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Living in the Freedom World:

Personal Stories of Living in the Community by People Who Once Lived in Oklahoma's Institutions

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UNIVERSITY OF MINNESOTA

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COVER PHOTOS:

Barbara today in the community and Barbara when she was admitted to an Oklahoma institution 30 years ago (inset photo).

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Introduction

Despite the dramatic decrease in recent years in the number of people with mental retardation and other developmental disabilities living in large (16 or more people), state-operated facilities, nationally over 95,000 individuals with developmental disabilities remained in large, state and non-state institutions as of June 30, 1996 (Anderson, Polister, Prouty, & Lakin, 1997). In the face of feared budget cuts and pressures from vested interests, some states are resisting or slowing former commitments to closing institutions and reducing these numbers. Consequently, it has become imperative for supporters of deinstitutionalization to continue the pressure to move people out of institutions and into the community. One tool that can be used in this effort is the perspectives of persons who have left institutions and are now living productive, satisfying lives outside those walls.

Although there are numerous studies that support community living for people with mental retardation and other developmental disabilities, they are empirical in nature and do not relate the experiences of the individuals in the individuals' own words. Those untold personal stories can breathe life into the statistics and remind us of the human beings behind the numbers.

The primary purpose of this booklet is to share the life experiences of 22 adults with developmental disabilities who once lived in Oklahoma institutions and now live in the community. They were asked questions related to five areas of their lives: home, employment, relationships, community, and dignity and attitudes. Their interviews have been condensed in this publication and, for ease of reading, organized under questions that reflect the themes in their comments. The text, however, remains the actual words of those interviewed.

It is through stories such as those told in this booklet that policymakers, service professionals, advocates, families, and others can see the realities of life in institutions and the necessity – as well as the feasibility – of moving people from such segregated settings into the freedom of community life.

"One thing I'm proud of is I'm living in the freedom world. I'm just as happy as can be. I feel like that I can achieve much better to live in the community than what I did in the past."

Warren
Previous resident of an Oklahoma institution

Their Stories . . .

in
their
own
words

Warren

What was your life like in the institution?

When I first moved into the [institution] I didn't know I was going to be. There's things I saw that I really didn't like and I wanted you to know about. I didn't know what it was like until I was about 4-years-old. What breaks my heart is my family took me there. I didn't have no place to go to school in. I was in the institution. I didn't do anything wrong. They beat me up and they got me with hot water. I couldn't do anything. I couldn't have freedom like I do now....

We would go to dances and stuff, movies and things...I did some work there. When I first got up in the morning and they made me – well, I'd make my bed....The work I did is the kitchen duty and I was washing dishes. I worked with some ecologists they have down there. I really enjoyed work but what I did – wash dishes, pots and pans, and helped them cook and stuff, many things....

What is your life like in the community?

When I lived in the institution, you wouldn't do anything like you're doing now. Now, I can go to town. I go to the mall in the downtown area and meet the people and talk to them and tell them about People First. Well, some of the stores, you know, I talk to them. They kind of – everybody in this town really likes [me]. I've got so many friends here in town, you know, some of them in Tulsa and some in Oklahoma City. Friends is most important for everybody....

The city council – I go to those meetings about every third Tuesday of each month....I do community work at a TV station. I've been involved with that almost 9 or 10 years....I've been involved with People First since '89. I am involved in other community things – clubs, social, and other clubs. Well, they [People First of Oklahoma] gave me a speaker award. It makes me feel good....

I don't want them be pushing us back to the institution if we want to stay as it is. We want freedom and we don't want to go back to the institution. I love it as it is now. ■

"When I lived in the institution, you wouldn't do anything like you're doing now. Now, I can go to town. I go to the mall in the downtown area and meet the people and talk to them and tell them about People First."

Warren

Barb

"I work for Vista Volunteers. Experiences like working with a lot of people and going to different places and being able to have experience in other areas instead of in one area."

Barb

What was your life like in the institution?

When I went to [the institution], I did not know anything hardly, and they took a picture of me in the main office. So they did an interview with me and took my picture....I went to the hospital and stayed there for a few days. They checked you out and then you went to the cottage. They made sure you was okay and they wanted to run some tests....

The cottages that I was on, the one, we had to share – you had to store your footlockers on the back porch. When they did the laundry, they put it in a room that we only had just one little cubby hole apiece to put our clothes in. Each one had like one shelf apiece.... There was two of us that shared a room. There was about 18 or 19 girls that lived all in a cottage together, and we shared a room with me and another girl. Half the room was ours and it was kind of – you didn't have very much room for two people. We had to have half-and-half of both sides of the room. Very limited drawer space and shelf space, and we didn't have any bathrooms in the hallway. We had to go down the hall to take a bath. We didn't have hardly any privacy at all....We got to decorate our room. We didn't have too much on the walls. We had a few pictures. I didn't have so many pictures, but my roommate had some pictures of her family....

Everybody got up and ate breakfast together and we did different duties. Some of them would take turns doing and they'd sign you up for areas they wanted you to clean. They'd change duties every week. You might sweep the steps off or you might clean the hallway or the lobby and take turns cleaning up the dining room. We didn't get paid. Felt kind of bad because we didn't get paid to stand on the cottages....

Some of us older girls went down and helped sometimes to feed [the boys] because it was kind of a hard job for one person to help feed about 50 or 60 boys on a cottage. The ones I worked with, they wasn't able to do very much. They couldn't feed themselves, so we volunteered to go down a lot of times and help them feed them so they could at least get their lunch, so they wouldn't be left out of eating or something....

They didn't want you to see the boys or have anything to do with the boys and the girls. So that's why a lot of times the girls and boys would get in trouble because they wasn't allowed. But they did sneak around and do it anyway. They didn't care if they got in trouble or not. Yeah, you had to sneak around. But they didn't feel like that the boys and girls need to have anything to do with each other, just maybe talk to each other at the dance or at the jobs that you went to on campus. They didn't like you to do anything with the other boys hardly. If we got caught with boys, they would write you up or send you back to another cottage, like they did me for two years. That really caused a lot of problems for me and for them because that just put me a little farther back instead of ahead. Every time I'd get worked up, then it seemed like I'd get in trouble and then I'd fall back down in a lower grade....I had to be punished for a couple years and sent back to another cottage. Then I was put back on the dorm. Then eventually I went to the halfway house. That's when I kind of got in trouble with that boy at the halfway house. Then several times I got in trouble. Then I went back to the dorm and then back from the dorm back to the halfway house. A few times I was back and forth from those two buildings quite a bit....It wasn't fair because it took away a lot of my things that I had planned and my pride when I wanted to have my privacy....

I smoked before I went out there. When I first went out there, the boys was only the ones that was allowed to smoke. Then I'd been there probably about a couple of years, about two years later, then they started letting the girls smoke because we were sneaking around anyway. They'd go home with their parents on the weekends or for a visit, and they would somehow, find a way to smoke anyway, and they'd bring them back. So they decided that if they were going to sneak around, they might as well let everybody smoke. So when they changed that rule, the residents felt a little bit better about everybody doing like the boys did.

What was it like to leave the institution?

When I left the [institution], I was glad to leave because they was kind of mean to you, treated you kind of bad. And when I left and walked out the doors that day, it felt good leaving there because it was a very bad place to live at.

What is your life like in the community?

I lived here 5 years and then I decided to move out with my aunt in Oklahoma City. I'm down there a couple years and it didn't work it out, so I found out that I had more friends here. I'm living in the same apartment now when I did the first 5 years. Then I've been back here about 9 years in this apartment this time.

Oh, I pretty well like living in my apartment....I have friends that I like, that I do things for other people....We have very good neighbors. The neighbors and I – everyone has a good friendship. When I go to the store, I run errands and I get little things for them each time I go to the store. I don't forget anybody else. I always think of them if they need something because if I'm going out, it just saves them an extra trip for going to get it because that's how I care about people....I like to come and go when I want to. I tried to have roommates and it just doesn't work out because they wouldn't do their share of work cooking, washing dishes, anything. I always had to be the one that did all the work....

I've had different jobs. I used to clean people's houses and then I used to work with a lady helping her in a bridal shop doing bride dresses and pressing. Then I worked in a laundry here in town in Enid. Then I worked at the air base and I took care of the kids in a nursery. When I started getting paychecks, it felt like that I deserved the work and a paycheck because I worked hard and knew that I could keep a good paycheck and keep on making good money so I could get a raise. Everybody looks forward to a raise....

I'm going to a lady that's teaching reading. She seems to be really interested in me. Every time when I was younger, it seemed like everybody who worked with me didn't want to take the time or didn't give me a chance to let them work with me. I have found a real nice teacher now. As I've gotten older, she seems like she's interested and is willing to work with me in reading because that is one of my things that I have always been liking is reading. I'm finding now that I'm learning how to read a lot better than I used to, and I enjoy learning and setting down and working with somebody who is interested

"I'm finding now that I'm learning how to read a lot better than I used to, and I enjoy learning and setting down and working with somebody who is interested and is willing to work with me and listen to me."

Barb

and is willing to work with me and listen to me. It makes me feel good, but when I first started reading there are some words that I remember when I was younger. If I had got the chance that they would have kept on reading with me, I don't think I would have gave up. I find that in some things that we read about and some of the books that I remember some of the words. The reading teacher is really surprised that I can remember as much as I have. I think that [reading] is very important to me because, like I say, I never did get to do any of that before and I'm learning more now than I used to. I feel real good about myself being able to have the chance, the opportunity. They didn't let me have a chance to get out and learn on my own, because that's been always one of my goals to try to read some. Even if I don't read all the way, at least I'll be able to read some things that's interesting to me and will help me later on in my lifetime coming up....

