

# **COMMUNITY BUILDING IN LOGAN SQUARE**

*How a community grew stronger with the contributions  
of people with disabilities*

by Mary O'Connell

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The Community Life Project,  
*Project of the Neighborhood Innovations Network*  
Center for Urban Affairs and Policy Research  
Northwestern University  
2040 Sheridan Road  
Evanston, IL 60208

John L. McKnight  
*Principal Investigator*

Kathy Bartholomew-Lorimer  
*Project Director*

Rosita De La Rosa  
*Field Researcher*

Mary O'Connell  
*Research Writer*

**THE COMMUNITY LIFE PROJECT WAS FUNDED BY:**

The Department of Rehabilitation  
Services  
State of Illinois  
623 E. Adams  
Springfield, IL 62701  
(217) 785-0218

and

The Chicago Community Trust  
222 N. LaSalle Street  
Suite 1400  
Chicago, IL 60601  
(312) 372-3356

## **I. Communities, Big-City Neighborhoods, and the People Who've Been Left Out**

Most Americans live in big cities, but our myths center around an ideal small-town past: a place where people sipped lemonade together on the front porch, watched out for the neighbors' kids, shared the work of the town and the fruits of their gardens. These images, still powerful despite exploitation in a thousand advertisements for fast-food franchises and tasteless beer, touch a collective vision of community. Garrison Keillor has lovingly (and sharply) drawn the details in his stories of Lake Wobegon, the mythical Minnesota town of his youth. Keillor also draws the contrast with big city life, which he and most of the rest of us have chosen; of his exile from Lake Wobegon, he writes:

*I haven't lived there for twenty-five years. I've lived in a series of eleven apartments and three houses ... in St. Paul and Minneapolis. Every couple years the urge strikes, to pack the books and unscrew the table legs and haul off to a new site. The mail is forwarded, sometimes from a house several stops back down the line, the front of the envelope covered with addresses, but friends are lost — more all the time, it's sad to think about it. All those long conversations in vanished kitchens when for an evening we achieved a perfect understanding that, no matter what happened, we were true comrades and our affections would endure, and now our friendship is gone to pieces and I can't account for it. Why don't I see you anymore? Did I disappoint you? Did you call me one night to say you were in trouble and hear a tone in my voice that made you say you were just fine? (pp 19-20)*

Many Americans lament the loss of neighborliness, the disappearance of community that sometimes seems an inevitable consequence of big-city life. For some, the lost community is not a small-town past, but "the old neighborhood," "the way things used to be": before the neighborhood "changed" and friendly faces on the street were replaced by strangers. Other people simply find that sustaining

community life is difficult in the face of poverty, violence, drugs, gangs, racial tensions, fear: common problems that plague neighborhoods in every city. Such problems make people harken back to memories (or myths) of a place where people knew one another, looked out for one another, and shared what they had even if (especially in city slums and ghettos) there wasn't much to share.

In part, this book is about one effort, in one Chicago neighborhood, to try to build a new sense of community.<sup>1</sup> It's about shared work and shared pleasure, about intimacy and celebration, about taking time to know one another and look out for one another, about accepting things that cannot be changed. It is a story of small beginnings, but beginnings that carry a hope of regeneration.

The book has a second focus as well: it looks at the experience of people who have often, by neglect or by design, been shut out of communities. These are people who are "different" in some very visible ways from most other people: because they don't talk, or they move awkwardly, or act differently, or can't quite handle ordinary tasks the rest of us take for granted. Such people have been labeled in different ways (mentally retarded, developmentally disabled, handicapped). All the labels focus on what is "different" about them, and obscure what about them is "the same" as the rest of us: the same needs for dignity, for pleasure, for friendship, for a sense of the future and a place in the community. The differences and the labels have been a justification for deliberately taking these people out of their communities and placing them instead in social service institutions where people are trained (and paid) to help them.

In recent years, people have questioned whether such institutions really help the people they are supposed to serve. And other people have questioned their huge costs. Those questions led to "deinstitutionalization": many people were

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<sup>1</sup> This report was based on experiences through September 1989.

moved out of big institutions and into what were supposed to be "community settings." In Chicago, that meant in practice that people were put in halfway houses and group homes, usually in neighborhoods they had no previous connection with. Some of these people ended up on the streets. Others stayed with family, but often still remained isolated from other social contact. Others found themselves in group homes that were officially located in "the community" but really had no contact with what was going on in the neighborhood all around.

People like Pete, for example. Pete, a man in his forties, lived most of his life in a large institution until it was closed down a few years ago. Now he lives in a group home. Physically Pete lives in a neighborhood, but he isn't part of it. He doesn't know his next-door neighbors, and people on the street don't stop to talk to him (even though he is friendly and responsive if you do). If he got sick or died, nobody in the community would even know he was gone. He is as isolated in the "community setting" as he was in the state hospital.

This book brings together these two themes: it is about building community, and about finding a place in the community for Pete. It tells the story of a small effort called Community Building, and what happened during its first year and a half in a Chicago neighborhood, Logan Square.

## II. Getting Acquainted

**Community Building.** The Community Building effort had its origins in a research project at the Center for Urban Affairs and Policy Research at Northwestern University in Evanston, Illinois. The purposes of the work are, first, to examine ways that people around the country have found to bring people with disabilities into the everyday life of communities<sup>2</sup> and second, to try to achieve this kind of integration in a Chicago neighborhood.

Although the work started in a university, it is not primarily an academic endeavor. And although, in the popular view, people with disabilities should be taken care of by social services, the Community Building effort has remained separate from social service agencies. That's because, in the experience of the people involved in the work, the connection of this kind of work to social services usually means disconnection from typical community life: a person is pulled off a path of a community member and onto a path as a client. The magnitude of this disconnection has been a major finding of the research to date. It was also felt that being a member of a community is different from being a client of an agency or institution.<sup>3</sup>

Instead, the aim has been to work with a neighborhood organization. Neighborhood organizations are voluntary groups where neighbors come together to work on common problems: getting new stop signs and better police service, stopping the spread of drugs or graffiti, fighting housing deterioration, working to

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<sup>2</sup> For more information on this, see *Gift of Hospitality*, by Mary O'Connell, Center for Urban Affairs and Policy Research, Northwestern University, Evanston IL, 1988.

<sup>3</sup> This paper is in no way an argument against formal (paid) support in people's lives. Many people with disabilities need formal support to enhance and make possible a life in community. It is, however, a criticism of services by social service agencies that segregate and group people. Segregation isolates people from community and diminishes personal autonomy, choice, dignity, and access to community.

keep local banks, shops, and employers investing in the neighborhood. Usually (though not always) they have small paid staffs, long agendas, and a history of having to fight hard to accomplish anything. The decision to work with a community organization offered a chance for contacts and connections with people involved in their community as citizens, and was also a way of distinguishing this work from traditional social service work.

**Logan Square.** Logan Square is located on Chicago's Northwest Side. It is a racially and economically mixed neighborhood: Approximately 60 percent of the residents are Hispanic (including Puerto Ricans, Mexicans, Cubans, and South and Central Americans); people of different European backgrounds make up most of the rest. Economically, residents range from middle-class professionals to low-income families struggling to keep up with rising rents.

