

WPASBIBLIOGRAPHY

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Subject: Community Living

Date: December 1996

This bibliography lists resources available at the Washington Protection and Advocacy System (WPAS), unless stated otherwise. (WPAS Library call numbers are in parentheses at the end of the citations.)

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MR-WA-0002-0005

I. Books

1. Abuse Monitoring Project of Equip for Equality, Inc. Not Our Problem: Executive and Legislative Response to Violence to State-Operated Institutions in Illinois. Chicago: Equip for Equality, Inc.; 1994. (RIG 078)

This is the first report of an independent, external evaluation of the quality of investigations conducted by the Office of the Inspector General of complaints of abuse and neglect at four Chicago area institutions.

2. _____. Not Our Problem: Executive and Legislative Response to Violence in State-Operated Institutions in Illinois: Final Report. Chicago: Equip for Equality, Inc.; 1996. (RIG 078 Final)

This second evaluation of Office of Inspector General investigative reports focused on a comparison of the 1993 baseline findings with results obtained for investigative reports received during the second half of 1994 when all investigators had been trained and many of the policy changes had been initiated.

3. American Association of University Affiliated Programs (AAUAP); Association for Retarded Citizens of the United States (ARC/US); National Association of Developmental Disability Councils (NADDC); National Association of Private Residential Resources (NAPRR); National Association of Protection and Advocacy Systems (NAPAS); United Cerebral Palsy Associations, Inc. (UCPA). Continuous Active Treatment. Washington, D.C.: The Associations; 1991. (RES 001)

This looseleaf binder contains material from a working conference held in Washington, D.C., on March 21-22, 1991. Attendees at the conference discussed the provision of "active treatment" to people with developmental disabilities.

4. Blake, Ellen M.; Prouty, Robert W.; Lakin, K. Charlie; Mangan, Troy. Reinventing Quality: a Sourcebook of Innovative Programs for Quality Assurance and Service Improvement in

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Community Settings. Minneapolis, MN; University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration; 1994 and 1995. (MIS 017)

These reports describe activities to assure and enhance the quality of services to persons with developmental disabilities.

5. Blatt, Burton; Kaplan, Fred. Christmas in Purgatory - A Photographic Essay on Mental Retardation. Syracuse, NY: Syracuse University; 1974. (RES 037)

This book of photographs depicts the conditions of public institutions in the period just a few years after deinstitutionalization was begun and major federal reforms were instituted.

6. Bogdan, Robert; Taylor, Steven J. The Social Meaning of Mental Retardation: Two Life Stories. New York: Teachers College Press; 1994. (DIS 024)

This book addresses the question "What does it mean to be 'mentally retarded'?" by interviewing two experts, "Ed Murphy" and "Pattie Burt," for answers. Ed and Patti, former residents of institutions, tell what it means in their own words. This book was originally published under the title Inside Out.

7. Braddock, David; Hemp, Richard; Bachelder, Lynn; and Fujiura, Glenn. The State of the States in Developmental Disabilities, 4th ed. Washington, D.C.: American Association on Mental Retardation; 1995. (MIS 005 1995)

This volume reports statistics on public and private institution utilization and expenditures for each of the states and the U.S. In addition to detailed statistics for 1988-92, trends are provided on a number of important indicators of change beginning with 1977.

8. Carling, Paul J.; Besio, Susan W. Community Integration: The Challenge of the 1990's. Burlington, VT: Center for Community Change Through Housing and Support, University of Vermont; 1992. (HOU 002)

This is a collection of material from the Pre-Conference Training Institute, Western Regional Conference on Housing and Supports, held in Portland, OR, May 31-June 3, 1992.

9. Conroy, James W. The Hissom Outcomes Study: A Report on Six Years of Movement into Supported Living--The People Who Moved from Hissom Memorial Center to Community: Are They Better Off? Brief Report Number 1 of a Series on the Well-Being of People with Developmental Disabilities in Oklahoma. Ardmore, PA: Center for Outcome Analysis; 1995. (INS 013)

This report, the first in a series, addresses the main question, "Are people better off?" for the 520 people who lived at the Hissom Memorial Center (Oklahoma) on or after May 2, 1985.