I work for Vista Volunteers. Experiences like working with a lot of people and going to different places and being able to have experience in other areas instead of in one area. That means a whole lot to me because I don't have to set back and wait on everybody else. I used to have to set and wait on other people a lot of times. That kind of got boring, and I just wanted to give up a lot of times. But being on my own and being able to have a job with Vista, I can work with people with disabilities. That's something I always wanted to do is to work with older people and go different places.

What does it mean to you to have a disability?

I just think that people with a disability are able to do things and they don't need to be made fun of because of their disability. They're just as capable of doing things like a regular person would because a handicapped person is, in my words, regular loving people like anybody else would be. A disability does not mean that you can't do nothing. ■

Jim

What was your life like in the institution?

I used to live with [my mother] in Midway City. Graduated from high school in 1966. Then, after that, I got in some trouble. So I had to come down to [the institution] then. I lived there for 19 years....It was the worse because everybody got into fights every day. People were always trying to hit you and everything they could hit you with, and everything.

[The staff] were considerate and nice. They were there to help the same as anybody else. We got along with them just like they was part of the family. The employees were very nice. If they needed help, they would ask us to help. Like tie somebody down or help them do things for them, you know, like buffing or helping them mop or stuff like that.... Well, to keep them from hurting themselves and the employees too [staff would tie them down with leather cuffs]....

You couldn't go where you wanted to. You had to have permission to go to the store, and you had to have permission to go walking if you wanted to go walking. I figured they were cheating us of our pride, of not going where we could go anywhere we wanted to....

There was no privacy at [another institution]. Down there, if you took a shower, people would come in while you was taking a shower and they would stare at you. Kind of weird, I tell you.

What is your life like in the community?

Well, I moved out and I went into a group home. I was there at that group home learning to set my goals that I needed to get on the outside. [After that, I moved into my own place and met my wife]....

My wife is my closest friend. She's loving. She's always caring. She always asks if I would do things for her, and I would reply yes. Me and my wife, we have our ups and downs every day but it's always nice to know we can sit down and talk the problems out and solve them ourselves. Me and her go out to eat. Sometimes we go to the bowling alley and watch them bowl. We own our home. Well, it's ours and nobody can take it away from us. We enjoy the house very much. At our own house, we have our own set of keys. At the institution, we did not have any keys there. They didn't give us any keys at all. [It made me feel] sort of like you was in prison almost....

[I like] talking with [friends] and enjoying them being there. Just to get along with them and make sure that they're still your friend. If there's nothing to do, we sit back in the break room [at work] and talk about old times, what it was like when we first started.... Now I don't sweep and mop any more. Don't get on my hands and knees and clean the cracks when there's an inspection coming up [at the institution]. Well, when there's an inspection, it has to be cleaned. So that means it's got to be waxed and buffed and cleaned before the inspection the next day, which we probably don't get into bed until about one or two o'clock in the morning....

Really, I'm in control of my own life. I think about myself is that I've come a long way in life. I've accomplished the things that I want to accomplish, and I'm very satisfied with that....In the next couple years, I hope to own my own business someday. Either mechanic work or fire shop or something, you know, that I know how to do. Because I think if I had my own business, I could see really what it's like to have my own business and see if I could make it. ■

"My wife is my closest friend.... We have our ups and downs every day but it's always nice to know we can sit down and talk the problems out and solve them ourselves."

Jim

Kevin

"I'm proud seeing all my buddies getting out in the community and stuff. That's one thing I'm proud of. Seeing all my friends doing real well and they all have a family. They all driving and going to get jobs and stuff...."

Kevin

What was your life like in the institution?

I can tell you some horror stories and some good stories. I had some staff that I did like. I had a best staff. I had several staff. They all out in the community now....[Abuse] happened and went on and on with several clients. So, like I said, I'm not afraid to tell you what happened. I don't care if people say, "Kev, don't tell your people about this."... They don't want to hear about the bad side. They only want to hear about the good side of the story. Stuff did went on at [the institution]. I was one of the clients, one of the few clients, that got whooped with scrub brushes and flipped with rubber bands and stuff like that. Several clients did get hit by staff and threatened with hair brushes and stuff like that. Like I said, I'm not making this up.... I was scared. [Staff] say, "If you tell anybody, we're going to write you up." I was scared. I didn't know what to do, so I just kept quiet. It's kind of scary. I'll be honest with you. Some of the staff used to whip me with a scrub brush. Take me behind the place where they keep the mops at and whoop me. They say if you tell anybody, we're going to light you up, and stuff like that. I was scared. One time, this incident happened when I was about 16 years old. We all acted up and this one staff got mad. He threatened me. He almost came close to hitting me with the door opener. They used stuff like we was in prison. They used to make us scrub walls. Scrub the shower walls if we act up. And also they had those straight chairs and tie your arms down. Those behavior chairs and stuff. Tie your arms down. I was never in those chairs, thank goodness....

This is kind of sad, I'll be honest with you about this. We went to skating parties. It was kind of like skating by ourselves, no other people skating because we skate by ourselves. It was kind of like nobody would be going in – the regular customers would be coming in as we were going out. We just go skating at nighttime. It'd be nobody else, just us skating at nighttime. It was just we were segregated to skate by ourselves and I got used to doing stuff like being around people isolated and stuff. On Sundays, we were supposed to go swimming. They didn't teach me how to swim. I'd just get in the water and stuff. They didn't even know swimming skills at all because they didn't have time to. They had a bunch of these people they had to deal with and stuff back then. They didn't have time to teach me how to swim. That's why I figure out how to swim myself. The only time they teach me how to swim if they wanted to teach me how to swim for the special swimming team. That's the only time. Mostly I did it myself....

The job in the institution was in the workshops. We used to do pins and arms. Pistons on those greasy stuff deals. Sometimes we used to do those box boards. We used to do like workshop jobs, like how to do a simple job. We need to take on a real job. We was kind of lacking some job skills. For me personally, I really didn't like it. I'd like to see the institution workshop close and see all of those people like everybody else to get a chance to get a decent real job in the community...

I was just young back then. I was 5 years old and I didn't know what to expect back then... I didn't know why I went there for.

What was it like moving out of the institution?

I was scared getting out of [the institution]. I didn't know what to do! I was getting adjusted to the community. How to get around. How to deal with people.... In the community, I was having a hard time back then getting adjusted to it and stuff. It was lack of training back then. If I had some training when I was younger, maybe I wouldn't be so far behind and stuff.... I was lacking lots of skills like my reading skills. I didn't know how to catch the bus back then. I had people take me back and forth to school. I went to an off-campus school before they got the [lawsuit] started with [the institution]. I went to regular public school. Then I was scared of several things. We used canteen money – it was kind of like tickets and stuff to go to the canteens.... I have trouble identifying money and stuff like that but I can identify money now. I can have trouble past certain digits and stuff like that, but I have some friends that might help me. Staff helps me figure my checkbook and stuff out. I'm doing really good with money now.

What is your life like in the community?

NOTE: At the time of the interview, Kevin is 4 months into a new job at a local grocery store. He likes the job a lot and gets along with his coworkers. The favorite part of his job is "seeing those happy customers come in. Makes my day go good sometimes." Kevin had lived in a foster care home, but became tired of staying at home with "nothing to do and stuff." As a result, he decided to move in with his two friends. He lives in a house with two roommates. All three men lived in an institution at one time. Kevin met them in the community and became involved with them.

I'm proud seeing all my buddies getting out in the community and stuff. That's one thing I'm proud of. Seeing all my friends doing real well and they all have a family. They all driving and going to get jobs and stuff....

I have a close friend. I used to talk to her on the phone, but sometimes it's hard for me to call her sometimes. I met her at Tulsa during the [national People First] conference. Since then, we be talking and we be going out and stuff. We really enjoy ourselves....On weekends, we go out dancing sometimes, me and my roommate. I like to dance. The music I like to dance to is like hip-hop music. On Sunday mornings, sometimes we go to church....

I got involved in People First in '94. I started getting involved. Someone was telling me about People First. I went to the meetings and stuff. I wasn't sure what they was talking about back then. I went to the meeting just to be going to them.... Now, I listen because they have some very important things they got to say. I listen. In 1996, me and James went to D.C. [to attend the President's Committee on Mental Retardation]. I went to this one workshop on policy. They talk about closing institutions and welfare reform....

[The staff who support me] are pretty nice people. They look out for me. They make sure I don't get mistreated and stuff. The staff make sure I don't get taken advantage of. Yeah. Make sure not like mistreating you and stuff like that.

"I like that I can have some chance to be a little bit more independent. A chance to get out into the real world."

Kevin

Make sure if you got food in the house and stuff like that. So far, they've been real helpful and stuff like that. Sometimes I don't agree on some things, but then I respect that decision....

[What I don't like in the community] is some places I can't go because of activities and stuff. Some things I have to sacrifice, and stuff like that. Activities and stuff, like if a person don't have the funds to go nowhere, they can't go.... Sometime you don't have the money and they don't go but I can go sometimes if I want to and stuff. Like sometimes I want to go somewhere but it's hard. You've got three roommates in the house and it's hard to sacrifice one person. You've got all three roommates and it's hard to have to overcome that.... I'm fixing to move out and going to the companionship program. The companionship program means that two persons split – kind of like roommates and stuff. You both pay half the room and board and stuff.... I chose the companion. I know him well. He used to work at [the institution] too....

I'm learning how to drive. I plan on going to driving school too. It's going to be a matter of time but I'm being patient too, so it's going to come eventually; it just have to be patient....

I plan on getting married, then hopefully get married and have a family and stuff like that. I plan on being a good father to my kids, and hopefully giving them the same lessons I teach them. I hope I'll be a good role model to them and stuff. Try to encourage them to do the right things. Teach them to stay out of trouble and hopefully they can do it....

I like that I can have some chance to be a little bit more independent. A chance to get out into the real world. ■

Roxanne

What was your life like in the institution?

