is not always done in an effective or meaningful way. We all know that teams and groups have more power than individuals. Including self-advocates on teams or in different groups of people who are their allies would seem to be a good way to make sure the voices of self-advocates are heard. However, if "self-advocacy" means that one or two people with intellectual disabilities are singled out, and placed within a team of people involved in decision-making who are different from them (people who don't have intellectual disabilities), typically the larger group of people—the non-disabled majority—will have the voice of power and the smaller group—the self-advocates—will not. Their participation is not really meaningful. We see this often in the developmental sector. We have also all seen another type of inclusion that does not work. When a self-advocate is placed on a committee and expected to be involved equally in decision-making, but the necessary information is not made accessible to them in a way that they can effectively comprehend, the end result is tokenism. Their voice is not actually being included, because the time has not been spent to make the information accessible. In both of these examples, the attempts to include self-advocates fail because the self-advocates are not afforded any real power to effect change. Those in power are not acting as true allies.

Having effective allies is key, but direction must come from within a community for a movement such as the self-advocacy movement to be successful. We talked, for example about how, when Canadian women advocated to be recognized as "persons" in law in the 1920's, it wasn't men who led the way, it was women. (Hughes, 2002). Our group also discussed how success in Aboriginal protests seems to hap-

pen when these protests are led by Aboriginal people themselves, with allies and supporters close by. Allies and supporters are needed in the self-advocacy movement, but the real force of the movement has to come from within—from self-advocates themselves. That’s why when Peter first formed People First over thirty years ago, he thought it was most effective to keep the movement separate from organizations or institutions, even service organizations in the developmental sector. He found that when self-advocates worked within big organizations, their voice was more likely to be constricted.

“It’s all about respect.” Peter Park had a serious tone as he looked down and said this during one of our conversations about the history of advocacy for people with intellectual and developmental disabilities within the developmental services sector. Self-advocacy, has had a long and tumultuous history. Peter is someone who has lived through the changes from the inside. Having lived in an institution for 18 years, he has witnessed the constant changes taking place in the sector and the many efforts around advocacy and self-advocacy over the years. He’s lived first-hand through these struggles. After all his many years of experience, he remains a critic of the system. He does, however, bring a particular warmth to his critique and advocacy work that shines through in his smile. Peter doesn’t let the shortcomings wear him down. He continues to be there to support the movement to be more effective, and it doesn’t look like he is going to go away. He maintains that rights are critical to the self-advocacy movement and how it is not true rights work, when the respect is missing. This is tokenism and it needs to be addressed.

We spent a lot of time discussing the question “How can we support self-advocacy to effect change, and eliminate the tokenism?” The group discussed the distinction between “support” and “direction” when talking about how self-advocates are assisted in their advocacy efforts. It is important for a self-advocates group to have a sense of autonomy, of working together on their own issues, the issues they identify as important. But they may, at times, request support from allies to carry this work out. Peter clearly articulated: “Self-advocates are supposed to be in control of their own destiny, not someone else.”

Rhea spoke about her feeling that there is often no “true” voice for individuals with intellectual and developmental disabilities who are self-advocating when the work of self-advocacy is being done within a service organization or large-scale residential program. Kim agreed with Rhea and added, “To be really effective, advocacy work should not be housed within organizations—it just turns it into tokenism.” Self-advocacy under in these situations isn’t meaningful self-advocacy; it is often little more than show as non-disabled staff are the ones who are in charge. Peter, Rhea, and Kim talked about how sometimes it feels as if the discussions are being controlled, and how self-advocates feel their voices are often edited. All of us sitting at the table agreed that having the freedom to discuss what is really important to self-advocates is often not possible at some of these organizationally-based advocacy groups. As Rhea said:

“There’s more wrong than right with self-advocacy today. We (people with intellectual disabilities) are directed by staff and their managers to do things. If we want to talk about something, we aren’t allowed, we are told it has to be a certain thing. So we can’t advocate about what is important and meaningful to us. It’s bad. You don’t have a voice.”