10. Conroy, James W.; and Bradley, Valerie J. The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis. Philadelphia: Temple University Developmental Disabilities Center. Boston: Human Services Research Institute; 1985. (RES 038)

This report describes findings of the most comprehensive study of persons released from a large public institution in the U.S. It reports on a major court-ordered deinstitutionalization effort in Pennsylvania and highlights outcomes for people as well as issues related to financing post-institutional community life.

11. Crocker, Allen. Medical Care Needs of Persons with Developmental Disabilities. Omaha, NE: University of Nebraska Medical Center, Department of Psychiatry; 1986. (HEA 201)
Dr. Crocker is Professor, Department of Pediatrics, Boston Children's Hospital, and Adjunct Professor, Harvard Medical School. His presentation concentrates on the medical care needs of persons with developmental disabilities. This video cassette was produced as part of a series ("Effective and Efficient Community Services for the Most Challenging to Serve") funded by the Administration on Developmental Disabilities.

12. Davis, Meredith, ed. From Dependence to Independence. Boulder, CO: Western Interstate Commission for Higher Education (WICHE); 1981. (MEN 007)
This document provides the necessary framework for the development of a clear statement of the staff capabilities necessary to serve the people with chronic mental illness.

13. Duke University Medical Center, Department of Psychiatry, Division of Social and Community Psychiatry. Hospital Without Walls (Programs for Assertive Community Treatment - Pact). Durham, NC: Duke University Medical Center, Department of Psychiatry, Division of Social and Community Psychiatry; 1993. (RES 202)

An in-depth introduction to the Programs for Assertive Community Treatment (PACT), which is a community-based service approach that helps people with severe mental illnesses remain in their own homes, control symptoms, and become contributing members of their communities. (48 minutes)

14. Fahs, Jeffrey J. Psychopharmacologic Interventions with Mentally Retarded Individuals. Omaha, NE: University of Nebraska Medical Center, Department of Psychiatry; 1987. (PHA 200)

Dr. Fahs is a psycho-pharmacologist at the University of Alabama at Birmingham. He specializes in treatment of people who are dually diagnosed (MR/MI). This video cassette was produced as part of a series ("Effective and Efficient Community Services for the Most Challenging to Serve") funded by the Administration on Developmental Disabilities.

15. Ferguson, Philip M.; Ferguson, Dianne L.; Taylor, Steven J., eds. Interpreting Disability: A Qualitative Reader. New York: Teachers College Press; 1992. (DIS 025)

This book offers a collection of qualitative research affecting people with disabilities and their families.

16. Gettings, Robert M. Serving Delaware Children and Adults with Severe, Chronic Medical and Developmental Disabilities. Alexandria, VA: National Association of State Mental Retardation Program Directors; 1992. (DIS 050)

This is the report of a comprehensive study of the organization and delivery of services in Delaware to children and adults who are medically fragile.

17. Goldman, Sybil K. Crisis Services (Vol. 2 of a series on Community-Based Services for Children and Adolescents Who Are Severely Emotionally Disturbed). Washington, D.C.: Georgetown University Child Development Center, CASSP Technical Assistance Center; 1988. (SUP 005)

The focus of this report is on the mental health system and its linkages with other providers and systems to provide crisis intervention and stabilization services to children and adolescents who are severely emotionally disturbed and to their families. It also focuses on community-based services.

18. Harris County (TX) Psychiatric Center. Involuntary Interventions: the Call for a National Legal and Medical Response. Houston: University of Texas-Houston Medical School Department of Psychiatry and Behavioral Sciences; 1994. (RIG 071 Proc.)

These are the proceedings of a symposium, May 5 - 7, 1994, designed to bring together knowledgeable professionals, consumers, and families to discuss the issues involved with involuntary interventions. One of the objectives of the Symposium was to identify methods for improving the quality and availability of community-based services and supports.

19. Howell, Mary. Clients Who Are Mentally Retarded and Also Old: Developmental, Emotional, and Medical Needs. Omaha, NE: University of Nebraska Medical Center, Department of Psychiatry; 1987. (SUP 200)

Dr. Howell is Head of the Kennedy Aging Project, Eunice Kennedy Shriver Center on Mental Retardation. Her presentation reviews what types of services can be provided and how to set up a demonstration project for this under served population. This video cassette was produced as part of a series ("Effective and Efficient Community Services for the Most Challenging to Serve") funded by the Administration on Developmental Disabilities.