Logan Square is not a "typical" city neighborhood (it's hard to say exactly what would be typical). But it does have some patterns that are common in other neighborhoods and illustrate what people mean when they talk about loss of community. First, it's a "changing" neighborhood — and has been for some time. The changes are complex. When the Hispanics moved in, many older Anglo families moved out. More recently, parts of Logan Square have been facing the pressure of "gentrification," as more affluent families, attracted by its graceful older homes and convenient location, are buying in (and pushing housing costs up). The consequence of all the changes is a good deal of cultural and linguistic diversity. The changes are reflected in its institutions, particularly churches. Its older, established congregations with the solid brick buildings often have dwindling memberships; many parishioners have died or moved away and the newer residents haven't joined those churches. Storefront churches that cater to Hispanics, on the other hand, are thriving; but they can lack the stability and the resources of the older churches.

Second, there are many young people in the neighborhood. High dropout rates and gang violence are particular problems; in consequence, many agencies have established youth service projects in Logan Square. Overcrowded schools are another problem for which neighborhood residents and school councils are struggling to find a solution.

Third, some neighborhood residents for a variety of reasons don't participate actively in community life. There are many poor and elderly people on fixed incomes living in the neighborhood; one newcomer to the area observed "lots of people struggling and in need." But the neighborhood is also home to many young, affluent professionals who typically lead very busy lives and have little time for participating in community life; they mostly work, shop, and socialize outside the neighborhood.

**Logan Square Neighborhood Association.** The decision to work in Logan Square was based partly on the fact that the Logan Square Neighborhood Association agreed to play host to the work. Founded in 1962, Logan Square Neighborhood Association works on issues of concern to neighborhood residents: housing, education, and gang crime/drug issues are paramount. Working through LSNA meant that the Community Building effort would have a recognized identity in the neighborhood and, through LSNA's membership, access to the community.

Like many community organizations, those in Chicago in particular, LSNA has a history of organizing "against" something. Historically, such groups bring people together who are angry about something: high taxes or rents or utility bills, poor city services, crime, failing schools, deteriorating housing, denial of credit for home mortgages or rehabilitation. The neighborhood organization mobilizes people to demand something they believe is due to them: better police protection, access to credit, improved schools, etc. A strong (and often explicit) theme in such work is power: neighbors must organize to achieve a collective power strong

enough to challenge other powerful interests (city government, corporations, slum landlords, etc.) — just as unions, for example, organize workers to achieve collective power to challenge the power of the employer.

The Community Building work, on the other hand, is not about conflict or power in that traditional sense. Instead, it is about a second kind of power: the power to take care of our own, to be responsible for one another. It involves reaching out to people, bringing them together around a common, positive purpose, building relationships — and in the process building the strength of the community.

This orientation was potentially something of a stretch for the community organization. They agreed, however, to allow the work to proceed under LSNA auspices. According to two board presidents — one past, the other current — their reasoning was that the Community Building work was consistent with a central purpose of LSNA: to overcome differences and bring people of different backgrounds together. Says Joel Monarch, past president, "It wasn't typical organizing, where you have an enemy and you press them to make changes. But this was a constructive project, that was about including people who've been left out. We felt it was consistent with our pluralistic approach, to make sure everyone is represented." Deborah McCoy, current LSNA president, says, "One of the biggest barriers in organizing is fear: fear of people who speak a different language, or whose skin is a different color, or who have a handicap — all of those things that make us different from each other. The more people in our community learn to reach out over these differences, the stronger our community will be."

When Nancy Aardema, LSNA's executive director, took over that job, she pushed to have the relationship between the Community Building effort and LSNA made clearer, and to get LSNA to take responsibility for the work. As a result, the

LSNA board committed itself in spring 1990 to carrying on the work and to raising money to support it.

**Neighborhood people.** Once the decision was made to work in Logan Square, the first step was to find out about the community itself. We spent time reading, studying, driving around, talking to people, trying to learn everything we could about the neighborhood and the people.

We were particularly interested in the associational life of the neighborhood: What groups and institutions do people belong to: churches, block clubs, park programs, boys and girls clubs, ethnic associations? To find out, we did an exhaustive survey, taking information from local newspapers, church and community leaders, and a telephone survey of selected blocks. We found 575 groups organized in the neighborhood or that neighborhood residents belonged to, everything from the 33rd Ward Democratic Party and the Palmer Square Arts Fair committee to an affiliate of the LaLeche League and a charismatic prayer group. Unfortunately, many of the groups existed on paper only, and/or were not doors for building relationships.<sup>4</sup>

As part of this first step we were looking to find neighborhood people who might be interested in getting involved in the community building effort. We were looking for people who live in the neighborhood and are "well connected": that is, they have family and friends, are active in local churches or parks or block clubs, and so on — the sort of person "everyone knows." We were also looking to identify people with disabilities who might be isolated and want to meet new people and become a part of the community.

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<sup>4</sup> For more on this part of the work, see "Getting Connected: How to Find Out About Groups and Organizations in Your Neighborhood", August 1988, available from the Center for Urban Affairs and Policy Research at Northwestern University.

After an opening presentation to the board of LSNA, we began talking individually to board members: they seemed a likely place to begin identifying "well-connected" people in the community. We first asked people to tell us about the neighborhood: how long they'd been there, what they knew of its history, how it had changed, why they lived there and what they thought were important values of neighborhood residents. We asked them about how people got to know each other in the neighborhood, and what kinds of things they personally were involved in — clubs, churches, relationships with neighbors, and so on. We then introduced the general idea of community building, and invited them to get involved. Finally, we asked them for names of other people: community people like themselves who might want to get involved, and people with disabilities they might know about.

These original interviews gave us a great deal of information about the neighborhood. People told us about how they had first come to Logan Square, what they remembered about it, how they had seen it change, what their fears and concerns were. We also learned about different groups and organizations from the "inside" — we found, for example, about once-strong churches that had lost most of their members and were groping for ways to relate to newcomers in the neighborhood; or about organizations that existed on paper but had little active involvement. Several people expressed a sense of having lost the sense of neighborliness: said one woman, "we used to leave our doors unlocked; now we build fences." On the other hand, we also heard stories about hospitality and neighborliness; people really enjoyed talking about their community and reflecting on what it means to them.

The interviews also gave us additional names of community people to contact. We followed up each one of these, mentioning the name of the person who had recommended us, and repeating the process: introducing the work, inviting participation, asking for information about the neighborhood, about the

person's community involvement, and asking for names of other people, with and without disabilities, who might be interested. Eventually, through this "trust network" of personal contacts and referrals, we talked to over 100 people. All these contacts and conversation elicited a handful of community people who were willing to get personally involved. They became the basis of the first. Community Building group (described below).

All the people who initially accepted the invitation to get involved are women.<sup>5</sup> Most are in their thirties; they have families, jobs or school commitments, and in general very lead busy lives. Here's how one woman, Mary Ellen, described her decision to get involved:

*It sounded like a wonderful project; but I have three kids, I'm going to school full-time, etc., etc. I didn't know if I had the time. But the vision captured me, and I said o.k.*

That theme of "busyness" — people being overcommitted, having too much already on their plates — came up over and over again in the interviews. Several people expressed genuine interest in the idea, but then backed off because they were unwilling to take on another commitment. People felt they had enough work already, in their jobs, families, and communities; getting involved seemed more like "work" than like an extension of friendship. But that's not the way Mary Ellen sees it: "My life hasn't got any less busy since I've known Pete. But I have another friend. In fact, I've met many new friends through this project. It's funny how friendship multiplies itself."