Our conversations often return to our experiences or knowledge of those times when people with intellectual disabilities were given scripts to read at public events—scripts that were not written by the self-advocates but by staff; not staff who were trained to support people with intellectual disabilities but staff persons trained and involved in fundraising and publicity. Like the rest of us, Rhea has seen this, and she shakes her head over it, understanding it this way: “It’s control.” At one of our discussions, Kim asked Rhea if she could add to what Rhea had said, to comment upon what she has learned from other conversations with Rhea about this issue. As she spoke, she looked to Rhea to confirm that she was getting the message right:

“Rhea has said she feels like she is a monkey on a string. They (self-advocates) are in a role to speak for people with intellectual disabilities, but the “higher-ups” are controlling what they are allowed to say. What real purpose is there for the people? Are the people actually a part of change? The bottom line is, the organizations are supposed to be there to support self-advocates, not control what they say.”

There was a quiet in the room as Kim spoke. “Self-advocates’ groups seem to be important when the organizations need them for funding and marketing purposes. It is pure control.” She then added, “True self-advocacy needs to be free to say something different, and not be scared to say something.”

Kim mentioned, as Peter and Rhea nodded in agreement, that she notices a difference between “support” and “direction” as practiced by different types of self-advocacy groups. Kim works as a facilitator with Rhea and is part of the *Circle of Support* for the Parks. This *Circle of Support* is a circle of advocates whom Peter and Rhea have requested to provide assistance in their care and whose members are concerned to take their lead from the Parks, not to impose their own will upon them. Thinking about the differences between this group and others, Kim is particularly concerned with whether self-advocates are being supported to advocate for what is important to them or are being directed to make certain decisions—not necessarily the decisions they may have chosen to make on their own. Kim talked about often witnessing this difference in the developmental services sector:

“When staff people use leading language, they are manipulative, using body language and words to encourage people toward certain choices; they are directing them. They pretend it is support, but it’s not. It is direction. Self-advocates can be vulnerable to this.”

Kim talked about the need for allies and a system that supports the voice of self-advocates, rather than more “top-down” direction with non-disabled others telling them what to do and she talked about how powerful this type of influence could be:

“Nobody wants to feel stupid. In a meeting where the self-advocate is “tokenized,” often people just want to fit in, and just agree, rather than having the time to understand the whole issue and truly weigh in on it.”

Peter added to this:

“I’m going way back in my life, but I have made a lot of decisions on different boards, just because everybody else was voting that way. I just voted

with them. I’ve been on national boards as a self-advocate. I then learned after time, and after being supported, I asked to record meetings, so we knew whether the board was supporting self-advocates or not. I would interrupt the minute taker, and make sure that they were including parts of the meeting where I disagreed. If I disagreed with something, I made sure it was in the minutes.”

Peter started his thoughts with a smile on his face, but as he reflected on these moments of self-advocacy as tokenism, his expression become more serious “It’s a huge problem” he said. “People need to have the freedom to speak. Again, that is about respect.”

Peter spoke about some techniques he has used with *People First* to help people with intellectual and developmental disabilities find their voice. “When I was facilitating a lot with *People First*, I gave people space to talk about whatever they wanted to, on any particular day. People had choice to talk about what was on their minds—anything at all.” He went on to say, “Here is how true advocacy starts—talking circles. Help people to share stories, find common ground. It takes skill to facilitate these circles. You can’t have an agenda, but rather, truly want to hear what people want to say” But he acknowledges, too, that this has not always been easy. Peter laughed as he remembered details of the early days of *People First*, of self-advocacy in Canada:

“It was founded back in May 1978. At that time it started in Brantford and then it became a provincial organization in 1981. At that time a bigger organization gave us a space and they told us we couldn’t meet unless there was a staff person there because of liability issues. It was a struggle, and I nearly walked away many times. People need to have freedom.”

Peter finds that over his thirty year span in self-advocacy, that this issue of service organizations often restricting the voice of those with intellectual disabilities (self-advocates) has been quite consistent.

“We are here as real tokens, not as individuals who are respected. They don’t want to respect us. That’s too much like work.” Peter smiled broadly with a glint in his eye when he followed this thought by speaking about

a subversive idea he has had more than once: to create t-shirts that read "Self-Advocates are Tokens." The group all laughed together. What is clear to the rest of us is that while Peter has lived through a lot, he has not lost his sense of humour. Not by a long shot. After the group enjoyed a good laugh, Peter repeated himself, coming back to the core concept, once again with a thoughtful look; "It's all about respect. Period." The group grew silent again, but not for long. As we said goodbye, everyone participating in these conversations agreed we need to continue to have these talks.

## References

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