Just couldn't hardly stand it at all. Just couldn't, from everything that was going on. Breaking everything, stealing.... [Could not] leave [the institution] without permission. Couldn't be breaking anything. You'd end up getting in trouble for it. Made them stay there in the bedroom. Wouldn't let us walk out. We couldn't go out on dates because we had to get the staff to go out with us....

Worked right there in the laundry where the door's shut. Kept on getting all the laundry in the washer and dryer. I got paid....

[The institution] is all locked up now. Shut down and locked. Yeah, I'm glad about that anyway. I really am. I think they [people living in institutions] are going to need to find group homes and anything. So they can get out on their own.

What is your life like in the community?

I like everything we're doing down there at home. Get to decide what I'm doing. Going down to the store. Well, would have to go down to the store with the staff. I would have to help them write the menu out with what to get. We're able to go out on dates now without staff....

Just want to keep working down at the workshop. I'm proud of work. I like everything about work. Everything. I want to get a job on filing if I can. There's filing from down there at work every day. I've been working hard and studying hard from down there at school....

Just started going back to school last month for a G.E.D. And everything's going okay. Been going out back down to school on Monday, Tuesday, and Thursday. The most thing I'm real glad about now is that I'm going back to school so I'm getting my G.E.D. Well, if I get the diploma, I'll leave it there in the bedroom. But I'll probably hang it up on the wall. Probably. Yeah....

I'm the secretary for Oklahoma People First. ■

"Just started going back to school last month for a G.E.D. And everything's going okay. Been going out back down to school on Monday, Tuesday, and Thursday."

Roxanne

Stanford

What was your life like in the institution?

Well, it started back when I was five, a young age to remember many things. I never knew my dad....well, my mom had me at a very young age, at 17. For reasons being, my mom just wasn't able to take care of me. I thought it was all my fault. After looking back at it, it wasn't my fault after all. She began to abuse and began to neglect me, for reasons being I don't know. So anyway, this went on for awhile. I just didn't get the love that I needed from my mom. So after awhile, the state took me. I realize now it wasn't my fault. So I was in state custody after this. I was sent to a foster home from there. Then the foster parent died. Then this is how I began to go into an institution. I'm sure my mom – I'm pretty sure she would have been a good mother if given the proper guidance. Then maybe I would have never had to be in an institution or in a foster home. That's how it all started....

When I was living at [the institution], as a child at age seven after going through this thing with my mom and then the foster home and then to [the institution] – no, I didn't get the love that I needed. At that age, I felt like a caged animal. I understand why I felt like I didn't need to be there. I used to just give people problems there. I didn't always act right. I was not a good little boy. I just felt like I just didn't get the love that I deserve if I had it from my mom....

I was at [the first institution] for 3 years. I went to [another institution] and I was there for 8 years. The reason for being moved is they just couldn't handle me there. They just wasn't equipped enough to handle any of the problems that I was having, so they decided to send me to another institution. At [the second institution], it was sort of the same deal. I felt like I should have never been in both institutions. Well, I've been in two institutions. The first one – actually, I didn't like living there. There's some good things about it. There's some bad things about it. Good news is that it kept me warm, it got food on the table for me. Everything there was provided. But the bad part is it just wasn't really my home. And the second one was pretty much the same way....I didn't like living there because I feel like that I missed what was on the outside of the institution. I just didn't like living there because I felt like I was in a prison. And the labels of so-called mental retardation....

Some people were my good friends. The rest of the people were just friends. Do things with them like walking and talking and doing activities like playing in the park and basketball gyms, women....I liked playing outside with the other kids. I liked swimming, playing basketball for fun. I did a lot of other activities there....

Well, the staff that worked out there – most of them were friendly. Some of them kind of wasn't so friendly. I liked a lot of them. I was friends with some of them....

At the institution, I washed dishes, bused tables, and that was basically it. I didn't get paid.

What was it like moving out of the institution?

After 8 years being there, finally on November 18, 1984, I was released. I felt happy. I was glad. When I came to Tulsa in 1984, I felt good. I was placed in a group home here in Tulsa. I felt – I mean, it was good to be out. I mean, I didn't know what to expect from being outside of the institution. It was a whole new world for me to experience, and I was glad to be given that opportunity....

What is your life like in the community?

My experience at the group home [where I first lived] was good. I learned some things there. I learned how to live on my own. I learned how to budget money. I learned how to write checks. I learned how to hold down a job. It was more like a family setting, like I've always wanted, but not quite like if I had a mother and father. But the group home was good to me. I learned some things there by being in a group home. After I got out of the group home, in my first apartment, it was good to go from the group home being totally on my own with some assistance. It felt good to accomplish what I've been through....

The place I am at now is a nice apartment. I like where I'm living at now. It's good. I can budget my own money. I can hold down a job. I've learned through trial and error that I have to – well, in order to have a place to live and to keep everything paid, a job was important. Well, I like it much better. It's independence. It was much better than living in the institution. I am grateful. Well, I am just grateful to have a place on my own, which I never had living in the institution anyway....

I am grateful to be the person that I am now. I am grateful to be the person – well, after going through all I've been through, I am happy to be the person that I am now. I felt like I've accomplished a lot....

The job I work at right now is at a deli. The job I do mostly is everything, from washing dishes, busing tables. Just anything that they need done, just to help make the deli look good. The job I do sometimes gets a little rough on days when it's busy. It gets busy sometimes. The co-workers and the staff I work with are good people to work with....

My dreams for the future is marriage, kids, and I can be a good father to my kids. I can teach them and raise them and to share the experiences that I had. I want my kids to know who their father was and who their mother was. And a better paying job as well. ■

"I am grateful to be the person that I am now. I am grateful to be the person – well, after going through all I've been through, I am happy to be the person that I am now. I felt like I've accomplished a lot...."

Stanford

Billy

What was your life like in the institution?

I was in [a nursing home]. [Staff] said I can't even go into town and be back. What time you be back, and had to be back the same time, and stuff like that....The staff were mean to me. Can't do what I want to. See, I like to do what I want to. I can't do what I want to....I just work in the kitchen....There wasn't much to do except work in the kitchen and get up in the morning and go back in the kitchen. If I get all my work done, then I would go...and then go downtown and mess around and then come back to the home.... I know I don't like that place anyhow. I know I don't. I just had followed the rules. You don't follow the rules, you get in trouble. So I just follow the rules and then move out to the group home, to the local group home, and I'm on my own.

What is your life like in the community?

I'm my own person living by myself. I got my job... I like it real good. I can do what I want to. I can come home when I get ready. When I come home, I just stay home and watch everything and then get back up in the morning and take a bath and get ready to go to work in the morning. Then I start walking to work....I clock at 9 o'clock in the morning...then go back in the kitchen, work in the kitchen, and then by 1 o'clock I take my break. Then by 3 o'clock, I get off work and then go back home. I get home. I put my pot up and Julie cooks some cocoa and stuff like that. Then when I get done, I sometimes walk around. When I get done walking around, get tired, then I come back home and make dinner and get up and go back to work again....

I like my job good for I get along with people good. I like that job for how much I make. I make pretty good money, you know. My check's a pretty good check. I like that check. I look at the job, and that's a pretty good job....

When I'm off, I like to ride around with my bike. Then I ride around and see my friend and go places. Then when I get ready to come back, I go back home. Then when I get off of work on Thursday, I may see my friend. I just go and call him up and ask him can I be by and see him? Sometimes he'll say he be home and sometimes not. If he's not home, I just wait for him to be home and then come see him. ■

Leon

What was your life like in the institution?

I was about 8 years old when I went to [the institution]. My mom don't know how to take care of me and put me in [the institution]. They can't make my life. Someone drop me off and leave me and never got back. I didn't like it....

When I was at [the institution], it was very, very depressing. It was not very nice because I was scared. I was really scared. I didn't know what to do. I mean I ain't scared anymore.... I didn't like it in the institution. Didn't have no privacy. The food was all right. No good. [School was] not like real school. I wanted to have friends around me. We only made friends with people in your building. Not from other buildings. Well, if we wanted to go do something on our own, we couldn't do it. We're always with a group. Didn't pick where I wanted to go. I didn't have no privacy. I was in a room with umpteen beds or more. I didn't have nothing. I didn't have a thing to show. It was bad. It was bad. I was scared to death. I didn't want to be there. They used to pound me and beat me up. My staff [made me stand] in a corner for two hours, and I didn't like it. They'd pop me with a towel. They'd beat me, hit me, all that. Make me mind. There were some staff that were nice. We'd go out. They'd take me out for an overnight visit. But we had fun....

I was a dishwasher. Yeah. I did [get paid] but it went in my fund. Don't like [being a dishwasher]. I worked at a greenhouse. I worked at a farm. I get to pick [the job]. I liked it. I really enjoyed something for me to do. My least favorite job was cleaning house....

After [work], we come back to chapel and we had recreation. Go recreating. Recreation. We go to the gym and play basketball. Leisure activities [were on] campus. We'd play basketball. We'd play dodge ball. I had friends. I had my good times there....

[I'd like to] close every institution in the United States....Most people can live in the community.

What was it like moving out of the institution?

The first time in the community was scary. [People told me] I might get hurt. Somebody in the institution. But I had friends help me when I got out. My mom didn't want me to come out. She was scared. She's not scared now. Oh, [she is] happy for me....

What is your life like in the community?

I get up in the morning. I go to work if I have a job. I have a good life now. Make my own coffee....I live by myself now, and I have my own apartment. I feel good about it because I'm happy I'm living out here. I really like it. I can do anything I want and I prefer doing anything I want to, yeah. I just live by myself. It gets lonesome sometimes but I deal with that...by watching TV. Do stuff to keep myself occupied....

"When I was in the institution, I was shy. I like where I am now. I like myself. I'm better off now. I'm more happy now. I'm a regular person...."