**People with disabilities.** We also asked everyone we talked to whether they knew any people with disabilities who might be interested in becoming involved.

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<sup>5</sup>Though some men, especially pastors and some of the LSNA leadership, offered support in other ways.

We wanted, not only to find people, but also to find out how a community would identify its own members who are disabled.

The overwhelming majority of community members didn't know anyone with a disability. Some people knew of someone perhaps they had seen around, but they didn't know a name or a way to contact them. A few people did know the name of a person, but didn't know the person directly — they usually knew the parents. But the most common response, when people were asked about people with disabilities, was to refer us to a human service agency or program — not to a specific person there, but to the place itself.

This kind of consistent response is very revealing: it indicates that community people see people with disabilities as "belonging" to some kind of human service. Beyond that, there was also a sense of confidence that such agencies were good places, doing good things for people. The general public perception is that people with disabilities are special people, needing special places with specially trained people with them — and "special" really ends up meaning separate. This myth offers little motivation for community members to even wonder at the absence of people with disabilities in their personal lives and in typical community life.

We did follow up the few people with disabilities mentioned in the interviews, by talking to them and their parents to see whether they wanted to get involved. None of these referrals went anywhere, for a variety of reasons. First, many of the parents were suspicious of an invitation coming from a group (LSNA) that had nothing to do with disabilities; their experiences led them to believe that their son or daughter needed professionals who are trained in the field of disabilities. The invitation itself — to get involved in the everyday life of the community — was also foreign: in fact, the whole notion of their son or daughter having friends who were not part of the world of disabilities was strange. And the

nature of social services in Illinois backs up those concerns: there is little effort at community integration and few community services; those that do exist are often segregated — that is, they congregate people with disabilities. The consequence is that parents have almost no vision of any other kind of life for their son or daughter.

Having failed in this effort, we next contacted "special" groups (not agencies) affiliated with neighborhood institutions: for example, special church services or park district fitness classes for people with disabilities. Over half the families contacted this way were interested in the work. The fact that the initiative came from a "special" group that the family already understood — rather than a group in the broader community — apparently gave it legitimacy. However, of the six people identified in this way only two are still involved; two of them moved out of Chicago, one person ran away, and one family quit and their son now lives in an institution.

Finally, we also contacted human service agencies. People from three of these agencies have been involved in the community building effort. The connection to the social service agencies has created some tensions, which we discuss in a later section; but it also proved to be the most effective way to identify people with disabilities.

From this work, we identified twenty-five people with disabilities who wanted to find some way of connecting to the community around them. Their stories, and the stories of the people who welcomed them, are told in the next section.

### **III. Making Connections: People to Know and Places to Go**

**People to know.** Clara, Connie, Mary Ellen, Nora, and Jane are part of a community building group in Logan Square. Each of these women (and their families) has built a relationship with a person they met through the Community Building effort. They've gotten to know that person as an individual. They didn't start with a label or a diagnosis ("retarded," "developmentally disabled," etc.). Instead, they met the person first, got to know something of their life history, spent time with them, found out what makes them laugh, what makes them angry, what they look forward to, and — probably most important — what they contribute to others around them.

Clara, for example, is friends with Alice. The original connection was simple enough: Alice loves jewelry — she wears rings on all her fingers — and Clara used to sell jewelry. Clara is a lively woman who works for a hospital, the president of her block club, politically active, smart and articulate. Alice is a gentle woman with a ready smile who lives at home with her elderly parents. Now Clara takes her shopping, or invites her over for dinner — simple things like that. Clara has a lot of demands on her time, but makes some time to spend with Alice. She also thinks about what other kinds of things Alice can be involved in — she's had her sign up as a deputy voter registrar, for example. And she worries about what will happen when Alice's parents die.

Connie and Julie have become friends as well. Connie is a homemaker who loves gardening, a warm woman with beautiful long red hair who is a ready neighbor for many people in Logan Square; her husband Joel was the president of LSNA. Julie is a woman in her 30s who has lived in group homes since she was nineteen; until she met Connie, she had no friends outside the system, although her family live in the suburbs and see her regularly. Connie takes Julie out to dinner, to movies, museums and plays, and spends time with her every couple of

weeks. Julie enjoys doing those things; she also enjoys her association with Connie and Joel. Julie can be very articulate about the problems of life in a group home, and Connie has come to share those concerns — she has acted in some ways as an advocate for Julie.

Nora has taken Catherine into her life — almost made her part of her family. The connection is important for both of them. Nora, is a woman in her 30s with young children who is finishing her nursing education. Nora was born in Germany, and both she and her husband live far away from their own families. Catherine is in her 70s, and she too has been isolated from her family (though she remembers them vividly); she has lived almost her entire life in a large state institutions. Catherine is a "grandmotherly" woman who loves being with Nora and especially her children; and the children respond with love as well. Nora explains it this way: "Because our parents and grandparents live very far from us, she represents a grandmother for our family. The love the children and she feel for each other is nurturing all of them. She not only fills a gap in the lives of our children, but in ours as well. I have always been committed to community group work, but this relationship has taught me something new.

Mary Ellen has become friendly with Pete. Mary Ellen is another lively, energetic woman: an artist and political activist, raising children and going to school full-time. Pete has lived most of his life in a state mental hospital; since it closed down, he has lived with six other men, including his brother, in a group home. Pete is a man of few words but great enthusiasm: he especially loves good food and music. Mary Ellen has also taken Pete to Cub games (another place where enthusiasm pays off: to Pete, every hit is "A HOME RUN!") and has involved him in her political activities, getting him to help out with mailing projects at the local office of SANE/Freeze.

Besides spending time with each of the people they've met through the community building effort, Connie, Clara, Mary Ellen, Jane and Nora get together occasionally in one another's homes, often around a meal, to talk about what they're doing and what they're learning. Kathy Bartholomew-Lorimer, who works on the Community Building staff, meets with them. Kathy was the one who originally invited them to get involved in this effort, and she introduced them to Alice, Julie, Pete, Catherine and Scott. We'll talk more about these meetings in [cross reference].

**Places to Go.** The Community Building effort has also brought other people into community by directly involving them in a particular setting in the neighborhood. Here are a few of their stories.

Lorraine is a woman in her 60s who lives in a group home. One thing she especially likes is going to church. She used to attend services with her mother, who died a few years ago; now going to church reminds her of her mother. *The Episcopal Church of the Advent* has welcomed Lorraine to its congregation — not to a "special" service for disabled people, but as a regular member. Lorraine's introduction to the church came about through Mary and her mother, Jessie, both long-time members of the congregation. When Mary was first asked if she would take Lorraine to church, she was reluctant to take on the responsibility on a regular basis. "Once I met Lorraine, there was no way I could not take her to church," Mary says now, praising her friend's enthusiasm and her genuine ways. Lorraine loves the liturgical rituals, especially exchanging the "kiss of peace"; when the Bishop visited the parish for a special service and gave the blessing right by Lorraine's pew, Lorraine enthusiastically waved back at him. Lorraine has been welcomed by the pastor and the rest of the congregation; the Sunday services and other church activities have become a high point in her life.

