

COMMUNITY PARTICIPATION AND SOCIAL NETWORKS: AN INFORMATION PACKAGE

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PART I: SELECTED READINGS

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A Guide to Knowing Your Community by the Center on Human Policy (CTAT Field Report, 1(1), Winter 1990, pp. 8-9.)

Other Than Clients: Reflections on Relationships Between People with Disabilities and Typical People by Zana Marie Lutfiyya (TASH Newsletter, September 1988.)

Citizen Participation: Connecting People to Associational Life by Sharon Gretz (In D. Schwartz (Ed.), Crossing the river (pp. 11-30). Available from Brookline Books, P.O. Box 97, Newton, MA 02464 1-800-666-BOOK)

"Community Building" in a Chicago Neighborhood by Michael Ervin (The Neighborhood Works, December 1989-January 1990, 5-7.)

PART II: ANNOTATED BIBLIOGRAPHY

PREFACE

This information packet focuses on community participation and social networks. It was previously prepared by Zana Marie Lutfiyya in 1991 as an information package on "Personal Relationships and Social Networks." While many more people with developmental disabilities live in the community, many of them still lack opportunities for participation in community places, activities, organizations, and events and for social relationships with other community members. Such participation and relationships are the key to a sense of community membership and belonging. Traditionally, human service agencies have, in many ways, created barriers to community participation and social relationships. In recent years, however, increasing numbers of agencies are making significant efforts to assist people in meaningful community participation and relationships. This has involved supporting people to engage in social relationships and friendships; to join community organizations and associations; and to take part in neighborhood and community places, events, and activities.

Part I of this package begins with an article by Robert Bogdan and Steven Taylor that discusses critical issues related to community participation for people with developmental disabilities. The second article, "A Guide to Knowing Your Community," offers ideas to assist in thinking about the places, associations, and activities within your community. The guide is not intended to tell you how to connect people with disabilities to the community; it is intended to help you see aspects of the community you might otherwise overlook. Next, "Other Than Clients: Reflections on

Relationships Between People with Disabilities and Typical People" by Zana Marie Lutfiyya describes some key aspects of assisting people to form meaningful relationships. The final two articles, "Citizen Participation: Connecting People to Associational Life" and "'Community Building' in a Chicago Neighborhood," offer a number of stories, strategies, and reflections related to promoting community participation and social networks.

Part II consists of an annotated bibliography of resources related to community participation and social networks.

Preparation of this information package was supported in part by the National Resource Center on Supported Living and Choice, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133A990001. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred. I would like to thank Rachael Zubal for her assistance in the preparation of this information package.

SELECTED READINGS

We are unable to reproduce the selected readings electronically within this document. You may obtain a complete paper copy of this information package by contacting The Center on Human Policy at thechp@syr.edu

Building Stronger Communities for All: Thoughts About Community Participation for People with Developmental Disabilities by Robert Bogdan and Steven J. Taylor

In A. Tymchuk, K. Charlie Lakin, & R. Luckasson (Eds.), The forgotten generation: The status and challenges of adults with mild cognitive limitations (pp. 191-199). Baltimore: Paul H. Brookes Publishing Co. Reprinted with permission.

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**Other Than Clients: Reflections on
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**"Community Building" in a Chicago
Neighborhood**

by Michael Ervin

The Neighborhood Works, December 1989-January 1990, 5-7.

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ANNOTATED BIBLIOGRAPHY

TITLE: Enhancing the social inclusion of persons with developmental disabilities

AUTHORS: Abery, B. H., & Fahnestock, M.

PUBLICATION INFORMATION: 1994

In M. F. Hayden & B. H. Abery (Eds.), Challenges for a service system in transition (pp. 83-119). Baltimore: Paul H. Brookes Publishing Co.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
<http://www.pbrookes.com>

The authors stress the importance of a wide variety of types of social relationships in people's lives. The chapter begins with a discussion of the nature of social relationships. It elaborates on issues related to social relationships and networks, including a review of related research. A person-centered approach to the development of social relationships is advocated, with examples and strategies offered.

TITLE: Friendships and community connections between people with and without developmental disabilities

AUTHOR: Amado, A.N. (Ed.)

PUBLICATION INFORMATION: 1993

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
<http://www.pbrookes.com>

This book contains chapters that discuss a wide variety of critical issues related to friendship and people with developmental disabilities. It is acknowledged that

"supporting friendships can be fragile, delicate, magical, and sensitive work. It is not work that easily fits into formalized systems and agency patterns" (p. 373). Authors discuss dilemmas and challenges related to this.