20. Institute on Disability/A University Affiliated Program, University of New Hampshire. Extending the American Dream: Home Ownership for People with Disabilities. Durham, NH: National Home of Your Own Alliance; 1994. (HOU 004)

This report is a summary of financial data for 16 participants in New Hampshire's "Home of Your Own Project." The project demonstrated that service funds and disability-related entitlements, if used imaginatively, can allow people to own homes.

21. Irwin, Marilyn; Wilcox, Barbara. Least Restrictive Environment: Commitment to Implementation. Bloomington, IN: Institute for the Study of Developmental Disabilities; 1987. (EDU 124)

This document contains the transcribed and edited plenary presentations as well as executive summaries of each concurrent session of the 1987 National Leadership Conference. Goals of the Conference were to: 1) determine that collaboration among

policy makers, local public school personnel, parents, and university professionals can result in system change; 2) demonstrate the effectiveness of school programs that incorporate best practices; and 3) explore strategies for change that are relevant to the needs of parents, teachers, administrators, and advocates of individuals who have severe disabilities.

22. Janicki, Matthew P. Building the Future: Planning and Community Development in Aging and Developmental Disabilities. Albany, NY: Community Integration Project, New York Office of Mental Retardation and Developmental Disabilities; 1991. (AGI 228)

This manual is an overview of what New York has experienced and of lessons learned in "building the future" for seniors with lifelong disabilities. The manual contains specific sections on aids to planning, networking, training, and program development and a brief overview of key federal enabling legislation.

23. _____. Integration Experiences Casebook: Program Ideas in Aging and Developmental Disabilities. Albany, NY: Community Integration Project, New York Office of Mental Retardation and Developmental Disabilities; 1992. (AGI 229)

These 38 case studies illustrate projects which were successful at integrating individuals with mental retardation and other developmental disabilities into aging services or promoting their inclusion in community life.

24. Jaskulski, Teckla M.; Lakin, K. Charlie; Zierman, Susan A.; President's Committee on Mental Retardation. The Journey to Inclusion: a Resource for State Policy Makers. Washington, D.C.: U.S. Department of Health and Human Services, Administration for Children and Families; 1995. (ADV 032)

The purpose of this document is to provide participants at the 1995 National Collaborative Academy on Mental Retardation with background on the theoretical framework that governs the provision of services and supports to people with mental retardation, the best practices that the field endorses, and the changes in the form, scope and substance that mental retardation systems around the country have experienced over the past several decades.

25. Johnson, Ann Braden. Out of Bedlam: The Truth About Deinstitutionalization. New York: Basic Books; 1990. (RES 041)

This book focuses on the deinstitutionalization of persons with psychiatric disabilities and a "great social experiment" that, the author feels, yielded much less than promised.

26. Karan, Orv. Mental Health Needs of Mentally Retarded/Mentally Ill Persons. Omaha, NE: University of Nebraska Medical Center, Department of Psychiatry; 1986. (MEN 201)

Dr. Karan is Training Director, Research and Training Center, University of Wisconsin, Madison. His presentation asks, "What is the community doing about the mental health needs of persons who are mentally retarded/mentally ill; and what are some of the issues that need to be addressed to integrate these individuals into the community?" This video cassette was produced as part of a series ("Effective and Efficient Community Services for

the Most Challenging to Serve") funded by the Administration on Developmental Disabilities.

27. Mangan, Troy; Blake, Ellen M.; Prouty, Robert W.; Lakin, K. Charlie. Residential Services for Persons with Mental Retardation and Related Conditions: Status and Trends Through 1993. Minneapolis, MN: University of Minnesota Research and Training Center on Residential Services and Community Living, Institute on Community Integration (UAP); 1994. (RES 017)

This report presents statistics on persons with mental retardation and related conditions in state-operated, non-state, and Medicaid-funded residential programs in the United States, including residential services operated specifically for persons with mental retardation and related conditions, nursing homes, and state psychiatric facilities. The statistics in this report are for the year ending June 30, 1993.

28. Martin, Leslie; Ludi, Dale Carter. Self-Determination: The Road to Personal Freedom. Albuquerque, NM: New Mexico Protection and Advocacy System; 1994. (ADM 042)

This manual presents a set of concepts which help explain what constitutes self-determination and provides teaching strategies that give students the best opportunities to practice what it takes to be self-determined.