Henry, who is seventy, has lived in a group home for the last several years; he spends a lot of his time watching television. One thing he likes to do is go bowling (Kathy Bartholomew, on a visit to the home, discovered a bowling ball among his things). Kathy asked around and discovered that St. Sylvester's Church has a Sunday afternoon bowling league, and that one of the teams would be willing to have Henry come bowl with them. The participants are all Puerto Ricans many of whom speak mostly Spanish, and Henry is Italian, but that doesn't matter as much as it might, since Henry doesn't talk much anyway. While the team was initially willing to have Henry join them, they got worried when they discovered he isn't all that good a bowler — this is a competitive sport, after all, and they didn't want their average pulled down. However, they worked out a deal whereby he could bowl in rotation — right after team captain Eddie Vargas — but his score wouldn't be added in with the rest. He is especially proud to wear the black-and-gold team shirt. Henry was originally brought to the bowling alley by a member of the Community Building initiative, but when she couldn't make it team members started taking him. At the end of the 1988-89 season, Henry attended the league banquet. He was delighted when the members awarded him a trophy and a black satin St. Sylvester's jacket, and he got up to thank them for making him part of their team.

Maritza, a woman in her mid-twenties, lives with her family and was involved in a day program for people with disabilities, where she spent her time on coloring and pegboard to keep busy. But she has much to offer. She is a warm woman who loves little children. Kathy Bartholomew began bringing her to Lutheran Day Nursery, where the director was willing to see if Maritza could help out. At the beginning, Kathy went with her each time; now Maritza goes by herself twice a week. She is called "Miss Maritza" by the children and staff. As any daycare worker knows, little children need a lot of hugs (which sometimes the worker may

be too busy or harassed to give). Miss Maritza is one the children go to for comfort and affection; she is never too busy for a hug. The children understand that Miss Maritza is different in some ways from the other teachers — she is the one adult the children sometimes have to help. But children enjoy being able to help adults. Interestingly, being around the children and partly responsible for them has helped Maritza become more personally assertive and independent.

Bill, a man in his 30s who lives at home with his parents, has been going to Norwegian American Hospital twice a week. Bill works in the mail room under Joe and delivers the mail on the first floor. This task is a tricky one for him, since he can't read, so the mail room staff have worked out a special color-coding for him to follow, and people in other departments have learned to expect him and watch out for him (and their mail). Bill loves being a volunteer: he loves wearing the vest and the volunteer badge, and is convinced "this place couldn't run without me." Bill is a great talker, and once prepared an elaborate report on how the mail room should be reorganized, which Joe takes with calm consideration. Joe has driven Bill home from the hospital and stayed to dinner with his family, and he is willing to get involved in talking about Bill's future.

Harold is a man in his late twenties who loves to play games and has some uncanny abilities (immediately after he's introduced to you, he can spell your name forward and backward). For the last several months, Harold has been a volunteer in the game room at the Boys and Girls Club, where he helps out with the games and teaches them to the children; he's also involved with the Palmer Square Arts Festival. Staff at the Boys and Girls Club nominated him for a "volunteer of the year" award. Sometimes Harold gets confused about whether he's there to teach the children the games or play them himself, but mostly that's not a problem.

Linda lives in a state institution, and she hates it. Linda's mother Maria asked Kathy Bartholomew for help. When Kathy discovered that Linda loves

animals, she arranged to have Linda spend some time each week at Animal Kingdom, a well-known local pet store. The arrangement was almost destroyed before it got started, however, when a professional at the hospital told the pet store owner that Linda had problems that might interfere with her role at the pet store. The pet store owner and his wife discussed this with Kathy, then decided to go ahead anyway. So far it's worked fine: Kathy takes Linda to Animal Kingdom once a week. Instead of being isolated in the institution, Linda spends her time surrounded by people. She shows animals to customers and helps with daily duties. Linda has a hard life inside the institution, and she desperately wants to get out. The people at the institution have told her she can only get out if she goes four months without displaying any aggression; given the nature of the place and what goes on there, that may be impossible. Linda tells Kathy: "Every night I go to bed, I say, I've got my boyfriend, my mother, and my new friend Kathy. And I've got to hold onto them and keep myself together because that's the only way I can get out of here." Linda, her mother, Kathy, and representatives of a local social service agency are now working to get Linda out of the institution for good. But they want her to live and be supported in Logan Square as a neighbor, not as a client. This means that the social service agency will support Linda in a more personalized way.

In each of these places (and there are many more examples), a community place has opened up "space" for a person with disabilities who would otherwise find most such spaces closed. In some places (for example, the church, the bowling league) the person is welcomed simply as a participant, a member of the group. Other places — typically those where there's a job to do — have created valued roles for the person who goes there: Maritza, for example, has become "Miss Maritza" to the children at Lutheran Day Nursery, and Bill glories in being the mailman at Norwegian American Hospital. In all the places, there's been a willingness to accept someone who may slow things down a bit, or create a few extra complications; in

exchange for that, people recognize the warmth, friendliness, and enthusiasms that the new person brings as something valuable to the community as a whole.

Usually, there have been one or two people who have especially taken the lead in welcoming the new person: the kind of role Mary played at Church of the Advent, or Joe at Norwegian American. In some cases, that's taken a fair amount of courage — it was certainly courage that enabled Bob and Sandy at the pet store to welcome Linda despite warnings from the state hospital.

In this chapter, we've told stories about the different ways people with disabilities are being connected into some aspects of ordinary, everyday life in Logan Square. They break down into two major ways:

- Community-building groups, which concentrate on relationships between individuals and families, and bring together those involved into a mutual support group.
- Affiliations with local churches, recreational groups, businesses and service agencies, where the person is welcomed as a valued member of the group.

Although the participation of the person with disabilities in most of these situations by now seems natural and unexceptional, it didn't come about naturally. The barriers that keep people out of community life and in segregated systems are strong. The fact that these barriers have been broken through in this handful of situations in Logan Square came about through many months of determined, persistent work by Kathy Bartholomew-Lorimer and Rosita De La Rosa of the Community Building effort. Kathy and Rosita first introduced to people the idea of community building, found (after hundreds of hours of conversations) people and local institutions willing to participate, made the introductions, and went along each time, for many months, to smooth the way. Over time the new person is welcomed and participating on his/her own without that kind of support; but until then Community Building staff are still directly involved week-by-week.

This is just one small effort, affecting a few dozen people out of the three million people who live in Chicago. Moreover, nothing about these relationships is fixed and permanent (any more than any real-life relationship is guaranteed permanent): the people described here aren't fit into a "slot" or arranged in a formal "program." Instead, these are informal relationships that are likely to change over time; what's presented here is really a snapshot of one moment.

## IV. Difficulties

The preceding chapter tells success stories; the ease in telling them gives the illusion that they were accomplished with ease. But they weren't. There have been many difficulties along the way, difficulties that illustrate some real issues about community and exclusion in American life today.