The book is divided into three sections: (1) dimensions of friendships, (2) stories of friendships and (3) strategies for building friendships. Chapters in the first section include an introductory piece by John O'Brien and Connie Lyle O'Brien discussing dimension of friendship, issues of attraction and power, and context of community; loneliness; intimacy and sexual relationships; the gendered context of friendships; and friendships between "staff" and "clients." The second section contains stories of friendship written by people with disabilities, parents, and advocates from within and outside of the service system. Finally, chapters in the third section offer important strategies based upon focused efforts to assist people to form friendships and connections at work, in community associations, and within the community at large.

TITLE: Amistad: Stories of Hispanic children with disabilities and their friendships

AUTHOR: Beach Center on Families and Disability

PUBLICATION INFORMATION: 1997

Beach Center on Families and Disability
University of Kansas
3111 Haworth
Lawrence, KS 66045
voice/tdd 913-864-7600 fax 913-864-7605
beachcenter@ku.edu
<http://www.beachcenter.org/>

This monograph, aimed primarily for families and educators, is the result of a study on friendship that focused on the Hispanic population. The intent was to find examples of "successful" friendships for children who experience significant disability. The stories are presented here, followed by a concluding section outlining "friendship tips" and giving additional resources.

TITLE: When spider webs unite: Challenging articles and essays on community, diversity and inclusion

AUTHOR: Asante, S.

PUBLICATION INFORMATION: 1997

Inclusion Press
24 Thome Crescent
Toronto, ON M6H 2S5
CANADA
416-658-5363 fax 416-658-5067
includer@idirect.com
<http://www.inclusion.com/>

Shafik Asante was a leader in organizing to fight against injustices in the African American community, as well as in the struggle for better community services. He lectured internationally to diverse groups on community organizing and alliance building. Topics addressed in this book include alliance building, inclusive community building, disability issues, and leadership and organizing, among others. The essays are based on reflections on the author's personal and work experiences.

TITLE: Building stronger communities for all: Thoughts about community participation for people with developmental disabilities

AUTHORS: Bogdan, R., & Taylor, S.J.

PUBLICATION INFORMATION: 2001

In A. Tymchuk, K. Charlie Lakin, & R. Luckasson (Eds.), The forgotten generation: The status and challenges of adults with mild cognitive limitations (pp. 191-199). Baltimore: Paul H. Brookes Publishing Co.

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The authors question how can we think about having people with disabilities be a part of the community when community has become such a problem for everyone else, when community is under siege? They suggest that we must approach the challenge of helping people with disabilities to become part of the community with full appreciation of what is at stake. Thinking about community for people with developmental disabilities might help us think about it for ourselves. This essay presents some thoughts and observations on what it means for people with developmental disabilities to be part of the community.

TITLE: Toward a sociology of acceptance: The other side of the study of deviance

AUTHORS: Bogdan, R., & Taylor, S.

PUBLICATION INFORMATION: 1987, Fall

Social Policy, 18(2), 34-39.

For a quarter century sociologists have concentrated on stigma and the labeling and rejection of people with negatively valued physical, mental, and behavioral differences. Yet, the authors argue that individuals with a wide range of differences regularly form close relationships with typical people. No attribute of a person, no matter how atypical, precludes accepting relations. Thus, the sociology of acceptance is directed toward understanding not only how people with deviant attributes come to be accepted in personal relationships, but also in groups, organizations, communities, and society.

TITLE: On the road to community inclusion
and
On the road (again) to community inclusion: It's about time

AUTHORS: The Elizabeth M. Boggs Center on Developmental Disabilities

PUBLICATION INFORMATION: 1999 & 2000

The Elizabeth M. Boggs Center on Developmental Disabilities
University of Medicine and Dentistry of New Jersey
Robert Wood Johnson Medical School
335 George St., P.O. Box 2688
New Brunswick, NJ 08903-2688
732-235-9300 TDD 732-235-9328 fax 732-235-9330
boggsweb@umdnj.edu
<http://rwjms.umdnj.edu/boggscenter/>

These two booklets were produced based on community-building forums and conferences sponsored by The Boggs Center-UAP. They are the compilation of many short reflections on community and community building by participants in these events, including direct support staff, people with disabilities, family members, and others who have an interest in issues related to community building.