29. McGee, John. Gentle Teaching. Omaha, NE: University of Nebraska Medical Center, Department of Psychiatry; 1987. (BEH 200)

Dr. McGee discusses his philosophical approach to serving persons with developmental disabilities. The essence of this approach is the bonding between the care giver and the individual. He is strongly opposed to using aversives. This video cassette was produced as part of a series ("Effective and Efficient Community Services for the Most Challenging to Serve") funded by the Administration on Developmental Disabilities. (Also see the book #BEH 136.)

30. McGee, John J.; Menolascino, Frank J.; Hobbs, Daniel C.; Menousek, Paul E. Gentle Teaching: A Non-Aversive Approach to Helping Persons with Mental Retardation. New York: Human Sciences Press; 1987. (BEH 136)

This book is presented as an option to the punishment practices that are often used by those who serve persons with mental retardation and behavioral problems. It challenges care givers to question these practices and to become teachers of bonding and reward rather than administrators of punishment. (Also see the video cassette #BEH 200.)

31. Minnesota Governor's Planning Council on Developmental Disabilities. A New Way of Thinking. St. Paul, MN: Governor's Planning Council on Developmental Disabilities; 1987. (DIS 112)

This report reviews the "new way of thinking" about how, where, and with whom people with developmental disabilities can live, learn, and work. (Also see the video cassette #DIS 200.)

32. _____. A New Way of Thinking. St. Paul, MN: Governor's Planning Council on Developmental Disabilities; 1987. (DIS 200)

This is a video cassette of the report which reviews the "new way of thinking" about how, where, and with whom people with developmental disabilities can live, learn, and work. (23 minutes) (Also see the report #DIS 112.)

33. Minnesota Mental Health Law Project. Room Enough for Everyone: People With Mental Illness and Community-Based Group Homes. Minneapolis, MN: Minnesota Mental Health Law Project; 1992. (RES 013)

This manual is designed to help community advocates increase public awareness that group homes offer substantial benefits and do not threaten safety or property values, and to advise the public and its officials of the advantages and of the legal rights of persons with mental illnesses living in the community.

34. Moise, Lotte E. As Up We Grew with Barbara. Minneapolis, MN: Dillon Press; 1980. (DIS 003)

This book is the personal story of Lotte, Al, David, Karen, and Barbara Moise and of twenty-five years of progress in community acceptance and services for children with severe and multiple disabilities.

35. Naiditch, Zena; Martin, Marilyn; Mayer, Susan. Abuse of Dually Diagnosed Persons in Institutions: Report of the Court Monitor - Protection and Advocacy, Inc.--Injuries, Alleged Abuse, Restraint and Seclusion of Dually Diagnosed Persons in DMH/DD-Operated Institutions. Chicago: Protection and Advocacy, Inc.; 1988. (ABU 010)

This is a court-ordered (Nathan v. Levitt) report on injuries, alleged abuse, restraint and seclusion of a sample of individuals who had a dual diagnosis (both mental retardation and mental illness) and who lived in institutions operated by the Illinois State Department of Mental Health and Developmental Disabilities (DMH/DD). The report covers a six-month period, April-October 1987.

36. National Association of Protection and Advocacy Systems (NAPAS). Community Services Litigation. Washington, D.C.: National Association of Protection and Advocacy Systems (NAPAS); 1994. (RIG 157)

This loose-leaf binder contains materials from the workshop "Participants of Community Service Litigation (II): Designing and Implementing the Remedy" presented at the 1994 NAPAS Conference. Included is information on all phases of preparation for and conduct of systems litigation seeking to move people from institutions to community homes.

37. National Resource Center on Homelessness and Mental Illness, Policy Research Associates, Inc. Creating Community: Integrating Elderly and Severely Mentally Ill Persons in Public Housing. Delmar, NY: National Resource Center on Homelessness and Mental Illness, Policy Research Associates, Inc.; 1993. (HOU 007)

This report is jointly sponsored by the U.S. Department of Housing and Urban Development (HUD) and the Center for Mental Health Services of the U.S. Department

of Health and Human Services (HHS) as part of their ongoing effort to encourage coordination of housing and services for low-income and homeless families and individuals, including those with severe mental illnesses. The information is designed to help management and staff of public housing agencies and community mental health agencies seeking ways to effectively integrate younger individuals with mental illnesses into public housing for elderly families. Includes a case study of the Seattle Housing Authority.

