

Advocacy in the Danger Zone

Note: During the First North American People First Conference, I had the opportunity to interview Debbie Robinson, President of the Board of Speaking for Ourselves. She has been working within the self-advocacy organization in Pennsylvania for five years. We talked about advocating for people in the Danger Zone.

— Mary F. Hayden, IMPACT Editor

Interviewer: What is the Danger Zone?

Debbie: When you speak for someone, sometimes it is a job that entails dangers. [For example,] when you're talking about another person's health, when they are not getting the proper care. Sometimes I have to go and try to find out why that particular person is not getting medical care. [I have to do it] in way to not get him or her in trouble with the people who they live with.

Interviewer: Using your example about medical care, how would it be dangerous for the person for you to help him/her?

Debbie: Well, mainly because you are stepping in a medical situation. I am not a medical doctor...

I will use a story. I was involved with a member's medical health because she stopped coming to the chapter meetings. I found out she was sick and where she was at. She was not getting proper medical assistance...they were not taking proper care of her. I visited her to try to find out what was going on...I tried to find out as much information as I could. I tried to help this person get medical assistance. So, I paid a couple of visits, talked to some people, and tried to find out what was really going on. I found out she wasn't getting the care she needed to find out what was wrong with her. This person needed to go into a hospital setting to find out what was going on with her.

Interviewer: Why was she in danger while you were checking things out for her?

Debbie: The way the situation developed and seeing where she was at, and how they took care of her, and

how she was treated while she was there, and trying to find out what they were doing to find out what was wrong with her. They didn't seem to be doing anything, or not much, because she was still sick. I didn't know. I was concerned.

So, I got in touch with a few contacts who were in the medical profession. I told them what I saw, the situation as I saw it, and my concern that no one was really looking at her to find out what was going

on...We went to see the friend who was sick.[After the visit, additional contacts were made to enable the member to obtain the medical care that she needed.]

[In another example,] members asked me to come down to the institution...see where they lived and see the situation. It didn't look good either. They were not getting proper medical and dental care.

Interviewer: What type of concerns did your members have about the facility?

Debbie: We saw things there that

would turn your stomach. It was a disgrace...

Interviewer: Were people afraid of other people doing something to them?

Debbie: Yes, that too. When you are dealing with people with disabilities [who live] in a setting like an institution...[where] they are not getting proper care, staff are not treating them right and some of them have been abused...something had to be done. On the other hand, we had to do it in a way that they [members] wouldn't get too much abuse from staff. It was not easy. They still had to live there. I can go home. They had to stay there.

You can't just jump into it. There are a lot of steps involved. It isn't something you can just jump into and say "I'm going to save you". It isn't like that. You have to do it slowly and step by step. It was too big for the chapter and our board had to get into it...I received permission from the board to step into it. The board backed me up. I had to report what was happening. It was touch and go. It's hard when you



Debbie Robinson addressing the First North American People First Conference.

see people crying. I've seen that. It's the saddest thing. You can't jump in. It was a slow painful process for our members.

Interviewer: What did you get for people?

Debbie: Not as much as I hoped. I was kind of disappointed. I wanted to close the place...We were able to get most of our members out that wanted out. We still have a few there that need to get out. The sad thing about this whole thing is that two friends had to separate because they were from separate counties[therefore, placed in their respective counties]. I want to get these two back together.

Speaking for Ourselves got the counties involved. We were the first ones to see what was going on in this institution. We called a meeting with the state and said, "Look, we have the evidence right here. Members are being abused. You have to do something about it. Something has to happen now...I'm not going to move until you say you will go down there

and see it for yourself." So, for a couple of weeks people [from the state] went down there and saw the same things that we did. The same exact thing... Everybody came back with their report.

I really had to do something because members were really scared to go back there. The scary part was that they were afraid that they'd go back to their staff and get hurt again. Unfortunately, it did continue to happen until I got it straightened out. Slowly but surely we were trying to get things done, but we had to get the report from them [the state] to find out what was going on. That is why we had a weekly meeting with the state to say to them, "This is what is happening. You have to do something about it."

You have to be careful. You are dealing with peoples' lives. They are in situations where it is easy for you to pack up and leave. I had to go home and leave people there, knowing in my mind that I couldn't do anything. I would pray that no one else would

Danger Zone, continued on page 18

Tennessee Self-Advocates Conduct Quality Assurance Surveys

Twelve members of People First of Tennessee, Inc., conducted quality assurance activities at two agencies in Tennessee during the summer of 1989. They split into two teams, each of which looked at two group homes and two sheltered workshops. At the end of the site visits they presented the results to the agencies at an exit conference. Members of the two teams describe their experiences in the following interview. Those interviewed were Beth Sievers, State President; Samantha Sasnett, State Secretary; Sissy Heatherly, Past State Officer; Walter Phillips, Past State Officer; and William Goodman, Staff Self Advocate. The interviewer was Betty Henderson, Office Manager with People First.