TITLE: The social basis of community care

AUTHOR: Bulmer, M.

PUBLICATION INFORMATION: 1987--out of print

Allen & Unwin, Inc.
8 Winchester Place
Winchester, MA 01890

This book analyzes the relationship between ideas about community life and the impact of social policy, demonstrating that, at least in England, there is "a vacuum at the heart of care policy which is likely to lead to ineffective or deteriorating provision of services" (p. ix). Bulmer's analysis is very relevant to North American discussions about community integration of people with disabilities. The book focuses more on informal support or care than on services and service systems, but he looks at both and at the interface between the two types of care in the community. His analysis draws heavily on a variety of research studies conducted in neighborhoods, within groups of families, and in other aspects of community life and is a major contribution to the discussion about community integration.

TITLE: Involving all neighbors: Building inclusive communities in Seattle

AUTHOR: Carlson, C.

PUBLICATION INFORMATION: 1990

Seattle Department of Neighborhoods
700 3rd Avenue
Arctic Building, Suite 400
Seattle, WA 98104-1848
206-684-0464

<http://www.cityofseattle.net/neighborhoods/involve/resources.htm>

This booklet was produced through the collaboration of the Seattle Department of Neighborhoods and the Washington State Division of Developmental Disabilities. It documents the "Involving All Neighbors" program, a program to promote neighborhood involvement by people with disabilities. One unique aspect of this program is that it is located not within a disability agency, but within the City of Seattle's Department of Neighborhoods.

The booklet contains many different examples of people's involvement in neighborhoods, including individual connections as well as participation in neighborhood organizations and projects. The stories are accompanied by reflections on some of the lessons learned.

A conclusion offers some overall lessons learned from the "Involving All Neighbors" program, and the appendix contains the mission of the Department of Neighborhoods, and a summary of key aspects related to what makes neighborhood organizations inclusive, qualities of community connectors, and suggestions for ways that neighborhood organizations can include people with developmental disabilities.

Overall, this booklet contains many diverse examples of neighborhood involvement and reflections and lessons based on these experiences. As such, it offers creative ideas and strategies for all those who are interested in helping to promote community connections and meaningful community participation for people with developmental disabilities. Finally, it provides a wonderful example of partnership between community and disability focused organizations.

TITLE: Interdependence: The route to community (2nd ed.)

AUTHOR: Condeluci, A.

PUBLICATION INFORMATION: 1995

CRC Press LLC
2000 NW Corporate Boulevard
Boca Raton, FL 33431-9868
1-800-272-7737 fax 1-800-374-3401
orders@crcpress.com
<http://www.crcpress.com/us/>

The book begins with a discussion of disempowerment--the ways people lose power and are oppressed and stereotyped. This discussion concludes with some lessons about change from the civil rights movement. Chapter 2 describes various paradigms within human services, including the medical, educational, economic, and maintenance paradigms. The next chapter outlines an alternative paradigm--the interdependence paradigm. In summary, the three goals of this paradigm are acceptance, relationships, and opportunity. Chapter 4 details four factors that are key to achieving interdependence: role competency enhancement, supplemental supports, relationship building, and systems advocacy. The fifth chapter focuses on "understanding community." It describes various functions of community, formal and informal dimensions of community, community space issues, communication issues, and learning about community issues.

TITLE: It's about relationships

AUTHOR: Forest, M.

PUBLICATION INFORMATION: 1990

In L. Meyer, C. Peck & L. Brown (Eds.), Critical issues in the lives of people with disabilities (pp. 399-408). Baltimore: Paul H. Brookes Publishing Co.

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P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
<http://www.pbrookes.com>

This is a personal reflection by Marsha Forest on the many relationships that have enriched her life and the lives of her friends and family members. Interwoven with the personal stories are stories about integrating students with disabilities into regular schools. Forest points out how much we all have to give each other, and how much we miss when people with perceived differences are excluded from schools, neighborhoods, and friendship circles.

TITLE: The common thread: A collection of writings about friendships, relationships, and community life

AUTHORS: Gretz, S., & Ploof, D. (Eds.).