38. New York State Commission on Quality of Care for the Mentally Disabled. Crossing the Line from Empowerment to Neglect: the Case of Project L.I.F.E. Albany, NY: New York State Commission on Quality of Care for the Mentally Disabled; 1994. (RES 019)

This report presents the results of a review of operations of the Project L.I.F.E. supportive apartment program in New York City. A number of serious problems were identified which affect the health and safety of the residents.

39. _____. Falling Through the Safety Net: "Community Living" in Adult Homes for Patients Discharged from Psychiatric Hospitals. Albany, NY: New York State Commission on Quality of Care for the Mentally Disabled; 1993. (INS 003)

This report presents case studies of two people who were long-term psychiatric center inpatients. Their discharge, from psychiatric centers where they had spent substantial parts of their lives to adult homes, ended in tragedies.

40. _____. Life and Death at New Queen Esther Home for Adults. Albany, NY: New York State Commission on Quality of Care for the Mentally Disabled; 1993. (RES 016)

This report provides a snapshot of conditions in one adult home in New York state. The investigation into a homicide at the home revealed problems affecting the safety and well-being of the residents.

41. New York State Commission on Quality of Care for the Mentally Disabled; Mental Hygiene Review Board. In the Matter of Jacob Gordon: Facing the Challenge of Supporting Individuals with Serious Mental Illness in the Community. Albany, NY: New York State Commission on Quality of Care for the Mentally Disabled; 1995. (RES 029)

This report presents the story of a young man's life and death at age 35 from Neuroleptic Malignant Syndrome, a rare and sometimes fatal reaction to psychotropic medication.

42. O'Reilly, Carol D. Family Connections/A Family Support Project/Families Making Communities: Book 1) An Introduction; Book 2) Getting Started; Book 3) Sharing Our Stories, Sharing Our Lives; Book 4) Families Empowering Themselves; Supplement) Family Voices. Lexington, KY: University of Kentucky Family Connections Project, Interdisciplinary Human Development Institute (UAP); 1995. (PAR 013 Books 1-4 and Supplement)

This series of documents are the final products of the Family Connections Project. They look at a philosophy of family support (Book 1), how to move from beliefs to action (Book 2), the way in which personal stories strengthen the community (Book 3), and how families go about the business of empowering themselves at home and in the communities

of their choice (Book 4). The supplement, Family Voices, records family stories told as part of an oral history project.

43. Potter, Jane, M.D.. Services for the Elderly Mentally Retarded. Omaha, NE: University of Nebraska Medical Center, Department of Psychiatry; 1987. (SUP 201)

Dr. Potter is Head of the University of Nebraska Medical Center's Gerontology Program. In this presentation, she discusses community-based services and normalization as they relate to the elderly who are mentally retarded and provides information on the historical development of these programs. This video cassette was produced as part of a series ("Effective and Efficient Community Services for the Most Challenging to Serve") funded by the Administration on Developmental Disabilities.

44. President's Committee on Mental Retardation. A Presidential Forum: Citizens with Mental Retardation and Community Integration. Washington, D.C.: President's Committee on Mental Retardation; 1989. (DIS 233)

This document is the proceedings of the Presidential Forum held in Washington, D.C., in February 1988. The purpose of the Forum was to examine the national effort to promote maximum community integration and to highlight the experiences of educators, service providers, community planners, Federal/State officials, parents, advocates, etc. that have achieved success in planning, designing, evaluating, and/or implementing diverse community integration projects serving persons with mental retardation.

45. _____. Collaborating for Inclusion: 1995 Report to the President. Washington, D.C.: U.S. Department of Health and Human Services, Administration for Children and Families; 1996. (ADV 036)

To further the prospects of inclusion, in September 1995 the President's Committee sponsored the first in a series of National Collaborative Academies on Mental Retardation. This report summarizes the principles emerging from the Academy's deliberations, provides guidelines developed by State Teams to enhance collaborative promotion of inclusion, and presents positions of the President's Committee on Mental Retardation regarding the relevant public policy issues under debate in the current era of reform.

46. Prouty, Robert W.; Lakin, K. Charlie (eds.). Residential Services for Persons with Developmental Disabilities: Status And Trends Through 1994. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration; 1995. (RES 028)

This report is based on statistics gathered and analyzed as part of the National Residential Information Systems Project on Residential Services (RISP).