Interviewer: Why did you all do the consumer monitoring surveys, what did you learn, and how was it valuable to the agencies surveyed?

Sissy: We've seen other people give a survey, but we didn't know what it was like. We did a survey so that we could be surveyors one day ourselves. It was important so that the centers and group home people can't walk on their [clients'] toes, so that we can see that things are going right.

Samantha: So they (the consumers) can have a better living and a better job.

Walter: To find out what they (the consumers) like about their agency and their jobs, and see what it was like to live in the group homes.

Bill: People First members ought to see what we can do so they can go out and do it also.

Beth: To show that we really do care about other people and the services they receive.

Interviewer: What kinds of things did you look for in the consumer monitoring survey?

Bill: I looked for wiring and things that were dangerous and I reported it to the staff. I read through the clients' files with their written permission. I found out some interesting things, their strengths and weaknesses. I asked questions about how much they get paid per piece or bimonthly. I asked the staff, not the clients. I talked to the

Survey, continued on page 17

Danger Zone, continued from page 5

get hurt...You know the situation. I'm dealing with peoples' lives. I had to be careful. That is how you have to look at it. It is truly hard to advocate for someone. You go into meetings with them. Some of them tell the truth, some of them don't. You get caught sometimes. It is not easy.

Interviewer: Were you able to do things to protect people on a long-term basis?

Debbie: We had people go there constantly. They knew that we, my organization Speaking for Ourselves, were involved, getting the state involved and checking this institution out. So, what they did was stopped us from going to the rooms. We could only go to the lobby. They knew someone was going up there, whether it was us or someone from the state or region. Everybody from counties visited...We had meetings constantly on this issue. Reports were coming back.

The chapter meetings were very important. They were a safety net for them until we got other members talking about [the problem]. Confidentiality is the most important thing when you are working or dealing with people with disabilities.

Interviewer: How was it a safety net? Was it a place where they knew they could talk?

Debbie: Yes. They could tell us...I could get their confidence. It wasn't an easy thing to talk about. I could build confidence with the other members. Other people at the meetings were afraid to say what was happening. They were scared because they had to go back there.

I told them it was not going to be an easy process. We will work on it. It was very painful. A slow process. A slower process than what I was ever involved in. Then I invited people who worked in the system to the chapter meetings so they could hear from the chapters what was going on. The officials needed to know what was going on. I invited them, but I told the chapter that a person was coming down. Told them what [the officials] do...I had to talk to them [people from the mental retardation system] first. I told them that when they come to my chapter meeting, whatever you hear, I don't want it to go to the staff. If you do, people will get hurt. So they heard the stories. I had a list of things that were happening and I would bring it back to the state. I would tell them what was still happening.... We involved them in that so they could hear their stories. It was hard to get

them to talk about, but it was the most important.

The process wasn't going fast enough. They [the state] were trying to work with the institution to change it. Try to make it better before they can try to move people. When you try to move people out of an institution, you have to have a place to put them.

Interviewer: It sounds like self-advocacy is a long process. It isn't an overnight success.

Debbie: Yes. I helped a member move from his parental home. It started when he entered the hospital. He called me and told me where he was. We did not hear from him for months. We tried to get a hold of him. His mother didn't allow us to talk to him. He was sick at home. They tried to get nurses over there, they tried to get him care because his mother was old. So, they tried to get care for him, but a sibling wouldn't let them in.

He called me from the hospital and told me things. It was bad at home for him...He started telling me stories about his living arrangements. He begged me, "Don't send me home. I don't want to go home. I can't. It is bad at home." So, it was a bad situation. He was worried and upset. I had to try and calm him down. I had to try to work with the mental retardation system. Got in touch with a few people. We worked with them and him all week. I finally got him hooked up with people. That was a long process. [It took about three weeks.] The Danger Zone for him was that if I had not acted and they discharged him, he was afraid he was going home.

I had to keep him [in the hospital] and not send him home. He was begging me. He was really concerned that he was going home. It was really hard. He couldn't talk clearly enough. They [the people from the mental retardation system] had to verify what was going on. I had to make a lot of phone calls. I connected [another sibling] with the people in the system. What was scary for both of us was he was getting close to discharge. We had to act quickly. So, an agency took him [and provided him with a community living arrangement.]

Interviewer: So, that worked out real well.

Debbie: Yes, I'm still trying to get him medical care, he is still in a chair. He hasn't had any therapy. So, it is still going on.

Interviewer: When someone calls you and asks for your help, do you go through certain steps to provide assistance?

Debbie: No. I have to find out what is the problem. I have to find out all of the information. What is the problem in general. If it is an emergency, then I have to react to the situation quickly.

Interviewer: If it is an emergency, what do you do?

Debbie: I first think about it, this person is in real danger. My first reaction is to contact a person: a lawyer, a person in the system, or my organization. I call right away. If it is medical, I will call a friend (who is a doctor). If it is something else, I will call someone in the mental retardation system. Then I get down to see the person or get someone to check out the situation for me. Is this really a diehard situation? You need to see it firsthand...I try to react pretty quickly and get connections started. Try to cut through the red tape as quickly as possible

Interviewer: When you are working with people in a Danger Zone, what do self-advocates have to remember?