PUBLICATION INFORMATION: 1999

Pennsylvania Developmental Disabilities Council
Room 559, Forum Building
Commonwealth Avenue
Harrisburg, PA 17120
717-787-6057
info@paddc.org
<http://www.paddc.org/>

The stories in the monograph were originally published in a newsletter, "The Common Thread." The newsletter grew out of the work of the editors and others as

part of the Community and Relationship Building Project at the UCP of Pittsburgh, a project funded through a grant from the Pennsylvania Developmental Disabilities Council. The purpose of the newsletter was to share stories about community connections and relationships and in doing so to stimulate readers to think more deeply about these aspects of human social life. In reflecting on the significance of the title of the newsletter and this monograph, the editors' write: "There are many things operating in today's society which work against a strong social fabric. Many of us feel deeply that when some people are excluded from the life of a community, the social fabric contains a hole. Perhaps each of our efforts can be considered to be weaving threads that have the potential to repair the hold and make some of our communities WHOLE--at least in some places and for some people."

TITLE: Everyone here spoke sign language: Hereditary deafness on Martha's Vineyard

AUTHOR: Groce, N. E.

PUBLICATION INFORMATION: 1985

Harvard University Press
79 Garden Street
Cambridge, MA 02138
617-495-2577 fax 617-495-5898
<http://www.hup.harvard.edu/>

This ethno-historical study is an excellent portrayal of community life for deaf and hearing individuals of Martha's Vineyard. The reader is presented with the history of how the deafness was brought to the island. The book allows the reader to view the typicality of the lives of Islanders who were deaf, typicality due to the community's acceptance and ability to communicate with them. Groce takes us beyond the confines of medical or social definitions of deviancy and offers evidence that our pre-conceived stereotypes of what a disability may mean are really determined by the social construct we create as a society.

This well-researched book is a must, not only for people interested in the field of disabilities but for anyone trying to struggle with integration into community life. The book is a simple thesis offering a profound message in a wide array of disciplines. It will add thought to issues that will remain unresolved and discussed for a long time to come.

TITLE: A guide to building community membership for older adults with disabilities

AUTHORS: Harlan, J., Todd, J., & Holtz, P.

PUBLICATION INFORMATION: 2001

Training Resource Network, Inc.
P.O. Box 439
St. Augustine, FL 32085-0439
1-866-823-9800 fax: 904-823-3554
info@trninc.com
<http://www.trninc.com/>

This publication is intended as a resource of ideas, tools, and techniques that have been found to be effective in helping to promote community membership for older adults with disabilities. Examples and stories are drawn from experiences of community builders and individuals with mental retardation and other disabilities who participated in a demonstration component of The Community Membership Project, a training initiative grant funded by the Administration on Developmental Disabilities and awarded to the Center for Aging Persons with Developmental Disabilities at the University Affiliated Program of Indiana. The stories are interwoven with information and interactive training activities, based on a community-building approach. The information in the guide is applicable to supporting people of all ages in community membership.

TITLE: Friends: A manual for connecting persons with disabilities and community members

AUTHOR: Human Services Research and Development Center

PUBLICATION INFORMATION:

Human Services Research and Development Center
Minnesota Developmental Disabilities Council
300 Centennial Office Building, 658 Cedar Street
St. Paul, MN 55155

This manual grew out of the "Friends" project, a one-year grant project sponsored in 1989-90 by the Human Services Research and Development Center of St. Paul, Minnesota, and funded by the Minnesota Governor's Planning Council on

Developmental Disabilities. The purpose of the project was to learn about and develop methods for the staff of residential service agencies to support people with disabilities in establishing friendships and relationships with nondisabled people in their communities and to assist people with disabilities in being more a part of their communities.

Sections of the manual contain information on: planning with people; strategies to facilitate connections; introducing people; providing continuing support for relationships and friendships; assisting others in meeting and becoming friends with persons with disabilities; and agency support for relationship building. It describes the process used in the Friends project, strategies that seemed to be more and less effective, and it contains many stories and examples.

The manual would be useful for anyone who is interested in supporting a person with disabilities to widen his or her circle of relationships and to develop deeper friendships.

TITLE: Building communities from the inside out: A path toward finding and mobilizing a community's assets

AUTHORS: Kretzmann, J. P., & McKnight, J. L.

PUBLICATION INFORMATION: 1993

Institute for Policy Research
Northwestern University
2040 Sheridan Road
Evanston, IL 60208
847-491-8712 fax: 847-491-9916
<http://www.northwestern.edu/IPR/index.html>

This guide provides many stories, strategies, and resources related to building stronger communities. This involves looking at the capacities and contributions of all community members, including youth, people with disabilities, and older people, among others.