### 1. FROM THE COMMUNITY SIDE

**Too much to do already!** This was probably the single biggest barrier preventing people who were attracted by the idea from following through and getting involved. To some extent the problem was built into the work. We set out to look for people who were well-connected in the community, with rich, full lives that they might share with someone whose life lacks that richness. We found such people — but discovered that a "full" life meant just that: not much room for anything else.

It's significant that most of the people who got involved in the community building groups, for example, were women balancing multiple roles: working or going to school, raising a family, participating in community activities. And most people were in their thirties, a time when various life roles are likely to converge all at once: marriage, parenting, relating to your own family (parents, siblings, etc.), being involved in a career (or career preparation, as in the case of the women who attend school), owning property, being established and active in a community. Several people originally got involved in one or another of the community building groups, then pulled back when they feared it would just add one more demand onto an already too-busy life. The segregation imposed on people with disabilities only accentuates this problem: because people at first tend to see them as being somehow especially demanding, and see getting involved with them as a kind of work — rather than an extension of friendship.

But the problem of people being "too busy" is a broader one, and certainly is one factor behind the kind of breakdown of community that so many people lament. As more and more people spend more and more of their lives in the paid labor force, more of the "ordinary" work of life — raising children, preparing meals, caring for the sick, building porches and fixing plumbing — must be paid for because there is less and less time for ordinary people to do it. The work that can't be paid for — filling the obligations of citizenship or of neighborliness — suffers. For many people, so do the personal "tasks" that are important for personal growth: such things as reading, crafts, making music, or spending time with friends. Jackie, who's involved in one of the Community Building groups, commented: "My life is busy, crazy. I'm in graduate school, I have so little time for fun or relaxation. ... But spending time with Maureen is something I look forward to. We do things I normally wouldn't do, like going to a museum or a restaurant. It's something 'scheduled in' but not mandatory."

**What if...?** Many, if not most, people with disabilities live in some kind of group setting, and are therefore seen by outsiders as part of a group, to be viewed with pity or fear. Added onto that are the effects of segregation, which breeds ignorance that in turn gives rise to fear — the kind of fears one often sees expressed when a new group home is proposed in a community. Will "they" harm me or my family in some way? Will they run away? If something happens, will I be responsible? Will they do something that will be embarrassing, that I won't know how to control in some way.

Reinforcing such fears is the belief that the "experts" know how to deal with such people, and that ordinary citizens might make a mistake that would have some dreadful consequences. And often the experts reinforce such fears. That's partly because experts are used to seeing people strictly in terms of their labels and limitations: they can tell you all about what is wrong. But what they don't know or

talk about much is what is valuable and lovable about this person — affection toward children, love of animals, the ability to bowl or spell backwards: the system is not designed to celebrate such qualities.

The segregation imposed by the social service system can be self-reinforcing, as it keeps people in communities from knowing or reaching out to people with disabilities.

**We've got a job to do here.** Just as individuals are busy and reluctant to get involved, so many businesses and institutions in society are organized in ways that make it hard to include people who are slower or less articulate or less mobile than the rest of us. Of all the community places that welcomed people with disabilities, the easiest were the ones you would expect: the churches (though even in churches there are stories of rejection, as we shall see). The men in the bowling league were (understandably) concerned that Henry not reward them by bringing down their bowling scores — though that required just a little ingenuity to fix. The Boys and Girls Club, the hospital, the daycare center, were all willing to make some space for people, though it took some adjustment. But businesses proved a much tougher arena to crack.

Rosita De La Rosa brought Tomas to several restaurants and bakeries, trying to find a place that would allow him to come and help out in some way. None of them worked out, until she finally got him involved at the police station where people have accepted him.

Most of the small businesses felt they had work to do and couldn't afford to have someone around who could help a little but might interfere or limit employees' productivity. The same issue was raised by the director of an organization with offices in the area, where Kathy brought Pete. The director expressed concern that an occasional visit by Pete would interfere with office

routines, lower productivity, and impose an extra burden on already overworked staff.

A related issue that some employers raised was that of liability: if something goes wrong while Tomas is here, could he sue us? (Again, that same segregation-enforced fear that somehow the person with disabilities is a special problem, an accident waiting to happen.) That concern was even raised by one volunteer group. Susan belongs to a dieting group, of which she is a faithful participant. The Community Building initiative has a slide show illustrating all the different places people had found in the community; the slide of Susan at the group meeting made one woman nervous: what if this gets us in trouble with the national organization? What if we lose our charter for getting involved in this? (To which the other people in the group replied "What's your problem? This is no big deal!" And Susan responded by giving the woman a kiss, which may have soothed her concerns at least temporarily.)

We don't want her kind around here. Some people just plain do not see the value of welcoming people with disabilities into their community: they're convinced they belong in special, segregated programs. It's less common than one might think, but it happens.

Susan experienced one such rejection. Susan joined a faith-sharing group at a local church. She participated for several sessions, and the people in the group made room for her and accepted her eccentricities. But one day she became sick at a group session. One of the group leaders then insisted that she just didn't belong in the group, that the real place for her was in a special religious education program for disabled people offered by the Archdiocese. The group asked her not to come back.

Rejection is a common experience of people with disabilities. Susan, for example, showed up at a recent diet group meeting in tears; children on the street had spit at her, thrown rocks, kicked her. The group members were very

supportive. Something similar happened to Tomas when he showed up at the police station one day and was confronted by two officers who didn't know him and politely but firmly escorted him out of the station. (He was later welcomed back.)

## 2. FROM THE SYSTEM SIDE

The social service system exerts an enormous amount of control over the lives of people with disabilities enmeshed in it— control that is almost impossible for people outside the system to imagine.

**Limiting horizons.** Social services are extremely effective at making the case for why they exist and why people need their help. A vast, expensive network of "special" services, "special" homes and institutions, "special" education, "special" therapies, "special" programs exist for people with disabilities. Whatever the quality of these services (and their quality varies a great deal), one important consequence is to convince people with disabilities and their families that they need "special" everything, that they have no place that is not "special." (One mother, for example, said that her son loves basketball and lamented that she couldn't find a "special" basketball program for him.) This conviction dramatically limits the vision of people and their families for what kind of life they could have. Some families rejected getting involved with the Community Building effort because they were suspicious of anything that didn't come from an agency or special service that they understood. People have almost lost the ability to envision a future for their sons or daughters other than one controlled by such services; as one observer put it, the question "what would you like to do?" is met blankly, as though one were asking "where would you like to go in Tibet?": people have no data for answering, no dreams on which to build visions of a different future.

**We control things here.** People with disabilities are not in control of their own lives; decisions are made for them, in matters large and small. The

Community Building effort has uncovered some dramatic examples. One is the story of the professional who tried to stop Linda from working in the pet store.

Another is April, who became friends with Mary Lou, a member of one of the community building groups. Mary Lou and her husband Gerry are warm people who have raised a bunch of kids and are now raising a grandchild; along the way they have opened their home to other people in trouble as the need arose. They were glad to meet April and start taking her to their church, Avondale Presbyterian; April and Mary Lou immediately hit it off, talking about their myriad health problems. The relationship was flourishing, when all of a sudden the announcement was made that April was to be moved from the group home where she lives in Logan Square, to another in Rogers Park, on the city's far North Side.

The move made it much more difficult for Mary Lou and Gerry to keep in touch with April. Gerry and Mary Lou were angry that the system had disregarded their friendship and put so little value on the commitment they had made to each other.

