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Abstract

Linda Till, the mother of Becky a young woman with disabilities, describes her experiences of advocating on Becky's behalf, firstly to get her out of the nursing home in which she resided and secondly to get her included in the local school. The substance of the interview would seem to be invaluable advice for parents in similar situations. (We have part of Becky's story on video). **Keyword: Advocacy**

Profile of a Family Advocate: An Interview with Linda Till

Linda Till has spent more than 10 years advocating on behalf of her daughter Becky. She and her husband, Kingston, adopted Becky from a nursing home, where she had been placed because of her disabilities. At the time of adoption she was 11 years old and weighed 20 pounds. Now a happy, thriving and loved 19-year-old, Becky attends Roman Catholic separate high school because the public school in her neighbourhood, Sharon, Ontario, refuses to integrate her. In 1988 the Tills filed a complaint with the Ontario Human Rights Commission, charging discrimination on the part of the York Region Board of Education. The case is ongoing and Linda faces more than 60 days of gruelling testimony before a Board of Inquiry.

ent: What has been your role as an advocate?

Linda Till: My involvement in advocacy for Becky has had two major fronts. Most people are familiar with the front which sought to obtain and protect her rights around education.

Before that was the front which sought to get her out of nursing homes. Extended from that were my efforts in bringing about sufficient change to see that other kids got out of those facilities. My role became one of systemic advocacy. I had some professional connection, a paid role, and some was in a non-paid role. That front has a lot less public awareness and it was where I learned many of my skills. I learned them, I guess, out of necessity. If you really wanted to save the lives of these kids you had to do it right. You didn't have the right or the opportunity to do it wrong. You had to learn to be right. That means you had to think fast, move quickly, effectively grab the bull by the horns and do something any time you had the opportunity. Just like for any other person, it's not possible to be right all the time or know what's right.

ent: What guided your actions?

LT: I had to rely on a lot of things. One was simply gut instinct. I believe absolutely that a truly caring person is going to find the right way because they care. For example, I fell in love with Becky. There was no way



Linda, Becky and King Till: Becky's love "makes the world a happier place."

Photo by Chris McCallan.

I could tolerate harm coming to her. There was the absolute necessity of making sure she was safe and well and that changes occurred to get her out of the institution into adequate medical care, which was a critical component for her. The other critical aspect of care for her as a child was a home. We chose this to be her home.

Beyond that there was the necessity of finding homes for the other children, but the effort I put into advocating on their behalf did not have the same energy I put in for Becky. I know that the difference was that I was in love with Becky. I cared deeply on an empathy level for the other kids and I knew many of them well. But there are very different levels of advocacy between when you are involved because you care on an empathy level and when you care out of deep love. It has an impact I think on how right you are and how quick you are at being right and how determined you are that under no circumstances are you wrong.

ent: What were your resources?

LT: I had to be right, and to be right I had to know a lot of things as quickly as possible. Certainly I did

read. I tried to find sources of information that spoke to what one person can do when up against a wall that seems impenetrable. That meant I had to turn to information and to people who knew about oppression, who came from histories of experiencing one form or another of oppression, of isolation, segregation.

I found it was useful not to turn exclusively to information based on experiences of people with disabilities or people working on behalf of those with disabilities. There was much more and a much richer history of information and knowledge from other sources including groups that dealt with racial oppression. There was literature, information, experience and people who had knowledge. Turning to that information was very helpful.

Some of the most helpful people were those who had the most creativity and the most guts. It had nothing to do with position or salary or authority or even years of experience. These have no bearing, in my experience. It was the people who had creative minds and people who had guts, people who were prepared to act on their beliefs, who felt comfortable with that. [For example, Linda later related a story about a woman advocating for seniors in nursing homes. The woman, who was concerned about the conditions in which the seniors lived, invited a government official to lunch. He came expecting a regular meal. Instead, she served him the dinner that they had served to the seniors the day before. Her point came across loud and clear.]

The most helpful people didn't feel it was inappropriate to act because they had been taught through social service training and experience that one shouldn't act. There were many people who believed that to be involved was unprofessional. That's a very strong element of training. I encountered many people with that orientation — people who were afraid to rock the boat and didn't give you any help at all.

I hooked into a number of advocacy organizations for two reasons: (1) I wanted to be involved, I felt strongly that I wanted to act on their beliefs; and (2) I wanted them to know what concerned me and to take on my issue. My issue, very early on, was kids don't belong in institutions, kids belong in families. I wanted everybody everywhere I knew to hear my message while I heard theirs. I joined an advocacy organization on behalf of elderly people in nursing homes and said over and over, "And it's not just elderly people in nursing homes." I was very determined that the organization expand their horizons about this issue. They did; they made children in nursing homes a critical part of their initiatives. It was a matter of crossing the boundaries and saying, "This is as important, because you have something I need and I can give you something you need."

ent: How did you find allies?

LT: Much of the time by simply going to conferences put on by people with the same orientation, convictions and commitments. I found it was really helpful to know the philosophies, visions, goal statements of these organizations. I don't know how meaningful those statements are for a lot of organizations but at least they gave me an opportunity for immediate scrutiny as to whether these people or this group were progressive thinkers or if they were stuck in the dark ages. Then I could see whether they could operationalize their vision. If you hook up with organizations with progressive vision statements, even if they are not really implementing things comprehensively in line with their vision statement, there are usually a few key people somewhere, maybe a fringe element, who do believe in those vision statements. You can hook into them. They were the people I could get ideas from. They were the people I could bounce ideas off and give back to in return.

ent: What were some of your most useful strategies in working to get Becky and the other children out of the nursing homes?