Chapter 1, "Releasing Individual Capacities," introduces ways to find and use the gifts and talents of local people. Chapter 2, "Releasing the Power of Local Associations and Organizations," describes the efforts of community associations to solve local problems. Chapter 3, "Capturing Local Institutions for Community Building," provides examples of ways in which local institutions (e.g., parks, libraries, schools, colleges) form community partnerships with each other. Chapter 4, "Rebuilding the Community Economy," highlights ways in which communities can capture and build upon existing economic assets. Chapter 5, "Asset-Based Community Development: Mobilizing an Entire Community," summarizes the community-building process presented in this

book. Finally, Chapter 6, "Providing Support for Asset-Based Development: Policies and Guidelines," suggests ways in which people and institutions from outside the community can support asset-based community-building activity.

TITLE: Affectionate bonds: What we can learn by listening to friends

AUTHOR: Lutfiyya, Z. M.

PUBLICATION INFORMATION: 1990

Syracuse, NY: Center on Human Policy, Syracuse University.

In this monograph, Zana Lutfiyya describes a qualitative study conducted with four pairs of friends in the Syracuse area. In each of these pairs, one person has a disability label and one does not. The author offers perspectives on friendship found in the literature, describes each of her informants and their friendships, explores the dimensions and characteristics of friendship, and relates the rights, responsibilities and obligations of friendship in her informants' eyes. She discusses how some friendships move toward greater intimacy while others stay the same or die away, and lays out some of the implications of her study for the human service world, for families, and for people thinking about their own friendships. This ground-breaking study should begin to focus our thinking on what really goes on in friendships, including those between people with and without disabilities.

TITLE: "A feeling of being connected": Friendships between people with and without learning difficulties

AUTHOR: Lutfiyya, Z.M.

PUBLICATION INFORMATION: 1991

Disability, Handicap & Society, 6(3), 233-245

Recently, programmatic attempts to encourage close ties between people with learning difficulties and typical citizens have increased. It is believed that such relationships will extend the assimilation of people with learning difficulties into society. The researcher presents the perspectives of four pairs of friends about the meaning of their friendships. The informants shared similar ideas and expectations about the characteristics of friendship in general. These included its mutual, exclusive, and voluntary nature; the rights, obligations, and responsibilities of friends to each other; and the positive regard or affection found between friends. Despite efforts on the

part of service providers to support the development of friendship between people with and without learning difficulties, the biggest barriers for the individuals in this study were the practices of the human service system, which curtailed opportunities for people which would have promoted the development and maintenance of friendships.

TITLE: Making friends: The influences of culture and development

EDITORS: Meyer, L. H., Park, H. S., Grenot-Scheyer, M., Schwartz, I. S., & Harry, B.

PUBLICATION INFORMATION: 1998

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
<http://www.pbrookes.com>

Based on qualitative research, this volume offers a wealth of information, strategies, and perspectives related to promoting friendships for students with severe disabilities. Perspectives range from those of people with disabilities, family members, teachers, and researchers. Chapters address issues related to friendship and cultural diversity, challenging behaviors, students who are deaf-blind, classroom structure and interactive opportunities, and many others. Issues related to promoting friendships are discussed across the range of school years, from preschool through high school. As friendships are a vital component of schools, and of the concept of inclusion, this is a valuable resource for all those who are concerned with creating schools that promote true inclusion.

TITLE: What are we learning about bridge-building?

AUTHORS: Mount, B., Beeman, P., & Ducharme, G.

PUBLICATION INFORMATION: 1988

Communitas, Inc.
730 Main Street
Manchester, CT 06040

This monograph opens with the key premise of "bridge-building." "Real integration, the development of genuine networks of support, requires very focused

and assertive effort(s) on behalf of facilitators who initiate, support and maintain new relationships. We call these facilitators "bridge-builders" because they build bridges and guide people into new relationships, new places, and new opportunities in life" (p. 1).

As the sub-title of the monograph suggests, it is a summary of a dialogue between people who are trying to build community for people with disabilities by working as bridge-builders. Most of the monograph presents the reflections of five participants at a day-long discussion on bridge-building in 1988. As this publication appears to be a faithful rendering of people's words, with little attempt at a full written explication of the concepts and terms that form the new language of bridge-building, it may be unsatisfying for someone who is completely new to the idea. However, it does contrast the different perspectives held by proponents of traditional human services with that of bridge-building, and would be of interest to those readers already acquainted with this concept.