47. _____. Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1995 (Report 48). Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration; 1996. (RES 039)

This report summarizes the status of residential services in each of the states and the U.S. as of June 30, 1995. It provides breakdowns of public and private institution populations

as well as the number of people living in community settings of different sizes and types. It also reports completed and projected institutional closures.

48. Prouty, Robert W.; Lakin, K. Charlie. A Summary of States' Efforts to Positively Affect the Quality of Medicaid Home and Community-Based Services for Persons with Mental Retardation and Related Conditions (Report #34). Minneapolis, MN: University of Minnesota, Center for Residential and Community Services; 1991. (RES 040)

This study summarizes the kinds of activities engaged in by states to positively affect the quality of home and community-based services for persons with mental retardation and related conditions, and briefly describes specific innovative activities within nine states.

49. Racino, Julie Ann; Walker, Pamela; O'Connor, Susan; and Taylor, Steven J. (eds). Housing, Support, and Community: Choices and Strategies for Adults with Disabilities. Baltimore: Paul H. Brookes; 1993. (SUP 032)

This book presents case studies which demonstrate unique ways of thinking about supporting people to live in their own homes and participate in community life.

50. Robinson, Cordelia. Developmental History - Early Referral and Follow-up Project. Omaha, NE: University of Nebraska Medical Center, Department of Psychiatry; 1987. (PAR 201)

Dr. Robinson is Head, Infant and Early Childhood Program (UAP), Meyer Children's Rehabilitation Institute, University of Nebraska Medical Center. Her presentation examines the procedures for facilitating the referral of children with developmental disabilities who are hospitalized to their public school systems. This video cassette was produced as part of a series ("Effective and Efficient Community Services for the Most Challenging to Serve") funded by the Administration on Developmental Disabilities.

51. Rothman, David J.; and Rothman, Sheila M. The Willowbrook Wars: A Decade of Struggle for Social Justice. New York: Harper and Row; 1984. (Out of Print)

This study describes the implementation of the 1975 Willowbrook consent agreement on the closure of the Willowbrook Developmental Center in the state of New York.

52. Rowitz, Louis. Health Delivery Services and Residential Needs for the Elderly. Omaha, NE: University of Nebraska Medical Center, Department of Psychiatry; 1987. (HEA 202)

Dr. Rowitz is Professor, Department of Public Health and Associate Dean, University of Illinois at Chicago. He presents data and discusses issues concerning the health delivery services and residential needs of the elderly who are mentally retarded. This video cassette was produced as part of a series ("Effective and Efficient Community Services for the Most Challenging to Serve") funded by the Administration on Developmental Disabilities.

53. Schaftt, Gretchen E.; Randolph, Frances L. Innovative Community-Based Services for Older Persons with Mental Illnesses. Rockville, MD: Center for Mental Health Services, Division of Demonstration Programs, Community Support Section; 1994. (RES 030)

This report describes the experiences of 16 state mental health authority grantees and what was learned from them in order to stimulate better service development for older persons with mental disorders.

54. Searl, Julia, (ed.). Serving Children with Special Needs in Your Child Care Facility.

Syracuse, NY: Early Childhood Inclusion Network of Onandaga County; 1996. (EDU 040)

This manual is designed to assist child care providers with information on how to include children with disabilities in their facilities.

55. Smith, Gary; Ashbaugh, John. Managed Care and People with Developmental Disabilities: a Guidebook. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.; 1995. (SUP 017)

This guidebook is divided into two parts. Part I provides an overview of managed care. Part II includes a more in-depth examination of the potential application of managed care strategies to long-term supports for people with developmental disabilities.

56. Smith, Gary A.; Gettings, Robert M. The HCB Waiver and CSLA Programs: An Update on Medicaid's Role in Supporting People with Developmental Disabilities in the Community.

Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc.; 1994. (FIN 014)

This report summarizes the results of the NASSDDS' fifth nationwide survey of Home and Community-Based (HCB) waiver services for people with developmental disabilities. This report also includes a detailed layman's guide to the federal statutory and regulatory policies governing the HCB waiver program as well as other supplementary material.

