

## The Realities of Institutions

by Tia Nelis

"Should we spend money on institutions or to support people in communities?" As a self-advocate, it bothers me that people are still arguing about this. I'm not quite sure what all the graphs and charts and numbers mean, or what the latest research says, or whose reports to believe. So, I judge by what I know. I listen to the people who live in the institutions.

### ■ Privacy? What Privacy?

How can you have much privacy when you live on a campus with 100 or more people, in a unit with 10-15 people, and share a bedroom with at least one or two roommates? Struggling college students may need to live under such conditions temporarily, but not a 32-year-old woman with a job. Institutions provide little privacy.

When I visit the institution the staff think I'm another "client", so I get to see the real story. I see shower rooms with the doors open and curtains pulled back. I see staff opening the doors to people's bedrooms without knocking and walking inside. I see people carrying all of their valuables with them – "hoarding behavior" I think it's called by professionals; the truth is that people are afraid their valuables will be stolen when they leave their rooms. No free access to phones. No privacy when caring for personal matters, sleeping, entertaining that special someone, or just plain wanting to be alone. Bedroom doors are never closed or locked; I have noticed locks on nurses' stations, staff lounges and bathrooms, often with a sign that says "staff only" or "knock first." Whose home is this anyway? Administrators and state officials have escorted me through people's homes and invited me into their bedrooms without people's knowledge. I think the picture is very clear: Institutional living allows people very little, if any, privacy.

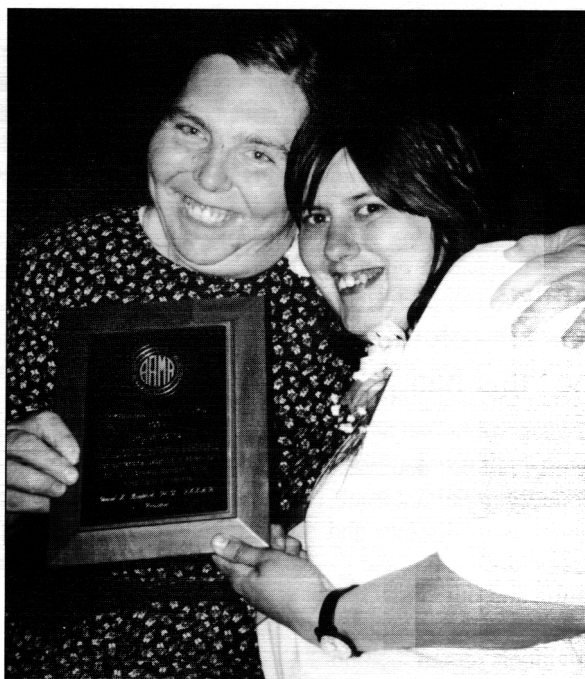
*Realities, continued on page 27*

## From the Editors

This issue of *IMPACT* is focused on a critically important step in the honoring of full citizenship of persons with developmental disabilities: the closing of institutions. We dedicate this issue to Roland Johnson, who passed away in August, 1994. Roland's personal experience of living in an institution propelled him to become a leader in the civil rights movement for persons with disabilities. His unwavering conviction that institutions must be closed and that people with disabilities need to live in the community continues to be a driving force behind the advocacy and self-advocacy efforts of many people who knew him.

Roland was one of the founding members of the organization, Self Advocates Becoming Empowered. Pat Gerke, an advisor for the organization, recalls that Roland, in personal conversations, would frequently ask the question, "What are YOU going to do about getting people out of institutions?" She believes that he knew in some way

that he wouldn't be around to see many of the changes he had dreamed of, so he sought to challenge others to understand that people's lives are at stake. With the help of self-advocates who, carrying on in Roland's spirit, worked with us on this *IMPACT*, we present that same challenge to our readers.



Tia Nelis (right) and Nancy Ward, on behalf of Self Advocates Becoming Empowered, receive an award from the American Association on Mental Retardation recognizing the organization's accomplishments, including efforts to close institutions. See story on page 12.

### CONTENTS

Overview	2
Self-Advocate Experiences	10
Parent Experiences	14
Closure Strategies	16
Resources	26

*Realities, continued from page 1*

Living “on the outside” as my friends who live in the institution call it, you decide how much privacy you want. If you like people around all the time, you may choose to live with five or six others. If you don’t like noise, then you live with a quiet person. Your phone conversations are private because it’s your phone. Your mail is private because you get it from your own mailbox. When people walk into your home, it’s because you have invited them. It is your home and you make up the rules. It’s called “choice.”

### ■ Choice...Another Popular Word

People who live in institutions or other large facilities have fewer choices to make because many decisions are made for them, including simple decisions that are made for staff convenience or cost savings. Decisions so important and basic to most people that if we insisted on making these decisions for our friends or families people would think we were nuts. When you are “placed” (my friends and I like to say “incarcerated”) many decisions are taken away, like where you will live and with whom, how you will spend your day, and when you want to eat, sleep, and work. Institutional advocates like to say we can’t make choices, don’t know how to make good decisions, and are not responsible, or that it is easier for us to have them make our choices.

Making choices about our lives gives all of us pride about who we are and what we have done with our lives. I was visiting an institution here in Illinois just last winter. The day staff came in from a shopping spree with new comforters for the 10 people who lived in this “cottage.” One of the men who lived there said he wanted a pink bedroom and the staff laughed. I could hardly believe what I heard – they actually laughed and said pink is for girls. Well, I have a Mickey Mouse comforter and purple walls and I love it because it’s mine. It says something about me. It may not be your choice. In fact, you may think that it was a bad choice, but it’s not your decision to make. It’s mine.

The bottom line about choices is that in the institution you get to make very few choices and the ones you do make are not the big ones. Living in the community you have opportunities to make choices about all parts of your life, from what comforter you may choose to where and with whom you will live. You even get to make bad choices and live with them. It sounds like making choices is a privilege, when it should be the rule.

### ■ Consumers...The New Buzz Word

I want to get a few things straight about this word “consumer” for all people who receive services. Consumer is a funny word to describe people who use some type of support services. When I first heard of people with disabilities called consumers, it was in a skit put on by professionals.

They showed people with disabilities shopping at a store and choosing different foods depending on what they liked. “We (providers of service) should treat people with disabilities as consumers of our goods and services. Our goal should be to provide quality services that people make choices about.” It sounds good, doesn’t it? But what government agency or service provider is going to say, “If I don’t meet the quality and demand of the services you want, then I will go out of business”? People with disabilities don’t have control over the money nor do they have many choices about what service provider or type of service they receive. The consumer idea is a nice thought, but really just another name to set us apart as being different from the rest of the world.

### ■ A Few Things I Am Sure Of

From my experiences with institutions and with life “on the outside,” there are some things that I know to be true:

- I’ve never met anyone who would choose to live in an institution once they have moved out.
- Putting people away because they have a disability is wrong, just like segregation is wrong. People should only be locked up if they are dangerous.
- Everyone should be allowed to make mistakes and learn from these mistakes. I’m not talking about putting people’s lives in danger, but about mistakes like spending all your money so you can’t buy snacks for a week.
- People with disabilities want to be friends and neighbors and coworkers with lots of different kinds of people, not just other people with disabilities.
- People who have lived in institutions all of their lives don’t know how to make choices because they are not given the opportunity. We need to teach people how to make decisions and allow them to fail, too.
- Community living is not always easy, perfect or safe, but at least the people who live in the community are free.

Next time people start talking about closing institutions, make sure you’re asking and listening to the right people – those who live there. They know the truth about these places.

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