LT: Without a doubt one of the most useful was *proof*: how to find a way to prove that what I wanted changed or done was possible and right and better. That was almost impossible when I was talking about "the most severely multiply handicapped kids" in a particular large area like a province in these particular facilities when no initiatives, up to that point, were providing for children with that level and complexity of care requirements anywhere other than institutional settings. So finding your proof is really difficult.

I didn't find that proof had to be the whole picture at one time. I found that you could get little bits of proof that moved you forward a little bit. For example, I found that first it was really important to be able to prove that those kids could learn. One of the presiding convictions that resulted in these kids being in these settings was that they were not capable of learning and developing and benefitting from programming. This was written into the rationales as to who would go into these settings. One thing you have to do then is prove that these kids can benefit from programming. If you can prove that, you have decimated one of the foundations on which children are put into institutions.

You haven't proven the whole thing. But you prove one part, then you've got the next thing to do, and the next thing. One of the things you had to prove was that these kids were more like other kids than unlike other kids in the sense that they needed nurturing and an opportunity to have a family. To do that you had to find proof, not necessarily for those kids, but for kids like them. You had to find kids in communities you

could use as models. Their situation could be used as a model.

ent: Who did you take your message to?

LT: There wasn't a particular key person. Those situations are not controlled by one person at the top of a hierarchical structure, they are controlled by multiple layers of people. So sometimes you had to prove it to the doctor who wanted to place the kid and you could stop the placement. Sometimes you had to stop a social worker who was constantly funnelling kids. Sometimes you had to prove to the family itself who had the child in a facility, who were concerned, and sometimes to the family that wasn't concerned. Sometimes you had to prove it to a government official, particularly when you were looking for broader systems-level change. Then you had to prove it not on a basis of individual situations; you needed a more comprehensive picture.

But it changed all the time. It depended on a multitude of factors and they were different for each child or each situation or each time period. You had to find who was the one to prove it to this time around, or who were the groups of people, the levels you had to prove it through. And to prove it you had to work to get wider and wider circles of people who were cohesively in agreement. You win each one over and they become part of the circle of people who are saying, "We believe this is true about this kid or this setting or this group of kids or this whole issue." You had more and more people pulled into belief in the system change which had to occur. The more people you had the easier it was to convince the next level of control. It was necessary to get people at the right times too.

You would have to set in motion a number of things to reach certain people, over a period of time, and bring them on side. Sometimes you would send letters to a doctor over a period of time that you would copy to 17 different people including a parent, the nursing home director and the government inspector. You might plan a comprehensive strategy like that. Or you might just catch a person at a case conference and talk in a back corner.

Inevitably you had to find ways of documenting the changes you were obtaining because people would waffle and drift back. The more that was in writing the better. The less you depended strictly on verbal assurances or commitments from people the better. But you often had to bite your tongue and grit your teeth and allow someone to save face in a situation when you really wanted to cast them to alligators. You had to maintain that person's good will and willingness to work with you. They often have to save face and maintain an impression of respect both

for themselves and among people in their circle if you want that person to help you with the next step.

ent: Your personal advocacy has been tremendous in helping move the issue forward at the national level.

LT: It is mind boggling that we still have to fight. I'm talking about 15 and a half years of fighting on behalf of this kid from the time we started trying to get her out of the institution. And Becky still has six months of hearings, of legal proceedings ahead of her [the human rights inquiry]. Six months! It's not a criminal case.

She represents, I think, the population of children or young adults who shouldn't have ... anything: shouldn't have survived, shouldn't have developed, shouldn't have been able to establish relationships with people, shouldn't have been able to walk, develop communication skills, get out of an institution, be integrated — who shouldn't have anything. There is such an investment in society in blocking the kids who shouldn't have been able to — fill in the blank. Much of it is being focused on blocking her.

I can see a certain element that we put ourselves in this situation by advocating so strongly for her. In order to make the gains we made for her we gained a profile. It was not an intentional outcome. But because of that profile the system may be saying, "If there's anyone we have to stop it's her because she's the one that will cost us the most if she wins."

The literature on advocacy tells us those outcomes can happen. They become major disincentives to advocacy — not only disincentives to initiating something but, once you're in it, disincentives to continuing, because at some point the pressure becomes more than you can handle. In Becky's school situation, I had a senior official in the school board say to me, "We'll see these cases go to appeal after appeal after appeal until these kids aren't even in school anymore."

ent: How old is Becky now?

LT: She's 19 and she is doing amazingly well. I was doing a paper on empowerment of people with disabilities, and, because a portion of the paper focused on Becky's story, I asked her permission to talk about her story. I asked if she had anything she wanted to say. She did. It was unbelievable. (Quoting from paper) "To her it is important to understand that a child with a disability, even of the most severe nature, can and should be loved and can love in return. Being able to love someone 'makes me happy in my inside self.' And letting people know that she can be loved 'makes the world a happier place.'" ☉