It's hard to understand just how total the control of the system can be. Ruth found that out in a small but telling incident involving her friend, Bridget. Bridget is concerned about her appearance and likes to look nice — like many people, she'd like to look younger than her age (48). Ruth works in a beauty shop, so she offered to help out by dying her hair. Bridget was thrilled. Later, Bridget mentioned the offer to the staff member at the group home where she lives. The staff member said, "OK, she can dye your hair — any color, as long as it's not red." Ruth was angry — not only about the pettiness of the comment, but about the implied insult to her own beautician skills: "After all, I'm not gonna send her out looking like a fire engine!"

Such system control can be a significant barrier to outsiders trying to make friends with someone in the system. Harold was not allowed to participate in a

Birthday celebration Rosita had planned for him because he was "being punished." Mary Ellen has called to talk to Pete and been told she couldn't; Mary Lou was told that she couldn't have April visit on a Sunday because of some infraction of house rules; Connie has run into similar restrictions. When Jackie came to take Maureen to Taste of Chicago (a huge lakefront festival featuring restaurants and music), she was told she couldn't because she'd been "bad": said the group home aide, "we can't allow people to do what they want and then trot off with friends as a reward."

People outside the system aren't used to finding such barriers to their efforts at friendship with other adults, and that can be a real eye-opener. Says Mary Ellen, "I find it hard to imagine that they could apply such totally arbitrary rules to people's lives." Ruth is more blunt: "It makes you want to just take them out of the country."

This chapter has illustrated some of the barriers that keep people with disabilities out of the life of community, and make it hard for people who want to break down those barriers. The next chapter looks at what kinds of supports can help those who want to break the barriers.

## V. Providing Support

Being part of a community seems like such a "natural" thing. Yet the experience of this work, and of other similar efforts around the country, shows that bringing isolated people into a community does not just happen "naturally." In the last chapter we identified some of the barriers that stand in the way. This chapter looks at what forms of support might help break those barriers.

**Bridgebuilders.** The lion's share of the work involved in creating the relationships described in this book has been carried out by two people who are paid to act as "bridgebuilders" between people with disabilities and the rest of the community.

Their work has been both demanding and delicate. It started with a great deal of effort to understand the territories on each side of the "bridge". That meant learning about the neighborhood of Logan Square, its history and its people; and it meant finding people who are hard to find — people whose disabilities keep them isolated. The next step was to introduce people with disabilities to people and places in Logan Square. That meant not only introducing Connie to Julie, or Mary Ellen to Pete; it also meant accompanying Miss Maritza to the Day Nursery, taking Henry to the bowling alley, driving Bill to the hospital week after week: "supporting" the relationships in their early stages. The goal of the "bridgebuilder" is to bring people together but not to remain a key figure in the relationships — to "back out" as much as possible yet stay close enough to support the relationship.

Making the work more complicated has been the fact that the bridgebuilders don't have any particular official (or "special") role in the lives of the people they're working with. They don't work for a group home or social service agency that is formally contracted to deliver this kind of "service". Instead, they work for a neighborhood organization. That decision was deliberate: it was an attempt to ground the work in a community-based institution, not in the social service system.

But it has created a built-in paradox (one that is also inherent in the work of traditional community organizers): on the one hand, they're attempting to build personal, voluntary, unpaid relationships between people in community; on the other hand, they are themselves being paid to do so. But their work is essential; without it, all the social service rhetoric about "community living" leaves people with disabilities just as isolated as ever.

The idea of having someone serve as a "bridgebuilder" didn't originate with this work in Logan Square; it has been slowly evolving in a number of related efforts around the country. A 1988 paper summarized the experiences of such "bridgebuilders" to date.<sup>6</sup>

The role of bridgebuilders in this work, in Logan Square and other places, has been critical — but limited. They could build bridges into the community. But they couldn't stand on the other side of the bridge and welcome the people coming across. That can only be done by community members themselves.

**Community Building Groups.** The "bridgebuilders" have found people who are willing to welcome people with disabilities into their communities and indeed into their own personal lives. These are people like Connie, Mary Ellen, Lois, Nora, and others. But it's been important not to leave people on their own in this effort: the institutional and societal barriers are so great that even very determined people can get discouraged. And for most people the "community building" effort is a new idea — though when people actually get involved in it, they find that it connects with much of what they've been doing all their lives.

To provide support for such personal relationships, the staff organized "community building groups." These are small, informal groups of people each of whom has agreed to welcome one person into their lives. They meet monthly,

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<sup>6</sup>See "What Are We Learning about Bridge-Building?" by Beth Mount, Pat Beeman, and George Ducharme, 1988. Available from Communities, Inc., 73 Indian Drive, Manchester CT 06040.

usually over a meal in one another's homes, to talk over their experiences. So far there are two such groups in Logan Square, and at this writing a third is in formation. By design the groups will remain small and intimate, with no more than about six people.

There's no formal structure to the group meetings, no orientation or training. They operate rather like a support groups, where people share their stories and trade ideas for coping with problems. At the beginning of the first group, the women worried about whether they were taking on too big a commitment, whether they had anything to offer. Since then, they've become more comfortable with their involvement; it is not traditional "volunteer work" but something more integrated into their lives, but they talk freely about problems and frustrations. They've had long discussions about the pain and loneliness they've discovered in peoples' lives; they've also been honest about things that have made them angry: when someone stands them up, for example, or when neighbors stare or ask insensitive questions.

They've also discovered a lot about the social service system that has made up most of these people's lives. They've learned how it treats adults as children, how people are managed, medicated, and manipulated, how little money they have, how stifling it can be to live in a group all the time.

These community building groups have built friendships among the women involved. And because each of these women is also very well connected into the community as a whole, the expectation is that they can become a guide or bridge to broader connections. For example, Connie, one of the original group members, helped look for other connections for her friend Julie. This is partly a response to Julie's very strong need for friendship, which was beginning to put demands on Connie's time. Connie, her husband Joel, Julie and Kathy met one night to talk about Julie's interests and about possibilities in the community. Julie now helps out one morning a week at LaProgressiva Day Care and one morning at Roosevelt

University, both located a block from Connie's house. Connie helps support Julie in these new connections, along with Community Building staff. Now the group is talking through ideas for broadening the connections for all the people they've involved with.

Another way relationships broaden is through the relationships of Community Building group members. Mary Ellen suggested Lois as a person she would recommend to get involved. Lois has lived in Logan Square over twenty years. She knows a lot of people. Now she knows one more, a woman named Eleanor. Lois found a neighbor to give Eleanor a permanent early in their relationship. And last Thanksgiving Eleanor sat with family and friends around Lois' dining room table.

**Community Task Forces.** The work of welcoming people can't be limited to just a few participants like those in the community building groups. There's also a need to draw more people into the work, by getting their suggestions and ideas and support.

For this reason the staff has organized a series of community "task forces." These are meetings of neighborhood leaders (business people, pastors, police, etc.), convened with two purposes: first, to inform them about the work and get their support, and second, to get suggestions about places in the community that might welcome a person with disabilities. So far, the task forces have come up with several places that have agreed to participate. These task forces broaden the support for the work and offer a way for people to get involved who are unable or unwilling to take on a more substantial commitment.