Leon

I have a close friend. She comes pick me up, take me out. We go to dances. My friends go out, play pool and all that, you know. My favorite thing is to go to a movie.... I can look in the paper, pick my own movie. I go. I get the paper every morning. Check what's going on....I'd like to move closer to friends so I don't always have to get a ride....

I'm with People First of Oklahoma. We talk about the community, community safety, voting. We do social things. Helped with (People First) national conference.... I help other people. Like I ring the bell at Christmas time. I help at People First...

I feel real good about myself. When I was in the institution, I was shy. I like where I am now. I like myself. I'm better off now. I'm more happy now. I'm a regular person....

[I'd like to] be a peer counselor to the high school and get them out in the community....[The staff are] very nice and they're very comfortable with. I really like them. Sometimes I have up and down, you know, and all that. They help me. There's my program, my IHP, and I really enjoyed it, you know? They can take me where I want to. [We go] grocery shopping. [They] help me cook....

Sometimes people give me a hard time. I walk off. I didn't used to be like that. I wanted to fight everybody. Now I walk off. I know I like myself. I like where I am now. And that's how I feel. If someone don't like me, fine. ■

Juanita

What was your life like in the institution?

I did board games and made potholders. I always liked the laundry work. I'd pick up things and fold them....I always wanted something to do. I didn't want just to be without work and sit out and do nothing. I didn't like that place. I just liked to show myself I can work and do it. At the nursing home, there's nothing to do and all the others got something to do. And then me would do without. So I got my embroidery work and did it.... Now I get to come over there and clean the three bathrooms.

What is your life like in the community?

I like the people I live with. They're nice to me. I like my bedroom. Yeah, new bed and new bedspread....I like to go to the flower gardens and clean up the flower gardens. Get them old dead leaves out of the flower garden, cigarettes, and everything else, that kind of trash. Just cleaned it up....

I have a best friend. One time we went out and two bosses were out there taking me and Toby with us. We went to taking pictures. They asked me, "Want to take a picture with Toby?", and I told them I would. And I did. ■

"I always wanted something to do. I didn't want just to be without work and sit out and do nothing. I didn't like that place."

Juanita

Bob

"I have my own lawn service. I got my own boss now. I have job coaches that help find me jobs. My own business."

Bob

What was your life like in the institution?

I was lucky. People wanted to get out. Close it down. Nothing to do there....[I had] a bunch of [friends]. My cousin. All of us moved out and stuff. Last time I seen them. I know him a long time. I go walk around. We go to the parks and do something. Yeah. I got a problem, we'll sit down and talk them out and stuff.... My happy to get out of there.

What is your life like in the community?

I work 5 days a week. Go home, clean the house up, go to the Laundromat. Go wash my clothes and stuff. Go grocery shopping. I got a helper to help me and stuff. Go where I want to go. Lots of things now that I can do now. A lot happy. I meet new friends. Going places like carnivals and stuff....

I like my own apartment and stuff. I like it. I like the things that we do and stuff. My friend and my brother moved me to my apartment. I have a lots of friends. I live with my aunt now. I lost my mom in '88, turn around and lost my dad in '89. I live with a couple good friends before we move down here in '84. I didn't know nobody. Now I know everybody now.... Me met [my best friend] two years ago. Sometime her come over to my apartment and help me cook and help me clean the house. Sometime her family over and her eat. Her cook. Sometimes I go clean her house or her apartment....

Fishing is one thing [I like]. Fishing. Go racetrack. Go somewhere to eat out somewhere. Yeah. Once a month, I go out to this mall in Oklahoma City, eat food, go to movie. Some of my friends live with me in Oklahoma....

I have my own lawn service. I got my own boss now. I have job coaches that help find me jobs. My own business. I got my own lawnmower....I'd like to find another job in the community. Walmart, Pizza Hut, McDonalds....My paying my own bills on time and stuff....

I like to help handicapped people in the wheelchairs. If you're not doing nothing themselves, they call me to go over and help them out. ■

David

NOTE: David participated in the Adult Companion Program. He lived with a young family – Kathy and Rob, and their preschooler, Lauren. Lauren and David were very good friends. They read books and played together. Kathy had previous experience working with people with developmental disabilities. She worked in the field for several years, knew David personally, and had a working relationship with him. Her biggest concern was Rob because he had no previous experience. When they started in the companion program with David, they had been married almost 2 years and their daughter was 6 months old. At the time of the interview, Lauren was 3 years old. Since this interview, David has passed away from cancer.

What was your life like in the institution?

I hated. No property. Don't want to move back. [Staff] were very nice. My favorite friend went to [the same institution]. I still see him.

What is your life like in the community?

I like the program better. I like the new classroom and a lot of people know me so very much....[I] watch movies. I do computers. Oh, listen to my [music] tapes; I like Michael Jackson. I like Karaoke. I practice the drum. Yeah, sports I love. I like bowling, basketball, football. I went to Washington, a tour of the White House. Go and look around. I saw pretty Christmas lights....I really like Kathy and people who know me. Play peek-a-boo with Lauren.

NOTE: When Kathy was asked for her perspective, she said the following:

We are under the foster care umbrella. It's similar to a roommate situation where David participates in household responsibilities. Anywhere from financial – we do the bills together and David contributes part of his expenses to the household bills – to meal preparation. We try to go shopping together once a week. David chooses his own foods for lunch and things like that. He actually will independently make his own lunches and things. Another goal that David is working on to become more independent is to stay by himself in the home when Rob and I go out on a date or something like that. He'll stay for up to 3 or 4 hours in one evening. During that time he has responsibilities like either vacuuming the house or his bedroom, cleaning up the bathroom, cleaning up the kitchen, things like that. So, it's kind of a shared family/roommate type situation.

NOTE: When Rob was asked for his perspective, he said the following:

It's challenging when you have no background at all, being around the developmentally disabled. It's difficult, but it's very rewarding as well. I guess the biggest challenge for me was getting used to having someone else in the house. I mean, you're this tight-knit family and you have to get used to having what starts out as somewhat of a stranger. But, you'd be surprised how easily that person becomes really a part of your family. You then begin to include them in everything that you do, and it just becomes second nature. When we have dinner together, David eats with us, although sometimes he likes to sit in his room and watch his movies as well. But, he eats with us, goes to church with us, everything. It's like we're not ready to leave until everyone in the family is ready, and David has just become part of the family. So, it's been a great growing experience for me how to broaden my thinking and include additional people into what's going on in my life. It's been very rewarding. ■

Karla

"I have a lot of people I talk to and, you know, get around with and stuff like that. I have an apartment and I love it. I do my own cooking. I do everything. I just do everything on my own...."

Karla

What was your life like in the institution?

Well, I liked the food, but that's about it. [The staff] tell me you can't do this, you can't do that, you can't do this. I didn't back talk or nothing to them....

I used to work at the workshop [at the institution] in the main building, but I didn't like it at all that much because the people didn't treat me like they should. I didn't like it there....

I want to just be on my own for awhile, and I like to stay out of the workshop completely for good. I don't want to go back to the workshop because I just didn't want to go back there because I didn't like it...I didn't make much money at the workshop at all, like I'm doing now....

[At the institution] there's a lot of [staff] that didn't think [residents] could be on their own, but I said don't think negative. Think positive. You can do things. That's what I kept telling them....It's not right for them to live in the institution because they don't think it's right for them or stuff like that. I don't think it's right for them at all, period. I think they need to get on their own, do what they need to do, stuff like that....Because if they don't get out on their own, they don't know what to expect. Just tell them if they want to get on their own, they can just call up whoever to give them advice. Call somebody up who will give them advice, and they'll give them advice.

What is your life like in the community?

I like it there. I have a lot of people I talk to and, you know, get around with and stuff like that. I have an apartment and I love it. I do my own cooking. I do everything. I just do everything on my own....I just like to go out and do things with people and go to work and stuff like that. [I] go bicycle riding and go out to eat and stuff like that. I swim at the Y every day. I walk there – depends if it's not cold. I ride the cab usually. In the cold weather I don't like to walk when it's cold. I go to the Y Mondays and Tuesdays and Wednesdays because I got an aerobics class I go to....

[My friends] help me. They always help me out. If I got any problems, I go to them sometimes and they help me out....I do have a boyfriend. We go bicycle riding. We do things together. We do this and that, we go out to eat. He takes me to get pop or drinks or something. We do a lot of things together and have a good time....Oh, I've got a bunch of friends. A whole bunch of them. They're nice to me. They're kind. They're sweet. I like them. They help me a lot. If I need anything or ask them questions or whatever, I ask them stuff I need to do and stuff like that. They come to me if they have any questions. If they've got any problems, they come to me, and I'll help them out....I've got a mom. I've got two sisters and a brother. I don't get to see my sister that much like I do my mom....

I work at [a fast food restaurant]. I do the lobby. Make sure it's clean, real clean and spotless. If you don't, they'll get on to you, like Dave does to me all the time....

I'm secretary of Shawnee People First. People First – we do different things. We do roll call and stuff like that. We do activities. We're going to get ready to do a garage sale pretty soon, in March. [We are raising money] for going on trips and stuff like that. Like going out somewhere to do things....It's better for me to not do what I used to do. Right now, I just like what I'm doing right now. I was one of the persons who was shy last time. I didn't speak up for myself. I was shy, but now I'm not that way anymore. I'm sure glad of that....

[I want to] get my own car! In the future, I want to get my own car so I can take my mom places so she don't have to drive that much like she used to, like she always does. I could help her out at least. I'm going to try to take my driver's test. I'm going to try to take my driver's test this year, I hope. I'm trying to. I'm just doing the best I can. Do what I can do....

I want to wait a long while before I get married. For a long while. If I want kids, I could adopt one....