57. _____. Medicaid-Funded Home and Community-Based Waiver Services for People with Developmental Disabilities: Long-Term Supports Project. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services; 1993. (FIN 006)

This report summarizes the results of NASDDDS' fourth nationwide survey on home and community-based waiver services to people with developmental disabilities. The report contains state-by-state statistics on home and community-based waiver utilization and expenditures.

58. _____. The Medicaid Home and Community-Based Waiver Program: Recent and Emerging Trends in Serving People with Developmental Disabilities. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services; 1996.

This report summarizes the results of NASDDDS' seventh annual nationwide survey on Home and Community-Based (HCB) waiver services for people with developmental disabilities. Among other topics, this report includes state-by-state statistics on HCB utilization and expenditures.

59. _____. Medicaid in the Community. Alexandria, VA: National Association of State Mental Retardation Program Directors, Inc.; 1992. (FIN 004)

This report examines the status of the Home and Community-Based (HCB) waiver program as well as the steps that are being taken to implement the Community Supported Living Arrangement (CLSA) program at the federal and state level.

60. Smith, Gary A.; Katz, Ruth E.; Gettings, Robert M. Medicaid Home and Community-Based Services for Persons with Developmental Disabilities: The Home and Community-Based Waiver Experience Federal Funding Inquiry. Alexandria, VA: National Association of State Mental Retardation Program Directors, Inc.; 1989. (FIN 002)

This report reviews the first eight years of the Home and Community-Based (HCB) waiver program (1981-1988) and examines its status. The report also discusses federal and state policy and administrative issues that affect the HCB waiver program.

61. Smull, Michael; Harrison, Susan Burke. Supporting People with Severe Reputations in the Community. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services; 1992. (SUP 001)

Nearly 50% of the people remaining in institutions are reported to have behavioral disorders. This handbook describes, through many practical examples, methods of planning community living with people who have histories of challenging those around them.

62. Taylor, Steven J.; Bogdan, Robert; and Racino, Julie Ann (eds). Life in the Community: Case Studies of Organizations Supporting People with Disabilities. Baltimore: Paul H. Brookes; 1991. (SUP 031)

This book presents case studies of community organizations and groups that are positive examples of community integration for people with developmental disabilities.

63. Taylor, Steven J.; Bogdan, Robert; and Lutfiyya, Zana Marie (eds). The Variety of Community Experience: Qualitative Studies of Family and Community Life. Baltimore: Paul H. Brookes; 1995. (SUP 033)

Filled with practical case studies, this book highlights examples of family and community life for individuals with developmental disabilities.

64. Treichler, Bruce; Hoogan, Gaye. The Rainier Follow-Along Project: Final Report. Olympia, WA: Washington State Department of Community Development; 1989. (DIS 063)

The objectives of this project were (1) to determine whether the system of services as developed by the Division of Developmental Disabilities, DSHS, adequately supported a group of persons with developmental disabilities as they moved from institution to community and (2) to field test a method of determining the adequacy of utilizing citizen volunteers rather than trained research professionals to evaluate the quality of life for people with developmental disabilities.

65. U.S. Court of Appeals for the Third Circuit. Idell S. v. Pennsylvania Department Of Public Welfare (DPW) Helen L. v. Didario. 1995. (RIG 608)

This file contains material relating to the landmark case in which the U.S. Supreme Court upheld the United States Court of Appeals for the Third Circuit decision holding that it was a violation of the Americans with Disabilities Act to keep a person with a disability "unnecessarily segregated" in a nursing home rather than to provide integrated services in the community.

66. U. S. District Court for the Middle District of Alabama, Northern Division. Ricky Wyatt v. State of Alabama: Order (December 17, 1991); Ricky Wyatt v. State of Alabama: United States' Response to Defendants' Motion for Judgment on the Pleadings and Plaintiffs' Motion for Summary Judgment on Plaintiffs' Claims under The ADA; Ricky Wyatt v. State of Alabama: Plaintiffs' Opposition to Defendants' Motion for Judgment on The Pleadings on Plaintiffs' Claims Under the ADA; Ricky Wyatt v. State of Alabama: Order (March 5, 1995). 1991 and 1995. (RIG 619)

This file contains material from two of the Wyatt cases: 1) the Order awarding reasonable fees to prevailing litigants in actions brought to enforce a constitutional right; and 2) Motions and Order concerning the question of discrimination under Title II of the ADA as it relates to the "unnecessary segregation from society" of persons with disabilities.