TITLE: What are we learning about circles of support?

AUTHORS: Mount, B., Beeman, P., & Ducharme, G.

PUBLICATION INFORMATION: 1988

Communitas, Inc.
730 Main Street
Manchester, CT 06040

The authors offer the experiences of several "circles of support" now in existence in Connecticut. Inspired by the efforts of the Joshua Committee over the past decade, the authors helped found circles of support around several people with disabilities. "A circle of support is a group of people who agree to meet on a regular basis to help the person with a disability accomplish certain personal visions or goals" (p. 3). The monograph gives practical information on the process of starting and maintaining a support circle, with several actual examples. Circles of support serves well as both an introduction to the concept and as a useful resource for people already familiar with the issue.

Acknowledging the current fascination with "personal futures planning," the authors provide an important comparison of support circles with person-centered and traditional methods of service planning. And they wisely caution that the process outlined in the monograph is not meant as a model for replication of other support circles. Rather, "the spirit of a circle...is more important than the details of the process, and we hope that the process we describe will help people invite the spirit of support into the lives of other people" (p. 1).

TITLE: Nasty girls, thugs, and humans like us: Social relations between severely disabled and nondisabled students in high school

AUTHOR: Murray-Seegert, C.

PUBLICATION INFORMATION: 1989

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
<http://www.pbrookes.com>

Based on a qualitative research study, this book is the account of one school's move toward integration, and the peer relations that developed in that school as a result. The author documents the ways in which the school's integration efforts affected student relations and teacher practices. In addition, she relates these findings to the broader themes of quality education, student diversity, and social inequity.

TITLE: Natural supports in school, at work, and in the community for people with severe disabilities

AUTHOR: Nisbet, J. (Ed.)

PUBLICATION INFORMATION: 1992

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
<http://www.pbrookes.com>

Promoting the position that assistance must be defined by the needs of individuals rather than the requirements of service systems, this volume includes research and first-person accounts related to use of natural supports. Chapters discuss natural supports in relation to: family issues, school, work, residential supports, social support and friendship, among others. Chapters include practice strategies, stories, and reflection on key issues related to developing and sustaining natural support networks.

TITLE: Designing policies in support of inclusive community: Making questions or decision makers

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1989

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

"People in association create neighborhoods, schools, workplaces, marketplaces, and civic organizations. They build inclusive community when their activity calls on, strengthens, and celebrates mutual capacity to welcome, join with, and care for people who have been left out." But, on the other hand as O'Brien tells us, when activities exclude and isolate people, community is diminished. Based on discussion sponsored with the Connecticut Developmental Disabilities Council, O'Brien poses a series of poignant questions to human service and government decision-makers. Examples of these questions are: "How can we decrease disincentives to participate in community life?" "How can we insure sufficient cash incomes for people with disabilities?" and "How can we invest in activities that build inclusive communities?"

TITLE: Signs of community building

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1989

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

Based on notes he made while visiting with people involved in community building activities in Phoenixville, PA, in this monograph O'Brien discusses the signs of community building that he saw during his visit: "I was struck by the characteristics that these diverse efforts have in common despite their independent origin and their lack of coordination mechanism." He also suggests that community building touches fundamental everyday concerns, including, "to be healthy and to die well," "to have a safe place in times of confusion," and "to reach out to people in other places."

TITLE: Community engagement: A necessary condition for self-determination and individual funding

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1999

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy or online at:
<http://thechp.syr.edu/ComEng.pdf>)

People with disabilities and their families and friends have a reasonable expectation that people with disabilities will live with security and dignity as contributing members of their communities. Security, dignity, and contribution depend on people, associations, economic actors, and governments each assuming their fair share of the personal and public responsibility necessary to assure the creation and use of accessible opportunities for contribution and the provision of the individualized support and assistance necessary to enable participation. In order to ensure this, it is necessary to implement policies that ensure adequate individual funding, controlled by people with disabilities and their families and friends. At the same time, the author argues that the "urgency and clarity of political action can overshadow the slow and ambiguous work of building wider and deeper relationships with and around people with disabilities and their families."

TITLE: Unlikely alliances: Friendships and people with developmental disabilities

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1993

In A. N. Amado (Ed.), Friendships and community connections between people with and without developmental disabilities (pp. 9-40). Baltimore: Paul H. Brookes Publishing Co.