My mom's going to take a cruise on a boat. I don't know when, though, yet. That's something I want to do. I love to go on boats. They're fun to ride on. ■

Don

"Well, now I'm living in a house of my very own, and I love it.... I go to dances.... Sometimes I go shoot pool. Sometimes I go to the movies."

Don

What was your life like in the institution?

It was kind of enjoying, but it was kind of boring at times. It was kind of bad at times. Well, it was like an institution. It was more – what word do I want to use – homebound institution. Had hardly any freedom, any rights, anything. I was the highest client up out here. If I wanted to, like for example, if I wanted to walk over to the store to buy a pop or cigarettes, I could. I didn't have to tell nobody where I was going; I could just walk...

I really liked the [school] teacher. I had a crush on her. And she did not know that I had this crush on her....

I worked at the workshop. Well, we had contract work, boxes, bolts, and leather, and all types of stuff. Got paid money. We went shopping [out in the community]. I bought almost anything I wanted.

What is your life like in the community?

Well, now I'm living in a house of my very own, and I love it.... I go to dances. We have dances every year all year round. We invite other companies to our dances but we have a Christmas dance. We do not invite people from other agencies to our Christmas dances....For fun I pretty much set around, relax. Sometimes I go shoot pool. Sometimes I go to the movies. I like all types of movies....

I would [like to] change the amount of money I'm being paid right now. Change that to being paid $15,000 a year every two weeks. Whew! I would have some serious dough in my pocket.

What does the word retarded mean to you?

Well, that makes me feel like they're not talking to me. I'm just gone. That they say it makes me feel. I would just say I don't know who in the world you're talking to or about, but I'm out of here. ■

Barry

What was your life like in the institution?

I didn't like it at all. Noise that went on around over there. I went berserks over there. I had no kind of chores there but I did have a job, which is at [a sheltered workshop, the same place I work now].

What is your life like in the community?

First of all, I'll get up and I'll dress and then I'll make my bed up. Then I go downstairs and sit at the dining room table and drink coffee. Then after that, I get ready to go to work. [When I come home from work] first of all, we go upstairs and take a shower. That way, we'll feel better after that....We have one person that cooks and another one that'll wash them up. The one that cooks will assist....

The main thing I like about it is I love living here. I have friends here. I live with three other guys. I'd like to live in my own apartment....I have at least one [close friend], and that'd be [a woman] over next door. We'd sit together a lot while we were there. Socialize. Other things like tell each other about what happened back in our lives as we were growing up....

I love my job and I love what I'm doing. I put in bottom turner fasteners on the carts we work on over next door. I had to mark and punch holes for them, and then set them in. Well, they're used for the army. But after I get through with putting them fasteners in, I send them off to the next sewing machine over from me. And then they have to go all the way through and send them on back to where they put them in boxes and put them on a pallet until we get ready to send them out to wherever they go to. [I'd like to work in] a grocery store. ■

"The main thing I like about it is I love living here. I have friends here. I live with three other guys."

Barry

Denise and Debbie

NOTE: Denise and Debbie met at a state-operated institution as young children. They say they were brought up together, and they now live together with one other woman. Debbie used an electronic communication board to talk with the interviewer.

What was your life like in the institution?

Denise:

No friends. Not really....There's some things we went to that we had to go in as a group. That was really hard....

I worked in the workshop. I worked on the screws. You put washers on the screws. Put them in a bucket and see how many you can get. They counted them. Yeah. They put them in a box. It was boring....

[The day I moved out] was good. It felt real good. It was warm, rainy. Birds. We picked our home and roommates.

Debbie:

We were not given many choices of activities. They were always planned for us, without asking our opinions. You never got to visit with friends without a hundred other people around....

At the workshop, the jobs were boring but I enjoyed seeing my friends. At the time, I wouldn't have changed anything about my job because I didn't know there was anything better....

I moved from [the institution] 7 years ago and I loved living in my home from the beginning, but I missed my friends a little at first. I wasn't really afraid to move into the community. I have visited my new friend two times before I left, and I was really excited about moving and having my own room.

What is your life like in the community?

Denise:

I live in a really nice house and I have my own room. I got a real job and I have a dog. I like living with my roommates. Well, I love them....[I'm] playing games, going shopping, going sometimes to the movies, going to work, dancing....

I love my job. I'm a guest server. Help people find things that they need or little lost kids. I love people and I love kids. They don't bug me. It felt good [looking for my job]. It made me feel more like a person. What I like the most about having a job is making my own money.

Debbie:

My favorite thing about living in the community is that I have my own stereo. I like everything about living in the community. There really are no typical days. Each day is different, but each week I learn and there's a reading class one day and communication therapy once. I go to a group session every other week. I enjoy my days....

My closest friend is Denise. Denise and I have known each other for many years. We lived together at [the institution]. She is very nice and helpful, and she has a kind heart. I enjoy talking with Denise and working at the store with her. I also enjoy going to parties and movies and other things in the community with her....My staff never gets in the way of my friendships and they are very supportive of that....

I like everything about my job. I use a scanner to check the prices of the items and make sure the prices are correct. What I like the most about having a job is making my own money. The only thing I would change about my employment is that I would like to work more than two days per week. ■

Mark

What was your life like in the institution?

Well, basically what I can tell you is mostly is very, very, very weird times because you're put in with some people that had real troubles, and you better – I mean, I can say that it was very, very bad in some ways, and some ways good in others. Well, some of them I used to live with were very good. I basically tried to get along with the good and the bad, too. I mean, I never got any grudges. I had this one friend named Tommy that I got along with real good. I had some others that I was fairly close to. Some of them stole from me, steal things. They would steal things that didn't belong to them. It was like you couldn't have any money on you hardly....

I basically thought I didn't need to be there because I obviously knew a little bit more how to handle situations. It sometimes was hard to relate to some people on the outside because when they would come to visit, I always felt kind of loose. I always got the weird feeling kind of because you were closed up inside a ward. If you've ever been in one of those [institution] cottages, you can relate to what I mean. I wish they would have had People First, or had a group similar to this, to where we could have all got together years ago. I mean, I think it's a good thing....

[I had a close friend who] always told it how it was. He was always very, very direct, but he had a very very kind heart. We got along great. I mean, we had our disagreement every now and then but it wasn't bad enough to hate him. I enjoyed listening to him....There were two things that I like doing with [friends] – listening to music and going to the camp. Going to the camp and some of the Special Olympics were really fun. Oh, most of [my friends] I met at the People First thing [outside of the institution]. I mean, we're allowed to do that at least. I mean, we had to wear a pin and certain things you couldn't do. There were certain colors that you'd wear....

I would say most of the staff I ever worked with, I always got along with them. I didn't have – I mean I had problems with certain people but they weren't real abusive towards me. But like some of the clients would try to tell lies on the other, and they would always try to get even or settle the score. Some of them were really good and some of them I wasn't so comfortable with....I would have to say I did [see abuse]. That's why I say it's half and half. I mean, it could be provoked from both sides. It doesn't mean I'm playing favorites when I say that, either. Because if anyone were abusive to me, I would have turned them in. That's the way I would have been. When you see staff lean on clients, it's hard to recall because some of that stuff you don't want to recall, unless you're under oath in a court. I can understand that because a lot of it I didn't really see but, from what I did, it was pretty rough. You couldn't always get away from it. [I didn't like] the way some of them approached me. They approached me real mean and I didn't like it, or real abrasive type of deal.....

Some of the time I did [work]. I worked in the recreation department. I got along pretty well with the people. Basically what I did there is I answered the phone, took phone messages, or tried to. I run errands around the campus to different cottages. And then I also worked on work adjustments. I didn't really like that very well. Because you made very, very little money. It's like the workshops that they have now, but basically piece-rate. You had to be really fast so you could make any money. I had

"I like [my home] very much, and it's lots better than the institution. I like having my own room and my own stuff without having to worry about somebody getting up and stealing it...."

Mark

wished it was, I guess, more money and more hours there, but I don't know if that makes any sense or not....

Some of [institution life] I did [like] and some of it I didn't, so it was about half and half. I think it taught some discipline to those that were troubled maybe. You didn't always know what they were going to do because I've had people jump me before as of that example. I mean, I didn't have to say anything or do anything, and the next thing I know, some were hard to control. It was hard to predict what they were going to do from the next minute to the next. I don't know if you can relate. Yeah, I mean some of the clients would accuse them [the staff] of beatings. I'm not saying it didn't happen. What I'm saying is some of it was provoked because they would sometimes go and push the staff, and some times clients could be at fault too. So it could work both ways....

[The institution] was like a jail. Is that a polite way to put it? It's like you're on a jail camp with fences around and you always had to get visitations just to go with somebody. How's that for people? I wish they'd have had homes and things like this that they could train people... [I'd like to see] more freedom there for the ones that are there, or have more options for them available to try, you know, to let them know that there are supported living or assisted living or independent or whatever. Make sure that they know there are options out there other than the institution. So how many of them have they closed so far?

What was it like moving out of the institution?

It was different [moving out] because I didn't know really what was available. Some of it was scary, but yet I was glad to get out of the institution because I took the first available thing I could find to get out of that. It was fun, but sometimes scary. It took awhile getting used to. I was afraid of what people thought of me because being in an institution, I guess. Some people still aren't accepting us into the community, but we have to try to do our best to change that....[Now] I pretty much overlook the people and what they think. I mean, I'm always open to opinions from both. So I just look at it and think they don't know any better and they aren't educated, if that makes common sense....

Actually, when I moved from the institution, I went to a group home and I lived there for about 5 years. After that, I moved back up here. Then I went, so far as living, to the companion program. [I was] not very comfortable. Just having to drag a bunch of people with you when you had to go somewhere, if that makes sense. Like if people see you with a bunch of people, they made you feel kind of weird, you know, if that makes sense....

What is your life like in the community?

