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ABSTRACT

This paper offers advice, from members of People First, concerning the process of having individuals with disabilities move out of institutions and nursing homes into community living arrangements. The first section lists categories of questions that express the potential concerns and worries of people who are going to move, such as "Why do you want me to move?" "What about the people I'm leaving behind?" "Is the place I'm moving to going to be right for me?" "What if it doesn't work out?" "What if I want to make a change?" "What about money?" "What will I do during the day?" "What will I do about getting to the doctor and the dentist?" "Will I have the chance to learn the things I need to know to look out for myself, to be more independent, and to get involved in things?" and "Will I be able to continue to get the help I need for as long as I need it?" Within each category, more specific questions are listed, concerning such issues as privacy, safety, jobs, and personal budgets. A second section outlines ways in which disabled individuals can help individuals who are moving out of institutions and nursing homes, such as inviting new people to do things together and telling people how to handle certain problems. (JDD)

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**MAKING A MOVE
ADVICE FROM PEOPLE FIRST MEMBERS ABOUT HELPING
PEOPLE MOVE OUT OF INSTITUTIONS AND NURSING HOMES**

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Making A Move
Advice from People First Members
About Helping
People Move Out of Institutions & Nursing Homes

In 1990 almost 800 people will begin moving from state institutions and nursing homes into community living arrangements like intensive tenant support, tenant support, adult family homes, and group homes. People First members who have already made the move have important information to share with the people who are moving

On Saturday, 4 March 1990, members of People First Chapters from Pierce and Thurston Counties had their regional meeting. About 40 People first members came and participated in a four hour workshop about how People First can help the people who will be moving from nursing homes and institutions. Connie Lyle O'Brien and John O'Brien* helped with the workshop by asking questions, by recording People First members ideas on big sheets of paper, by checking back with people to make sure they were understood, by grouping together the things people said and making summaries to check with the whole group, and by putting together this record of the meeting. When they made this record of the meeting, Connie and John used the big charts and the summaries that they made during the meeting. The ideas and most all of the words in this record are People First member's own. Connie and John have sometimes combined what different people said about the same issue and they put some of the points people made into the form of questions to the people who are helping someone to move.

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What questions concern people who are going to move?

Many People First members have moved from institutions, nursing homes, and congregate care facilities into their own apartments or into adult family homes or into group homes or into boarding homes. From our experience, we can say what some of the questions and concerns and worries people moving from institutions and nursing homes might have. Everyone has their own questions and worries and concerns. So what's most important is that the people who are helping someone move listen carefully to discover what's important to each individual. No one will have all these questions; and nobody could listen to all the answers at once. So it won't work to just dump the answers to all these questions on people. But by listening and talking to each person—and by having each person talk to People First members—those who are assisting a person to move can figure out how to tell the person what he or she wants and needs to know.

Not everyone may be able to understand the answers to all these questions. That doesn't matter. What matters is that the people helping someone to move have good answers to them.

One People First member pointed out that it's hard to remember if she had all these questions in her mind before she moved. Probably some of the questions come from things that happened after People First members moved. But the whole group agreed that these are good questions. And one person said, "if a person can't ask these questions himself, somebody else should ask them for him."

? *Why do you want me to move? And why now?*

? *What does my family think of this move? How will my family be involved? What if my family wants something different for me than I want for myself?*

- "My parents put me in here. Will they be mad if I move?"
- "I haven't seen my parents in a long time. Will they keep me from moving?"
- "Will my parents know where I am? Will they come and visit me?"
- "Will my brothers and sisters come and see me in my new place?"
- "I really wanted to go back to live with my mom and dad. I couldn't. But nobody ever explained to me why."
- "Will I live near my family?"
- "If I live away from family—like my nieces and nephews—will someone help me go and visit them?"

? *What about the people I'm leaving behind?*

- "Will I get to see my friends from here after I move?"
- "I don't think anybody should be in the institution. And I feel bad about leaving people behind. Why me and not one of them?"

- “I speak up for other people here. Who will do that when I move?”

? *Is the place I'm moving going to be right for me?*

- “Will it be safe?”
- “Will it be quiet? What if the people upstairs are noisy?”
- “Will I have privacy?”
- “I don't like it to be too quiet. What if I want to be (sort of) noisy (like having a party)?”
- “What will the rules be?”
- “What chores will I have to do? What will I have to do about cleaning and cooking?”
- “What if I don't get along with my roommate? Like if they are too noisy for me or if they take my things?”
- “What if I don't get along with the adult family home provider or the staff people? How will arguments with them get settled?”
- “I like to take baths, not showers. Can I?”
- “Will I be able to decide what I want to eat and when to eat?”
- “Will I be able to decide when to go to bed?”