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<http://www.pbrookes.com>

Friendships are described as "unlikely alliances" for people who are separated and isolated by prejudice against disability. The authors begin by posing a number of questions: What can people with developmental disabilities expect from their social relationships, particularly their relationships with people without disabilities? Is the meaning of "friend" exhausted by lack of hostility or by benevolent patronage? Or, are some deeper meanings possible, and, if they are, how can people understand them, call them forth, and support them? What challenges come with friendship? The chapter then discusses four dimensions of friendship: attraction, embodiment, power, and community. Through communities of resistance, people can counter the dominant social beliefs that devalue the community's members and their relationships and support one another to get on with their lives.

TITLE: Members of each other: Perspectives on social support for people with severe disabilities

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1992

In J. Nisbet (Ed.), Natural supports in school, at work, and in the community for people with severe disabilities (pp. 17-63). Baltimore: Paul H. Brookes Publishing Co.

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This chapter discusses issues related to community membership and belonging for people with severe disabilities. The authors state, "Because people with severe disabilities cannot take membership for granted, those concerned with building stronger, more inclusive communities must consider how people deny membership can be established." They assert that people with disabilities can teach all of us a good deal about the social relationships that are at the foundation of civil life. Some of these teachings can be categorized into three topics: (1) the consequences of long-term exclusion from common memberships; (2) the benefits implicit in recognition as a member, and (3) some of the explicit work necessary to change patterns of exclusion so that a person moves to being known and treated as a member. Examples are provided of each of these topics. The chapter concludes with discussion of the ways in which human services can help, as well as some of the paradoxes of community building.

TITLE: Unfolding capacity: People with disabilities and their allies building better communities together

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1994

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy or online at:
<http://thechp.syr.edu/unfoldin.htm>)

This paper discusses efforts to build community, based on what the authors have learned by listening to stories of people who have worked together to make important changes in their lives. These changes, all involving people with significant disabilities, include such things as: establishing adequate support for family life; moving from an institution, medical hospital, nursing home, or group residence into one's own home; moving from one's family's home to a home of one's own; getting a job in an ordinary community workplace; and attending school as a member of ordinary classes. As the authors' see it, "community building happens when people step outside the roles prescribed by the formal and informal administrative structures and the assumptions that typically organize life for people with substantial disabilities" (p. 6). They describe five commitments that contribute to building community: anchor, allies, assistance, agendas, and associations. Each is discussed briefly. The paper concludes by addressing issues related to the importance of community building and tensions in community building.

TITLE: The gift of hospitality: Opening the doors of community life to people with disabilities

AUTHOR: O'Connell, M.

PUBLICATION INFORMATION: 1988

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Northwestern University
2040 Sheridan Road
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<http://www.northwestern.edu/IPR/index.html>

This monograph is part of the growing literature that critiques the human service system even when it is based in the community. It describes the efforts of people with a variety of disabilities to take their place within the community and by others to accept them. O'Connell asserts that community-based services can isolate people with disabilities from community life. Surrounded by paid staff, many clients in the human service system are cut off from the opportunities to meet and develop relationships with typical people.

By sharing the experiences of individuals with disabilities who have been welcomed into the hearts and lives of others, O'Connell introduces a practical definition of hospitality. She suggests that hospitality is "...the fundamental sense that you have to appeal to in asking other people to get involved in this work of welcoming isolated people back into the community." For the author, achieving the fullest possible integration of individuals with disabilities into society involves acts of welcome and hospitality by those who are already members.

This monograph would be useful reading for those interested in the meanings of "community integration" for people with disabilities.

TITLE: Making friends: Developing relationships between people with disabilities and other members of the community

AUTHOR: G. Allan Roeher Institute

PUBLICATION INFORMATION: 1990

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This book examines many critical issues related to friendships. It looks at how the presence or lack of friends and other relationships affects people's lives. It also explores key elements of friendship, examines conditions that support the development of relationships, identifies key barriers that need to be overcome, and outlines practical options that can be pursued by those concerned with promoting friendships and other relationships.

TITLE: Crossing the river: Creating a conceptual revolution in community & disability

AUTHOR: Schwartz, D. B.