I like [my home] very much, and it's lots better than the institution. I like having my own room and my own stuff without having to worry about somebody getting

up and stealing it....I usually get up and go to work. I basically get ready for work. I try to plan a little bit of my day but sometimes things can change, as we all know. That's basically about all that I do....

Well, I basically work in the back [of a department store]....I check price and fix prices if they're wrong. I've worked there almost going on 6 years. It'll be 6 years in May. I would hope that more employers are educated on this because it could be a very good experience, sometimes a very frustrating experience, depending on how you really feel about the job. When I first started there, I did customer service helping people, so I liked that very, very much. Well, I like partly being able to get paid every week. Partly being able, I guess, to be a taxpayer, although sometimes I don't think that it's fair. When people just work part-time at a job and take half the paycheck but that's not for me to say. I would like to have some days off where I know what I'm doing in the schedule when they get off. The way it is right now, I have to call first to see if there's a schedule and then I have to call the night before and see if there's enough stuff to do for me to come in....

Well, I either take the lift or I either get somebody to take me somewhere. That's basically how I get around is probably the transportation or somebody takes me to these things. I just like being able to say yes or no if I don't want to go....

I have a very, very close friend. I have known her for about 5 years. It's a pretty good relation. Well, she's very, very understanding to the things that I have to say, and very very kind, if you could relate to that. She has a couple kids, a third one on the way.... I met some of [my friends] at Special Olympics back when they used to do track and field, which they don't do here anymore. I think that they should put that back in as an option for us, but who am I to say? Because when they tell them age-appropriate, what do they mean by that, I guess is my feeling....I go out to bars occasionally. I do that. Just go out to different activities and things. You couldn't go in there [bars and dances] then and have a drink like a normal person. I just like being able to have the freedom to go. There's more choices whether you want to go or stay or stuff like that.

I like the freedom to be able to choose my own clothes and being able to go out to restaurants, which we didn't do much of that at [the institution)]....One thing I don't have to worry about is someone beating me up or trying to knock me down, if that makes any sense. I mean, I know there's cruelty out in the community... I like being able to be terribly happy most of the time. I try not to stress about too many things. ■

"I like being able to be terribly happy most of the time. I try not to stress about too many things."

Mark

Their Stories . . .

in the
words of
family
members
and staff

Shawna

As told by her mother

What was her life like in the institution?

We placed her in [the institution]. When I took her there, it was like 6 weeks before I could see her again. I had to sign a lot of papers and do the paperwork. I did tell her that I would see her before I left, but after everything was said and done and I went back to see her, I couldn't see her because they were getting her ready. So I told them that I didn't want to leave until I saw her because I told her I would say good-bye to her. I knew at this time she didn't understand what was going on. They said no, that I couldn't do that. So I told them to get her ready and that I would just take her home, that I wouldn't leave her. So they said I could go back and see her, so I went back and told her good-bye and left her. Then when I did go out to visit her, it's like a big waiting room out front. When you went in and rang the buzzer, you had to wait. They brought her out. No one was allowed back in where the kids were. This went on for quite awhile until I decided I wanted to go back, so I just opened the door and went in because I felt like, you know, they were hiding something. I wanted to see how she was doing, what was going on. I would bring her home every 2 weeks – every other weekend.

What is her life like in the community?

Now that she's been out in the community, she gets out, she goes shopping, they go eat, they go places. She likes spending money. She's happy. She's really happy. Shawna likes it better in the community than in the institution....She likes new clothes. She likes getting her hair done. She likes to look nice. She likes her fingernails painted. She likes looking pretty, smelling good. She'll let you know if she doesn't like something. ■

"She's happy. She's really happy. Shawna likes it better in the community than in the institution...."

Shawna's mother

Steven

As told by his mother

What was his life like in the institution?

When he turned six, they had told me I needed to make some long-range plans because he was going to need a lot more help and a lot more training. At the time, [the institution] was the only answer that I had, so I took him there, which was one of the hardest decisions that I ever had to make in my life....

Even all the years that I'd go pick him up from Friday to Sunday, I'd always come back crying on Sunday when I took him back because we just relived it every week, you know, because you were so frustrated because you couldn't provide the services at home for him. That was your only choice and you knew it. You knew that it couldn't be any other way; that was the only way. It was the most frustrating thing. It just took a piece of you at a time over the years, you know, to do that. It's not something that you make a decision and you walk away and you never have to make it again. This was a decision that I had to make and I had to live with it week after week after week. I hardly ever missed a weekend through the whole 13 years, so they knew me. They knew....

Generally, I was in a dilemma. What I saw was okay. I knew that it wasn't what I wanted, but there was not so much anything I could do about it in a sense. I couldn't have accepted him being abused or anything like that if I knew of it. So I had to in my mind know that they were doing the very best they could with the circumstances....

[When I heard the institution might close] I was scared. I was really scared because you have to realize I was a single parent that had gone through relatively all of Steven's life....It wasn't really until more into the allegations and the closure that I found out there was a lot more involved. That's probably why it helped me to go ahead and make my decision. Then I decided that I would rather do this on my own than someone force him out and things. I knew that if I got him out when this first started, then probably I would have a little more say-so in what went on and I would learn as I went.

What was it like when he moved out of the institution?

I could truly say that once they really found out what the facts were, they wouldn't want them in an institution. Not so much that you're always pointing a critical finger at the institution because, all in all, probably there's a lot of dedicated people there that are trying to do the very best they can. But normal is normal. It wasn't really until more into the allegations and the closure that I found out there was a lot more involved. That's probably why it helped me to go ahead and make my decision. Then I decided that I would rather do this on my own than someone force him out and things. I knew that if I got him out when this first started, then probably I would have a little more say-so in what went on and I would learn as I went.

I developed some friendships with people that were a little further along in their understanding of community living than I was. I had a lot to learn. I had some good teachers, so that's what helped me: the good teachers that I had and some parents that really were a lot further along than I was. Then I went out and visited community programs and saw what it was to live out. My whole way of thinking became different. I just knew that Steven had those rights for life, liberty, and the pursuit of

happiness just like I do. He was no different. It was just that there had to be a vehicle or a means for him to have those things....

I got to visit some of the early placements, and I got to see it didn't look so bad them being in their own home with a real couch and a rug on the floor. I knew there was going to be a lot of decisions to make, like especially what kind of agency. So I interviewed. I always interviewed. Everything I go into, I don't take just what they give me. I was looking for safety factors and love and no abuse and so that he had plenty to eat. I knew that I'd be over there all the time, and I wanted it to be close. Mostly, I wanted him to be in as safe an environment as I thought he was housed in a big institution where he couldn't get out the door and run away and get hit by a car. I wanted his care and I wanted for them to be able to nurture and love him when I wasn't there and all those things that you would just look for in any kind of thing where your loved one was concerned....

What is his life like in the community?

Steven and his roommate have staff all the time because they need a lot of help. Both of them. The two of them do real good together....

Though it was not my own decision that he had to go to public school, it was best for Steven. I had my misgivings on him graduating, going through the graduation ceremony, because I knew he may not understand it. So I let him go through the graduation and the most wonderful thing happened. All the kids wanted to make sure that I let him go through the ceremony. When they went through and they called his name ...when he went up there, they gave him a standing ovation. It was one of the most wonderful experiences I've ever had. He had made all of these friends and they all knew him. They all knew that he had a disability and they knew that he wasn't going to go to [college] next fall or whatever. A student teacher volunteered to walk across the stage with him. He wouldn't put his hat on, but that didn't make any difference.

I also let him go to the senior prom, which you have to understand I'm a real conservative kind of person. I guess I didn't want it to be not appropriate because he wasn't able to tell me he wanted to go to the prom. A lot of it I had to make the decisions but I decided to get his tuxedo and let him go simply because the kids, the student body, was asking about him if they were going to go. He enjoyed it....

We had joined this little small Methodist church. Steven and his roommate were the first two people that came into this church with disabilities. Steven makes funny little sounds and kind of hollers. At first, everybody kind of looked at him like what's gonna happen here. But the longer we went, the more they got used to just Steven and his roommate, so we just became a real part of this church....Steven was baptized 2 weeks ago. Talk about an emotional time. Steven doesn't have the concept of church or anything like that, but I just wanted him to be baptized. So anyway, there wasn't a dry eye in the house when he was baptized. When he stood there, he was so good. So they baptized him and he turned around with just the most beautiful smile and looked around at everybody as if to say well you know this is really special. I explained that was something special between him and God. It was just a real neat experience...

"He has so many things now that he never had in an institution. And most of it's freedom. He's just got freedom. That's what it is. It's freedom. He's got freedom to do whatever he wants to do, and he didn't have that in an institution...."

Steven's mother

"I think, as a parent, we're all protective and we want our children to have the most safe everything that they possibly need...I can understand those parents being afraid. I was afraid too, but you've got to get past that."

Steven's mother

[While living in the institution] Steven never just got to go to MacDonald's if he wanted to. He just didn't get to go to the mall. He didn't get to go out and look at Christmas lights. They would plan a bus tour when they all went maybe once a season, but he has so many things now that he never had in an institution. And most of it's freedom. He's just got freedom. That's what it is. It's freedom. He's got freedom to do whatever he wants to do, and he didn't have that in an institution....

Now, Steven isn't able to talk for himself with words, but I know that he's happier. Sometimes we make those decisions for our kids and we don't really realize that maybe an institution wasn't the right decision....I just want him to be happy and healthy, and I want other individuals just like him because there's thousands of them out there that don't have any parents.

What advice do you have for other parents?

If these parents would just go out and visit these placements or if they would get involved in a program that we have here at Tulsa Arc called Oklahoma AIM (Advocates Involved in Monitoring), if they would just get involved in that, then they would be able to go visit these placements and they would see the real world. They would see what it's like. I'm not saying it's always perfect because it never will be, but it's a whole lot better quality of living.