Debbie: Self-advocacy people have to remember that you are going to come across a situation where you have to be really careful how you handle it, not be so hasty, and be patient. You have to be careful. You have to think about the people you are trying to help. The person is the first priority. They are living in that situation and you have to be really careful. You are dealing with people's lives.

Interviewer: Did you ever work with someone who wanted something, you honestly disagreed with them, and you were uncomfortable with the decision?

Debbie: Not too many times. If I don't think it is right for them, I'll explain it. Yet, I have to remember that is what they want.

Interviewer: If they insist?

Debbie: That is a hard question because it depends upon what it is. For example, if someone wants to live with a family member and we know it isn't going to happen but he really wants it, it is sad. We try to tell them, be as honest as possible, that it is hard to live with a family member. If the family member doesn't really want to take care of [the person with a disability] for certain reasons or is not equipped to take care of them, then you have to tell the person the reason. You have to be honest and truthful. It hurts, but you say to him or her that you will try to get them into a better place...

Interviewer: What about someone who wants to move into an institutional setting?

Debbie: We will tell them it is an institution like where you came from. If they really want it, we take them to see the place... We ask them if they want to stay in that type of setting. We try and give people options, better choices...

Interviewer: So, you give them information, and choices. You will respect their decision.

Debbie: Yes. We have to. We will stay in contact to see what is happening.

Interviewer: Anything else you want to say to advocates who work in the Danger Zone?

Debbie: Think about the situation. There are all kinds of problems. You will have to handle each in a different way. Sometimes it helps to go to people and get advice before you jump into it. Talk to other self-advocacy people that know about certain things. You need a general idea about a situation. Some people have a better idea about a situation than you do....

Interviewer: What advice can you give to other self-advocates about how to take care of themselves and avoid burnout while working in the Danger Zone?

Debbie: First, it is a hard question. You tell the person [with the disability] you can't really help them this week, but you will connect them with a friend of yours who will help them. You can't do it all by yourself. You need help. You have to be careful who you connect with who. How trustworthy is that person.

You'll know when you can't go on. Your body will tell you. Sometimes you need to take some time. Like a weekend. You let people know when you are going to be away. You have to cover your bases. Make sure you connect people up with one another.

You have to make sure you know what you are getting into. You can't go in blindfolded. That is a Danger Zone. You go in blindfolded, you are going to get a few surprises ...You have to go in with open [eyes]...Otherwise, you will get into trouble.

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Out of My Old Life and Into My New One

by Michael J. Kennedy

I grew up in three New York institutions. In 1982, when I was 21, I moved into a group living situation in the community called a supportive apartment. I lived with three other men with cerebral palsy, and we were supervised by staff whenever we were home. The supported apartment was much better than the institution, but in the six years I lived there I learned everything I could learn and was ready to be on my own. Also, the program was funded by Medicaid and had too many rules and regulations, like having to have goals and a service plan.

I knew what I wanted, but I needed help to get it. So I started talking to the director of the program about being on my own. I was listened to in one way, but not in another way because nothing was happening. What I had to do to get my point across was to threaten to move back into the institution near my family in the Adirondack Mountains area. The director got wind that I was actually going to do it, and the agency staff didn't want that. I know it would have been a mistake, and I didn't want to quit my job at the Center on Human Policy, but I felt my back was against the wall. That was the beginning of my getting my own home.

The agency told me about a new program they had just received funding for. It was called a Family Care program, but what it does is to match a person with roommates and the other supports he or she needs. One of the staff at the supported apartment, John, called me into the office one day and asked me if I would consider setting up a home with him and his roommate Gordy. I agreed, with the understanding that I didn't have to follow Medicaid rules or have a service

Life, continued on page 9



Michael Kennedy (right) at home with his roommates.

From the Editors:

Many people believe that individuals with disabilities are unable to speak for themselves. This belief is held by the general public as well as by professionals, policymakers, parents, and legal advocates. The self-advocacy movement has demonstrated that people with disabilities *can* speak for themselves and that they are valuable contributors to resolution of policy and service issues.

This issue of **IMPACT** gives people with disabilities the opportunity to educate others about self-advocacy. Twelve of its 17 articles are

by individuals with disabilities who are self-advocates, or by other representatives of self-advocacy organizations. It includes information on self-advocacy strategies and examples of its impact on lives. It is our hope that these articles will affirm for all that people with disabilities have the right and ability to advocate on their own behalf, and will encourage more persons with disabilities to be self-advocates.

CONTENTS

Overview of Self-Advocacy	2	Informed Choice	10
Starting Self-Advocacy Groups	3	Confessions	12
Advocacy in the Danger Zone	4	National Conference	13
Self-Advocacy and Legislation	6	Self-Advocates on	
Independence or Sponsorship?	7	Boards and Committees	14
Advisor's Role	8	Resource List	16