PUBLICATION INFORMATION: 1992

Brookline Books
P.O. Box 1209
Brookline MA 02445
1-800-666-BOOK
<http://www.brooklinebooks.com/>

As increasing numbers of people with developmental disabilities have been assisted to live in community-based settings, at the same time, the community services system has failed, in many ways, to help people become participants and members of the community. The conceptual revolution that Schwartz describes involves "rediscovering the importance for all people of being and feeling embedded in a web of personal relationships."

The book begins with two chapters describing efforts to assist people to form community connections (a chapter on connecting people to community associations, by Sharon Gretz; and a chapter on citizen advocacy in Beaver County, Pennsylvania, by A.J. Hildebrand). Following chapters discuss the idea and process of conceptual revolutions, and describe the efforts of the Pennsylvania State Developmental Disabilities Planning Council to foster and support conceptual change. The book concludes with a discussion of issues regarding what keeps people safe, the limitations of community, the role of human services, and the challenges to building community.

TITLE: A story that I heard

AUTHORS: Schwartz, D. B., McKnight, J., & Kendrick, M.

PUBLICATION INFORMATION: 1987

Pennsylvania Developmental Disabilities Council
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Harrisburg, PA 17120
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<http://www.paddc.org/>

This monograph is a collection of stories, poetry, and essays about the situation of people with disabilities in American communities. It includes writing by people who have disabilities, family members, and friends and advocates.

TITLE: Social integration and friendship

AUTHORS: Strully, J. L., & Bartholomew-Lorimer, K.

PUBLICATION INFORMATION: 1988

In S. M. Pueschel (Ed.), The young person with Down syndrome: Transition from adolescence to adulthood. Baltimore: Paul H. Brookes.

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In the first part of this chapter, Strully and Bartholomew-Lorimer neatly summarize the experiences of many people with disabilities at the hands of the human service system. By receiving services, individuals are turned into clients and become viewed primarily in terms of their particular disability. They are surrounded by programs and staff, and are cut off from typical people, places and events. One result of this is that people in the community come to believe that segregation is an appropriate response to people with disabilities.

The authors propose that freely given friendships between typical and disabled people "...are at the root of developing competent, caring communities for us all." They then present two case studies illustrating how to enable a person with disabilities to develop such friendships and the impact of these relationships for the people involved.

TITLE: Friendship and our children

AUTHORS: Strully, J., & Strully, C.

PUBLICATION INFORMATION: 1985

Journal of The Association for Persons with Severe Handicaps, 10(4), 224-227.

The close and caring relationship between two people known as a friendship requires shared experiences in order to develop and grow, and children who go to school together have the opportunity to develop relationships as well as skills. This essay about the friendship between Shawntell and Tanya, who attend intermediate school together, raises an important question: No matter what a school program has to offer, if it prevents children like Tanya and Shawntell from sharing daily experiences and becoming friends, is "special" good enough?

TITLE: On accepting relationships between people with mental retardation and non-disabled people: Towards an understanding of acceptance.

AUTHORS: Taylor, S. J., & Bogdan, R.

PUBLICATION INFORMATION: 1989

Disability, Handicap & Society, 4(1), 21-36.

This article outlines the "sociology of acceptance" as a theoretical framework for understanding relationships between people with mental retardation and typical people. As a point of departure, the authors review sociocultural perspectives on deviance and explore their contribution to the study of mental retardation. Based on qualitative research on community programs for people with severe disabilities, the authors next examine the nature of accepting relationships and describe four sentiments expressed by typical people who form relationships with people with mental retardation: family, religious commitment, humanitarian sentiments, and feelings of friendship. The article concludes with a brief discussion of the sociology of acceptance for the field of mental retardation.

TITLE: From community presence to sense of place: Community experiences of adults with developmental disabilities

AUTHOR: Walker, P.

PUBLICATION INFORMATION: 1999

JASH, 24(1), 23-32.

The places where people spend time and the experiences they have in these places are critical to the development of a sense of place and community connections. This study, based on individual experiences, reveals that adults with developmental disabilities commonly spend time in places designated for people with disabilities versus

the general public, in public versus private places, and in places characterized by business transactions versus social interactions. Within the community, the research participants have a variety of experiences. They range from a sense of vulnerability to a sense of safety, a feeling of being socially anonymous or isolated to a feeling of being known, from disaffiliation to identification, from unfamiliarity to familiarity, from a sense of being rejected to a sense of being liked or accepted, and from a sense of unwillingness/willingness to provide accommodations. The article concludes with strategies that service providers and others can use to increase opportunities for positive community experiences and sense of place.