I think, as a parent, we're all protective and we want our children to have the most safe everything that they possibly need...I can understand those parents being afraid. I was afraid too, but you've got to get past that. You've got to look out and say, "I can be afraid and go through this or I can be confident and go through this." And that's the way it is.

I've always been kind of protective of Steven, like everybody is. I'll never forget one time when we went to the park. They had a merry-go-round, one of those swinging merry-go-rounds. My sister was with me. My sister's more of a do-it kind of person. I'm more of a thinking kind of person before I do it. I said, "No, he can't ride that merry-go-round; he'll fall off." So Steven looked up at me as if to say, "Mom, I want on that merry-go-round." You could just see it. My sister said, "I'll get on the merry-go-round and hold him. He won't fall off." So Steven went on the merry-go-round. It was just what he was waiting for. You know, sometimes you're afraid to get on that merry-go-round because you're afraid you'll fall. But, if you have some supports to hold you on, you can ride it.

So, if you have the supports, you don't always have to depend on what you as a parent can be. You've got to look out beyond what you can do into something that someone else is able to help you do. That's how I see community programs. We can help develop them, but it shouldn't always depend on us to have to make the outcome. It has to be everybody kind of working together. ■

Carrie, Linda, and Barbie

As told by staff who had worked with them at the institution and who are working with them in the community

What's different here compared to the institution?

It's interesting the control that's in play in people's lives. I think somewhere I saw an estimate that it would take someone 70 years to meet all the criteria to move out of an institution and into the community. You had to jump through all the hoops that they want you to go through....

You know, one thing that did make it a lot easier when they moved into this home is a lot of the staff that work out there, some of them work part-time here, so the staff came here and they already knew some of them. We still have some of them that work part-time that have known the girls for 4 or 5 years. So I think that made the switch probably a lot more easier because they were used to seeing the same people. We didn't just put them in a house where they didn't know anybody. So there was always somebody here for the first 2 weeks that the girls knew already. It was kind of a way for the ladies to feel comfortable with the transition as well as the staff because they were able to get some on-site training from some folks who really knew them and had for a long time.

As a matter of fact, some of their furniture they brought with them. Like their decorations – Kathy had a home interior party here at the house and invited friends and staff and everybody who came over. So they selected their own decorations from that. For instance, Barbie has gotten new bedroom furniture since the time she's lived here and is getting ready to get a new recliner that she's going to be able to select.

[We] had brought them over to look at the house before we signed the lease or anything like that to make sure that it seemed like a place that they would be happy. Barbie and Linda were just beaming from ear to ear. We were saying we want you to just see if you like the place. Carrie went with her walker down the hall in every room and every closet, checking them out. The staff at the institution would come along and people that knew them really well were saying they are crazy about it. It was like when we put them back on the van to go back out to [the institution], Carrie started hollering and she was holding out her hand like "I want to go back! I don't want to leave!" So that kind of pretty much made it clear that she understood this could be her place if that was what she wanted, and she was all for it.

What are their lives like in the community?

It's calmer here [than at the institution]. It's not as hectic as it is up there. Like I said, everything is pretty much on a schedule up there. Here, it's like coming to your own house. Yeah, a lot more relaxed....

Things that everybody has, we have. We invite over their friends that they have. We would like a little more interaction with their friends from their previous housing, where they were at, because they enjoy meeting all their people, their friends. You know, the world is busy today, and we're busy also. It's not just everybody else, but it would be nice if we had a little more interaction with friends. They get out and go with us and we take them. I should not say – we could go out there and visit their friends....

We try to take them out into the community, like this summer we went to the rodeo. We like to take them to the zoo. Barbie and I went up at that Brent Price arena. They had Indians dancing and we went up there on a Saturday, and she seemed to enjoy that. They went [camping] to Salt Plains. They just went for the day. They didn't stay all night. They were going to stay all night but they quit for the day....

"It's calmer here. It's not as hectic as it is up there. Here, it's like coming to your own house. Yeah, a lot more relaxed...."

staff

We work in the garden. They love – they're just ornery when they get outside. Carrie Kay – she'll take the hose and she puts it down her shirt and on top of her head. She just loves it. Barbie – she would sit outside in the grass. She likes to sit in the grass. It doesn't bother her. Linda – she's very cold-blooded, so when she's outside and when it was 102 this last summer, Linda would sit on the patio. She just loves it. We had tomatoes, tomatoes. Yeah, they have a favorite little bunny that they see when they're having breakfast or dinner. The bunny loved our cucumbers last year. We just saw the bunny the other day. We were sitting at the table, yeah....

Here, they'll get pretty much whatever they want [to eat] and we know what they don't like. There are certain foods that Carrie doesn't like and certain foods that Barbie doesn't like, so it's not "eat this or you're not going to get anything." We can just pretty much fix them what they do like. And there's lots of things out there that they never got, like pizza and stuff like that that they love now. Yeah, we order pizza out sometime and we get chicken sometimes or fish, and they like that too, getting something that's already made and just brought in. They like ice cream and stuff that I'm sure they didn't get out there a lot....Carrie is getting pretty skilled at going right out to the refrigerator and getting something to drink for herself, which is not an opportunity she had before. They didn't really have access before to a kitchen. Now, when they want a snack, they just can go....

They got their VCR with their phone company refund. Yeah, because Kathy called me and said we got this money, do we have to put it in the bank or can we all decide on what we'd like for the house if they could all share. I said whatever you all decide you want, you go ahead. So she called back and said we've been talking about we want a VCR. I said well, then you all go get one!....

They're working at [a photocopy service]. The business is just now getting off the ground. They're not fully operational yet but they've been out there about three weeks, a month....With Carrie, [what she likes best about her job is] probably just leaving the house and getting out. She likes to go. She'd be upset if everybody left and she had to stay home because she likes getting out. She could work seven days a week. She likes to get out and go....Linda is not employed. As a matter of fact, we're having a meeting this next week for Linda to get started....

Things here aren't like on a schedule like they are out there [the institution]. You know, you do things at certain times, where here they go to bed at whatever time they want and it's not you have to do this at a certain time and take a bath at a certain time. It's not nearly as rushed here; they can just go at their own pace....Behavioral-wise, Carrie's a lot more relaxed and she doesn't have outbursts like she used to out there, and Barbie too. She used to tear shirts a lot when she'd get mad and things, and she very rarely does that. I recall them saying there were periods of time where Barbie would not eat for extremely long periods of time. Yeah, but there's some times where she'll go a few days not wanting to eat that we'll have to feed her. I had heard out there that it was to the point where she ended up in the hospital. I don't know if that's true. I think just their level of independence, too. Carrie goes out there and does laundry and, like I said before, gets something out of the refrigerator. Just never had the opportunity before to do that. ■

Stories of Staff...

in
their
own
words

Terry

NOTE: Terry is a QMRP who worked at a large, community-based institution. She is a residential director for an agency that provides group home living and assisted living to adults with mental retardation and other developmental disabilities.

What was life like at the institution?

[For the residents], when you walked in these doors, what you were is what you stayed. You didn't advance. You didn't grow because it's just what everyone knew you were and what you could do, and it was difficult for people to see beyond that....

Dignity equals privacy. Without privacy, there is no dignity. It's hard even in a house of 10 people to have privacy, but in a house of 200-plus people, it's impossible. Everybody knew everything about you. So if you did something that was horrible momentarily because you were just tripped out, then everybody knew and no one would let you forget....

How can you take a bath when there's 199 people in your living room when you come out? There's no dignity there either. I don't care how cute that robe is. There's just no dignity there....

When you're trying to reconcile what you've known was a good thing and then what you're seeing now, as far as things you would or wouldn't agree with, how can you agree with 20 people living on a hall, you know? How can you agree with doors being locked and people being forbidden to go off the campus here unless you were a certain level or whatever. So some people who had proven themselves or came in and figured out that if you were a good guy, they got to do things. But then some people who are just learning how to do things, it was hard for others to say okay they can have an opportunity to do this or do that....

I serve a lot of the people that I served while I was [at the institution] or that I knew while I was there. Actually, when I worked there, I worked with people who were considered severely profound and they lived in the back units. So I was one of those back people, too. Right now I am residential director for an agency that provides group home living, but also assisted living. The difference is that as long as I can keep everyone's opinions out of it except the person that we're talking about, then no one has any limits. There are some fences around our house or their lives. They are people who can live with as much help or with as little help as they desire. I sleep a lot better knowing that I contribute to that as opposed to contributing to people being left at night in these [institutions]. ■

"When you're trying to reconcile what you've known was a good thing and then what you're seeing now, as far as things you would or wouldn't agree with, how can you agree with 20 people living on a hall, you know?"

Terry

Steve

NOTE: Steve started working at a large institution in 1990 as a recreation therapist. He now works as a recreation therapist in the community.

What was life like at the institution?

I always enjoyed working [there]. The staff always – at the time I got there, they were at a point where they were trying to make it better. The attitude was let's make it the best we can make it every day until our individuals move into the community. That's kind of how we did things. We had never moved people into the community before. It's kind of neat because we've seen a lot of changes, and even living arrangements changed....I think when I arrived [there] in 1990, they'd already had the order to start getting ready to close, so the staffing levels were up. At that time, it was five individuals to one staff person. So they were pretty well helped out through the day as they needed. Like I say, they weren't getting a lot of individual attention because when you have five individuals – you know, the staff person may want to do a cooking lesson but you've got two individuals that are wandering away and three that are really wanting to be involved.

Towards the last year when [the institution] was open, we started having more community groups that wanted to come in and do activities and get more involved with our individuals with disabilities and just really come in there. We had the Girl Scouts come in and do a big picnic. All the Girl Scouts and [others] came out and put on a big party for everybody. We had a lot, like I say. The Friday night dances were a lot of fun...