**Circles.** The most ambitious, and demanding, kind of support group for people with disabilities is the "circle". This is a group of people who know and care

about the person and who are willing to commit, over a long period of time, to pooling their ideas and energies to create a better life for that person.<sup>7</sup>

The Logan Square Community Building initiative has made one attempt to create a circle, around a young man who lived at home with his family. A group of people including his pastor, his supervisor where he volunteers, and representatives of the Community Building effort met with his parents to discuss making plans for when his parents are no longer around to take care of him. The circle effort ended, however, when the parents decided they did not want to discuss plans for the future at this time.

At this writing another circle is being formed around Linda, who is desperate to get out of the institution where she has spent her last twelve years. The circle is very small: it includes Linda, her mother and three other people from social services. It is concentrating mainly on a plan to get Linda out of the institution and into her own apartment, with somebody paid to live with her. It's still too early to tell what the outcome will be. It is very difficult to form a circle around people who are so isolated; most of the people encountered through this work in Logan Square have no one in their lives except for paid staff.

These are some forms of support that have successfully pulled together the energies and talents of community people to break down the barriers keeping people with disabilities out of the ordinary life of communities. People who belong to them are modern-day Joshuas: they help make the walls come tumbling down.

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<sup>7</sup>See also "What We are Learning about Circles of Support," *Communitas*, Manchester CT, 1988).

## VI. Conclusion

We made clear at the beginning that, although the Community Building work is sponsored by a university, it is not a formal research project, with a hypothesis, research design, methodology, and results. Nevertheless, a number of lessons have been learned from what's happened in Logan Square.

### 1. WHAT INDIVIDUALS LEARNED.

We asked a number of the people involved in the community building initiative what they felt they had learned through it. Here are some of their responses:

*Helping him to learn the everyday things we all take for granted in our lives has enriched my life and made me appreciate small things much more.*

*Compassion! Everybody has responded to Bill with large amounts of compassion.*

*I believe firmly that disabilities help the community appreciate itself as a whole. There must be a balance. My uncle was blind all of my life. Through him I learned that we all were equal. His disability strengthened areas and senses that brought out my weaknesses. . . . The same thing applies with Bill. ... he makes me aware of many aspects of life that I tend to forget. Because of Bill I am a better father, son, friend and manager.*

*She has made me realize that she and her friends are a part of everyone's life.*

*A friend is a friend whatever her disabilities.*

*Our relationship helps me appreciate my own life more. Her simplicity and honesty brings out our love and true selves.*

*I view Alice as "just another friend" — I don't consider knowing Alice a "learning experience."*

*What I admire most is her ability to be herself. She is always ready to get involved in our children's make-believe play and is open*

*and flexible in new situations despite her age (72). Catherine is a friend who enchants me with her freshness.*

*At first I thought it would be impossible for Roberto to do anything here. I was worried he might get hurt. He proved me wrong. We all need to be proven wrong sometimes. I think having him around has taught some of us on staff that we need to open our minds a lot more.*

*Every human being has something to offer and give of themselves within their lives. She offers love and understanding just like any other best friend would.*

*She gets out so little, and she gets so excited when we do things together — it makes the things we do special to me too.*

*He makes me feel valued.*

*Because of her I talk to people I would never talk to — she will just walk up to them and start talking. Makes you realize that all the rules we make for ourselves can be broken. And people have been really nice — I've never seen people back away.*

*When I spend time with her, I feel somehow revived: I get a chance to look at the world through her eyes, and that opens up my eyes a lot.*

*It's her honesty — that's what I really appreciate. She'll come right out and say what's on her mind, and doesn't worry about being polite. When she's upset you know it!*

*Spending time with her is like a release — it gets me out of my own world, into someone else's.*

*For us she feels like a person we should have had in our lives all along. It feels just right that she is there.*

Although the answers were wonderfully diverse, there was a common theme. People mentioned the small pleasures (and surprises!) of associating with someone who is "different" in some ways from other people in their lives. People tended to acknowledge the differences in a matter-of-fact way, without believing

that they needed to be "treated" or "cured" (though one person expressed frustration that her friend would not "wake up" and take more initiative for her own life). But at the same time that people were conscious of differences, they also expressed the belief that the hopes and needs of this new friend were in the end very similar to what everyone wants:

*Being treated with respect and dignity.*

*Stability, love, and a friend to talk to about anything and everything.*

*The value of community acceptance, of "being known," is primary in both our lives.*

*To be a part of a community — all people should be able to have that.*

*She wants a boyfriend. She wants a car. These are things we tend to take for granted.*

*She is a person with the same needs as anyone else.*

*The things that are important in my life are my friends and family. I think that Susan wants to have friends and a family too.*

*Bill and I want the same things, to be content and successful.*

*I think he would like to be with his family like a normal person.*

*I am sure we want some of the same things in life: to be given a chance to do something really constructive with our lives, to be happy within our selves, to be able to do what we learn the best we can.*

*Understanding such similarities also made some people question the restrictions and isolation that so many people with disabilities face.*

## 2. WHAT THE COMMUNITY ORGANIZATION LEARNED.

According to board and staff members, Logan Square Neighborhood Association benefited in a number of ways from playing host to the Community Building work. Some were quite tangible benefits: the survey of local groups and

associations, for example, was useful in identifying people LSNA could work with on other issues. Also, the Community Building work "got our name out in a different way" in the community, to groups like the Boys and Girls Club or small businesses. It pulled in people who might not otherwise have had an interest in going to meetings or getting involved in a community organization.

Beyond that were the broader benefits, described by president Deborah McCoy, of reaching out across differences. "It's difficult to work across economic barriers, across race or language. Many of the problems we have boil down to fear of differences. The more people get used to reaching out, the stronger our community will be."

### **3. WHAT THE COMMUNITY BUILDING STAFF LEARNED.**

**About building relationships.** The process of building relationships has been long and laborious. Over two years of this work literally hundreds of people have been contacted in one way or another; all this intensive work has resulted in creation of connections for approximately two dozen people.

In part, this amount of time expended was only to be expected. If the work is to be genuinely community-based, it is essential to respect the community and take time to understand it: its history and traditions, its people, its churches and institutions, its politics and pleasures and problems. That kind of knowledge is important both for talking to people in the community in terms that they understand, and also for finding what opportunities the community itself offers. In Logan Square, for example, we found that many long-time residents were concerned about a loss of community, of "neighborliness"; it was helpful to present Community Building as an attempt to rebuild and reclaim that lost virtue. We also found that the high incidence of school dropouts, gangs, and gang violence in Logan Square has led to proliferation of social service programs targeted to young people; we used that knowledge to connect people as volunteers in such programs.

Acquiring that kind of detailed knowledge of an area takes time. We spent several months identifying hundreds of associations in and around Logan Square, then found that only a very small percentage of them really offered an opportunity for isolated people to build a new relationship.

But another reason the work has taken a long time to build is the very isolation we set out to counter. Interviews with hundreds of community people yielded very few who knew anyone with a disability. On the other side, it was difficult to find people with disabilities, other than by going through the social service system. Many families who have people with disabilities living at home with them tend to be very wary of this kind of connection as unfamiliar and very risky. And people who live in institutions are practically invisible to people on the outside.