? *What if the place I move isn't right for me? What if it doesn't work out?*

- “What if a staff person hits me? What if my roommate or another resident hits me?”
(This has happened to People First member, both in institutions and nursing homes and in facilities located in the community.)
- “What if people just don't treat me right?”
- “What will happen if the place closes?” (This has happened to a number of People First members since they moved out of the institution.)
- “If things go wrong, will I have to go back to the institution? Do I get another chance?”

? *What if I want to make a change?*

- “Now I'm in an adult family home, where I first moved from the institution. But I want to go to my own apartment. How can I do that?”
- “Are there enough apartments and tenant support program staff so that people who want to move can?”
- “Some people seem to have a long wait to move. They wait at home with their parents or in group homes or in adult family homes for a chance to move to their own apartment. How do I make a change if I want to?”

? *What about money? How will I afford to live outside the institution?*

- “Where will the money come from?”
- “What do all the letters and numbers mean –like ‘SSI,’ and ‘Section 8,’ and ‘Title 19.’ More important, how will they work for me.”
- “What will I have to do to get my money from these places? If I don’t have to take care of getting the money, who will? What if there is a problem with my money coming; will I get kicked out?”
- “How much will the rent be? What if the rent goes up and I need more money?”
- “Landlords want deposits. What is that for? How can I get it back?”
- “What if you are in an apartment and something breaks (like the refrigerator). Who will fix it? Who will pay to get it fixed?”
- “How will I decide how much to pay for food and clothes?”
- “Will I have any money left over for myself?”
- “Where will I keep my money safely? I kept mine in a lock box, but somebody stole the box.”
- “What if I need help with my budget?”
- “My sister gets my check but sometimes she doesn’t give me the money she’s supposed to. How do I get control of my own money?”

? *What will I do about getting to the doctor and the dentist?*

- “Will there be a doctor to see me who will understand my seizures?”
- “How will I pay for the doctor and the dentist?”
- “What will I do if the doctor or dentist won’t take medical coupons?”
- “What will I do if I need treatments that medical coupons won’t pay for?”

? *What will I do during the day?*

- “Will I have a job?”
- “Will I get paid?”
- “What will happen to my wages? If I work will I lose my other money for rent and visits to the doctor?”
- “If I lose my job, how will my rent get paid?”
- “Do I get to choose my job? If I don’t, who does and how will they know what I want to do?”
- “If I don’t want a job do I have to get one?”
- “If I don’t get I job, what else will I do during the day?”

? *Will I have the chance to learn the things I need to know how to look out for myself, how to be more independent, and how to be involved in things?*

- How to know the rules and the laws that you and other people have to live by.
- How to know and stand up for your rights or get help from someone else if you can't speak up for yourself.
- How to be safe: traveling, crossing streets, keeping away from unsafe places, keeping windows and doors locked, etc.
- How to handle your money. This is very important because people don't have very much.
- How to get good deals on furniture and things for the house (like dishes).
- How to save up for things; how to put things on lay away; how to buy things on time (and not get ripped off).
- How to keep your place clean and smelling good.
- How to keep yourself clean and smelling good.
- How to find out what's going on in the community – like recreation programs and sports and activities and the library.
- How to get places in the community.
- How to get involved in People First.

? *Will I be able to continue to get the help I need for as long as I need it?*

- "It takes time for some people who have lived in institutions and nursing homes to get used to living more on their own."
- "There are some things some people can't learn to do for themselves even if they try. Those people need help."
- "I've been out of the institution a long time. I have a job. I'm married. I have an 11 year old daughter. But I still have difficulties that I need help with and I still need assistance with my money."
- "Everybody needs somebody they know they can trust."

What can People First do to help people who are moving out of institutions & nursing homes?

- We can set up a People First Welcome Wagon. Members can meet people when they are visiting a new place to live and when they have moved. Members can collect and share information about transportation, about recreation, about community activities, about good places to shop, and about how to use places like the library.*
- We can invite new people to do things with us, like have dinner, or play cards, or just come over and watch TV.*
- We can tell people about how we have gotten jobs and how case management and other programs work.*
- We can tell people about what to do if they have a problem. People need to know they can go to their case manager or come to People First.*
- We can be sure to reach out and include new people in People First Chapter activities.*
- Those of us who are on boards and committees can be sure we meet and listen to people who are moving. Then we can find out how things are going for people who are moving (and people who have to stay behind in the institutions and nursing homes). Then we can speak up for people if problems come up.*
- We can get involved in the Quality Assurance teams and find other ways to monitor the services people get to make sure they get the help they need to learn what they need to know and to get involved in things.*
- We can be sure the People First Handbook about housing is up to date and has the kind of information people will need about leases and ways to pay the rent and the rights of tenants. We may have to do another handbook or add a section about adult family homes. People First members on quality assurance teams could distribute the handbooks to people who need them when they visit.*
- We can share information about our experiences with parents and guardians of people who are now in institutions and nursing homes.*
- People First members educate the whole community about how people with disabilities are contributors when they do their jobs well, when they are active in boards and committees and community activities, and when they are good neighbors.*