You know, it was very stigmatized when we'd go out in the community because there would be 35 or 36 of our individuals and about 15 staff. So we went in a group of about 50. So it was hard to get a lot of community integration and interaction when you've got 50 individuals all coming out in a community setting like that....When we go out now on leisure outings with one or two individuals, you don't get the stares. You get a lot better social acceptance. Interaction is almost always a lot more positive. They just are one of the crowd, and that's the way it should be because it is their right to go out for leisure activities and be in the community. I just think it's great to see community acceptance starting to build and grow. Eventually, it'll be that people with disabilities – that everybody's used to being with people with disabilities in the community, and it won't be a thing that that's a person with a disability. They're just people like us. I think it's getting better.

What is it like working in the community?

At first, we just put our individuals out in houses in groups of three and four. Now, our individuals are living in all kinds of arrangements. We have anywhere from you could live in your own apartment with staff as needed, or you could live with a family and that family would be provided support for taking care of our individual with a disability, and just be a family member living in their household. Or, we have the supported living arrangements where we still have a lot of our individuals living in three- and four-bedroom houses together. So we think it's neat that people are making changes, and they're making choices on who they want to live with....

[One] difference is that in the institution, the big focus in sporting events was the Special Olympics. That's

where our individuals participate in track and field. They've done that their whole life growing up. When they've moved into the community, we've been working on trying to get them more involved in sporting activities with the normal population. Now, a lot of our individuals are participating in unified sports leagues where, for example, they're bowling with a partner that is not disabled, or they're in a softball team where half the team has disabilities and the other half of the team doesn't have disabilities. These sports leagues are really good because, first of all, they build community awareness, and they build acceptance of our individuals with disabilities in the community. But also they teach our individuals skills in learning how to work with people and learning how to perhaps learn the skill of playing softball, which they never had a chance to do before. Now, through learning those skills in the sports leagues, we've had several of our individuals who have moved on. They're not in unified sports leagues anymore; they're in regular softball leagues that play with you and I during the summer, just like everybody else. We have folks that still choose to participate in the Special Olympics, but that is their choice because they've participated in it their whole lives. But we also have individuals that run in the 5K mile, in the runs around Tulsa, so a lot of our individuals are really participating in sporting events in the community, and that's really exciting to see. Like I say, that just promotes more community awareness and acceptance....

A lot of our individuals are going back to school and getting their GEDs. We have some individuals that are taking college courses in universities. We also have individuals taking classes in community education to learn new skills. So it's kind of neat to see that in the community, they're encouraged more to find their own educational opportunities, and we provide the support that's needed to be able to help them find that....

A lot of people in Oklahoma have been able to educate our senators and our representatives on the needs of people with disabilities, and it's because of groups like People First of Tulsa and Oklahoma People First. Now, not only do our individuals stand up for their rights and call their congressman and talk to them about what they need in their lives, but they also plan conventions on disabilities and what it's like to have disabilities, and about awareness and educating people in what it's like....

I would like to see that all of our individuals have the right to be involved in any program that they want to be involved in, and that they're provided with the support that's needed. A lot of our individuals in the community still want to do things. It's not always easy to fulfill all their needs. So, what I would like to see is the supports provided where individualized transportation could be there. If a choice was needed to be made that they wanted to go to the naturalist meeting that night and yet the other three ladies wanted to go to the mall shopping, that transportation would be provided so that they could go do what they wanted to do. Also, I'd like to see that the staff continue to learn about rights and responsibilities of people with disabilities, they should talk to them in people-first language, and always be encouraging and helpful and supportive but don't do things *for* our individuals. Let them do as much as they can do for themselves. ■

"When they've moved into the community, we've been working on trying to get them more involved in sporting activities with the normal population. Now, a lot of our individuals are participating in unified sports leagues."

Steve

Conclusion

Everyone we interviewed who had formerly lived in an institution was glad to be living in the community. Although there were challenges in community life – challenges not entirely unfamiliar to anyone negotiating life with roommates, public transportation, and budgets – no one with whom we spoke wished to return to the institution. When the necessary planning, monitoring, and support are in place, these experiences of successful transitions from institution living can reoccur across the country for many, many more people.

Improving communication across professions, providing more training and information related to individuals with developmental disabilities, and identifying effective means to increase availability and accessibility of services and supports will be critical to continue successful community integration. To insure a successful transition from institutions to the community and a successful life in the community, it is necessary for people who are in charge of facilitating the transition to remain focused on the person who is moving. Additionally, they need to be committed to supporting people in the lives that they want, to ask questions that tell them what should be present and what should be absent in the life of the person, and to be flexible and fluid in setting up services and supports. When assisting groups of people to move from institutions to the community, the following questions should be answered:

- What is important in relationships with others? What people should be present or absent? What material things are wanted? What are the activities that matter?
- How can specific issues of health or safety needs be addressed with the least compromise to how the person wants to live?
- How can the person get the life described at a cost that the system can afford? (Smull and Burke-Harrison,1996).

Smull and Burke-Harrison further explain, "Once the first two sets of questions are answered, the settings that will and will not work for the person become clear. The challenge is then to support the person in the life that they want at a cost that the system can afford. The better the description of what is important to the person, the more possibilities emerge for how they can be supported (p. 23)."

As supported living becomes more accepted, hopefully institutionalization will become less accepted and, as a result, people will leave private and public institutions and nursing homes at a faster pace than the current rate of deinstitutionalization. However, the goal is not to move people out of institutions at any cost. Rather, the goal is help people get the lives that they want with the appropriate supports and services needed to live a simple, ordinary life that permits them to practice their inherent and inalienable rights, among which are the preservation of life, liberty, and the pursuit of happiness.

Appendix: Methodology

THE PEOPLE

People First of Oklahoma and VISTA volunteers worked with the author to collect personal stories through face-to-face interviews with 26 adults with mental retardation and related developmental disabilities and with 3 parents and 8 staff. Nineteen of the 26 interviews were with the individuals, five interviews were with the individuals and a family member or staff who assisted them in answering questions. Two interviews were conducted with the individuals' mothers. Due to the quality of the audiotape or the difficulty in understanding the speech patterns of several individuals, we were unable to use four interviews. As a result, 22 personal stories are reported within the monograph.

PROCEDURES

Interviewer training. Interviewers were self-advocates from People First of Oklahoma and VISTA volunteers. Each interviewer was paired with an advisor or the author to provide interviewers with support and assistance. These pairs were called teams. Teams attended one, six-hour training session. Teams viewed a 90-minute videotape titled, *Interviewing: The Role of the Interviewer* (Mathematica, 1975). The videotape discussed topics that included roles, interviewer bias, and probing. Afterwards, the videotape was discussed and additional information about specific interview techniques were reviewed with the interviewers. Following the videotape, the teams were provided with a general overview of the study and a discussion of the survey instrument that included a review of each question. Afterwards, interviewers were provided with the opportunity to practice interviewing through role-playing. Each interviewer was observed while they conducted the role-play and was provided feedback on his or her performance.

Data collection. The coordinator of People First of Oklahoma identified individuals and families from around the entire state who wanted to participate in the study. A schedule was developed for the teams. Teams were given an audio-cassette player, cassettes, and survey questionnaires. All interviews were face-to-face and were audio-taped. All tapes were transcribed and edited to include relevant information.

Survey instrument. The author conducted a one-day focus group with representatives from Self-Advocates Becoming Empowered, the national self-advocacy organization, to develop questions for the face-to-face interviews. Representatives were asked to develop questions that related to the five life areas: home, employment, relationships, community, and dignity and attitudes. The final set of questions were the following:

HOME

1. a. Tell me about your home. What do you like about it? What don't you like about it?
   b. Tell me about the people you live with now. What do you like about them? What don't you like about them?
   c. Tell me about the staff that work with you.What do you like about them? What don't you like about them?
   d. What is the one thing you would like to change where you live right now?
2. a. Tell me about the institution you use to live in.What did you like about it? What didn't you like about it?
   b. Tell me about the people you use to live with in the institution. What did you like about them? What did you not like about them?
   c. Tell me about the staff that worked with you at the institution. What did you like about them? What didn't you like about them?
   d. What is the one thing you wanted to change at the institution?

EMPLOYMENT

1. a. Tell me about your job that you have right now.
   b. What do you like the most about the job?
   c. What do you like the least about the job?
   d. What is the one thing you would like to change about your job?
2. a. Tell me about the job you had at the institution.
   b. What did you like the most about the job?
   c. What did you like the least about the job?
   d. What was the one thing you wanted to change about your job?

RELATIONSHIPS

1. Who is your closest friend? Tell me about him or her.
2. What do you enjoy doing with your friend?
3. Tell me one thing you and your best friend do together that is fun.
4. Where do you meet your friends?
5. Do you ever have problems going out with your friends?
6. Do staff ever get in the way of you and your friends? How?

When you were at the institution,

1. Who was your closest friend? Tell me about him or her.
2. What did you enjoy doing with your friend?
3. Tell me one thing you and your best friend did together that was fun.
4. Where did you meet your friends?
5. Did you ever have problems going out with your friends?
6. Did staff ever get in the way of you and your friends? How?

COMMUNITY

1. When did you move from the institution to the community?
   What was it like at first?
2. What things were you afraid of when you first moved into the community?
   Are you still afraid of these things?
3. Tell me about a typical day in your life.
4. What are some of the things you do now that you didn't do when you lived in the institution?
   What are some of the things you did at the institution that you don't do now?
5. What is your favorite thing about living in the community?
   What is the one thing you dislike the most about living in the community?
6. What was your favorite thing about living in the institution?
   What was the one thing you disliked the most about living in the institution?

DIGNITY AND ATTITUDES

1. What do you like most about yourself?
2. What one thing in your life would you most like to change?
3. What does the word "retarded" mean to you?
   How does it make you feel when you hear it?
4. Who do you admire the most? Why?
5. What does it mean to you to have a disability?
6. What is one thing you have done that you are proud of?

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