Once people were identified, building the connections and relationships still took a great deal of time. Some people appeared genuinely interested, but then backed off; often, it was because they were "so busy" and they saw this as one more demand on their time. Some relationships flourished quickly, and required very little additional support beyond that offered in the community building groups or occasional phone calls; other required constant contact and encouragement. Progress was slow, and at many points along the way it has seemed that nothing at all was happening.

And because these connections deliberately aren't "placements", with formal contracts etc. — because they are informal friendships and places to spend time — they keep changing, growing or, in some cases, deteriorating. At least one apparently stable relationship has fallen apart; in another case a woman pulled out after her initial involvement apparently proved too demanding. One strong relationship is becoming stressed by its own success. The relationship has become so important to the woman with the disability that she wants more: her friend has

responded by looking for other ways to help fill that need. In places where people are volunteering, the connection may depend on one understanding staff member; if that person leaves, as one currently is, the connection becomes vulnerable. Of the two attempts to broaden the involvement — to create "circles" around a person to plan a more hopeful future — one is working, the other has fallen apart. The point is that relationships are more like trees than like structures or institutions. They are alive, they grow and change, and can also wither and die.

Finally, although the tree image might imply that such relationships are "natural," the fact is that they're not, at least not in contemporary society. Segregation is very strong: it keeps people with disabilities "in their place" and lets the rest of us live in ignorance. Such barriers don't break "naturally": breaking them demands conscious, concerted effort.

*The absence of experience with those who are excluded has led many citizens to imagine that these labeled people are somehow inappropriate for community life. Many have come to believe that labeled people are so incapacitated that their lives literally depend upon separate and expert attention. Having accepted this proposition, most citizens lead segregated lives in which they can only imagine labeled people ... [believing them] unacceptable in everyday life and helpfully isolated by the professional care that is the only "good thing" that a "good society" can do for them. Because it is so infrequently the case that excluded people are able to overcome [such] barriers we have found that the most frequently successful incorporation has taken place as a result of people who have assumed a special responsibility to guide excluded people out of service and into the realms of community life.<sup>8</sup>*

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<sup>8</sup>See "Beyond Community Services," by John L. McKnight. Available from Center for Urban Affairs and Policy Research, Northwestern University, 2040 Sheridan Road, Evanston IL 60201.

**About relationship to the community.** This assumption of the "special" nature of people with disabilities is a powerful isolating force. To counter it, and to establish this effort as community work and not human service, we located the work out of the social service sector, in a "civic" place — a neighborhood organization.

This decision caused a good deal of explaining. It also caused some tensions. Neighborhood organizations, especially in Chicago, tend to bring people together to fight a common problem or a common enemy; they focus on achieving power and on winning victories. This effort sought to build community in a different way. Many people simply didn't understand what the neighborhood organization had to do with disabilities. Some people — especially parents of people with disabilities — were suspicious of the neighborhood organization.

The tension about the relationship of the work to the neighborhood organization is ongoing, and has still not been resolved. Such organizations have small staffs and limited resources; and although this work was at first independently staffed and funded, it sometimes demanded a level of attention and involvement that went beyond what the organization staff felt they could offer. (However, when the time came to decide whether LSNA would continue the work on its own, the board voted — by a substantial majority of 9 to 2 — to endorse the work and raise money to keep it going.)

Beyond the simple question of its relationship to the neighborhood organization, the Community Building work addresses broader issues of community. First, and most obviously, it helps bring people with disabilities out of a role as clients and into a new identity as citizens. Any community is stronger for having active participants, or citizens, rather than mere passive clients.

Second, it helps address the need for a greater sense of community expressed by many people. The absence of people with disabilities in the day-to-day life of the

community weakens the community. It excludes their gifts — all those qualities of honesty and spontaneity and affection that people told us about. It narrows the community's standards of acceptance and reduces the ability of community members to include and incorporate people different from themselves. One woman expressed this broader connection very eloquently. Asked "what do you think about having people with disabilities included in community life," she responded:

*I don't think anything of it. To me, it's part of life as it should be. We weren't all born beautiful or rich or brilliant. I love the diversity of various peoples, ethnic groups, et cetera. For example, I spent three and a half weeks in Norway (my heritage) several years ago and I grew tired of seeing only blue eyes ... I guess I'm not meant for a homogeneous society — it's too boring! In the same vein, I'm very bitter about some of Logan Square's residents who don't accept people for what they are and they refuse to get to know the person because that person happens to come from a different socioeconomic class than they do. If people would only take the time to smell the roses ...*

The Community Building initiative has also identified, and tried to focus attention on, the strengths of the community: on the ways people already reach out to help each other. Side by side with the stories of ethnic hostility or gang violence are thousands of stories where people watch out for each other's children, look in on elderly neighbors, serve on the school council, or call the police when they see someone in danger. This is the hidden part of community life, the part that makes people feel welcome and safe and "at home." The Community Building work has learned that people don't always come together just because of problems; they also come together around hope and vision. It has found ways to

- *identify community members who want to reach out, and*
- *honor this piece of community life.*

**About the relationship to the world of human services.** This work has had very little to do with social service agencies for people with disabilities. This was by design, to break down the isolation so often caused by immersion in the "special" world of social services.

Nevertheless, the work did involve interacting with the social service system in a variety of ways.

First, contacting service agencies proved to be virtually the only way to identify people with disabilities. This is, of course, only a sign of their isolation.

Second, the agencies control access to people who live there and are their clients. It was essential to secure a minimum level of cooperation to enable us to have access. Sometimes the cooperation was graciously extended; at other times, as we have seen, it was arbitrarily withdrawn.

On the other hand, there are many people in social service agencies who have expressed interest in this and other "community building" ventures. They see it as a way to reform the social service system. Their motives are admirable; they are reaffirming the best instincts that brought them to work with people with disabilities in the first place. But this work is not about reforming social services; it is about breaking the grip of social services on the lives of people with disabilities and increasing the capacity of ordinary people, and ordinary communities, to incorporate those people. It is about community work, not social service work extended into the community. It is work that is not the way of formal systems; such formality would destroy it.

Therefore it is a conclusion of this project that this work must not be an extension of the formal system but be located in the civic sector. Even with all its inherent difficulties, the civic sector — the place where people come together as citizens — provides a broader perspective, access to people who are not functioning as paid professionals but as neighbors and citizens, and the fundamental condition

of informality. Another, related conclusion is that the work needs to be focussed on a particular geographic area — a neighborhood — rather than being spread out over an entire city. The work aims, among other things, to build — and to build on — a sense of community, and that doesn't happen at the scale of hundreds of thousands (or millions) of people.

**About vision and community.** This book has been an attempt to describe one effort at Community Building in one Chicago neighborhood, Logan Square. It has been a very small-scale effort, one that has touched the lives of a few dozen people. It has written no manifestoes, organized no movements, created no grand schemes for reform. But its vision is powerful: it is a vision not of authority but of community. It celebrates not individual achievement, but collective wisdom. It brings people together to appreciate one another's gifts, not diagnose one another's differences. It is a kind of community work that builds, not power in the traditional sense, but the capacity to take care of our own. A powerful community is able to achieve opportunity and security for its people; this work, in Logan Square, is doing both.