67. U.S. General Accounting Office, Human Resources Division. Board and Care: Insufficient Assurances That Residents' Needs Are Identified and Met. Washington, D.C.: U.S. General Accounting Office, Human Resources Division; 1989. (RES 004)

This report contains information on (1) the size of the board and care industry, (2) characteristics and needs of board and care home residents, (3) how states are monitoring and regulating board and care homes, and (4) the role the Department of Health and Human Services has played in overseeing board and care.

68. Washington Department of Social and Health Services. Implementation Strategy: to Discourage the Inappropriate Placement of Persons at State Mental Hospitals and Encourage Their Care in Community Settings. Olympia, WA: Washington Department of Social and Health Services; 1994. (RES 014)

This report presents the strategies developed by DSHS to discourage the inappropriate placement of persons with developmental disabilities, head injury, and substance abuse at the state mental hospitals and to encourage their care in community settings.

69. Washington Department of Social and Health Services, Aging and Adult Services Administration, Home and Community Services. Options: You Have a Choice. Olympia, WA Washington Department of Social and Health Services, Aging and Adult Services Administration, Home and Community Services; 1996. (SUP 205)

This video describes services that may help adults who have difficulty maintaining their independence because of health-related problems. (15 minutes)

70. Washington Department of Social and Health Services, Home and Community Services Division. Traumatic Brain Injury (TBI) Title XIX Home and Community Based Waiver Request.

Olympia, WA: Washington Department of Social and Health Services, Home and Community Services Division; 1994. (HEA 032)

This is a copy of the Home and Community Based Services model waiver request submitted by the Aging and Adult Services Administration of the Department of Social and Health Services. The waiver requests authorization to provide home and community-based services as an alternative to institutionalization for fewer than 200 persons with traumatic brain injuries.

71. Wisconsin Coalition for Advocacy. Out of Sight, Out of Mind. Madison, WI: Wisconsin Coalition for Advocacy; 1986. (RIG 023)

This report concludes that people with severe disabilities, and their families, and their home counties (Wisconsin), deserve a real choice between placement in a Developmental Disability Center or living in the community.

72. Wolfensberger, Wolf. The Origin and Nature of Our Institutional Models. Syracuse, NY: Syracuse University; 1975. (RES 035)

This book describes the evolution of institutional care in the U.S. from early "pioneers" to the current era.

II. JOURNAL ARTICLES

1. Blacher, Jan; Baker, Bruce L. "Family Involvement in Residential Treatment of Children with Retardation: Is There Evidence of Detachment?," Journal of Child Psychology and Psychiatry and Allied Disciplines; vol. 35, no. 3, pp. 505-520.

This study is an examination of family involvement during the initial years after residential placement of children with mental retardation.

2. Bogdan, Robert. "A 'Simple' Farmer Accused of Murder: Community Acceptance and the Meaning of Deviance," Disability, Handicap and Society; vol. 7, no. 4, pp. 303-320.

This article tells the story of Delbert Ward and the small town he lives in. A documentary, Brother's Keeper, was made about Ward's trial over allegations that he murdered his brother, Bill.

3. _____. "Looking at the Bright Side: A Positive Approach to Qualitative Policy and Evaluation Research," Qualitative Sociology; vol. 13, no. 2, pp. 183-192.

This article describes the design of a research study and its implications for both practice and basic sociological understanding.

4. _____. "Relationships with Severely Disabled People: The Social Construction of Humanness," Social Problems; vol. 36, no. 2, pp. 135-148.

This article presents the perspectives of non-disabled people who do not stigmatize, stereotype, and reject those with obvious disabilities.

5. _____. "Toward a Sociology of Acceptance: The Other Side of the Study of Deviance," Social Policy; vol. 18, no. 2, pp. 34-39.

This article discusses a sociology of acceptance, types of accepting relationships based on the sentiments of family, religious, humanitarian and friendship, and the development of caring relationships.

6. Brown, Ralph A.; Hill, Betty Anne. "Opportunity for Change: Exploring an Alternative to Residential Treatment," Child Welfare; vol. 75, no. 1, pp. 35-57.

This article reports on an innovative program for children with moderate to severe emotional difficulties which promoted the use of "wraparound" services as an alternative to residential care.

7. Crocker, Allen C.; Yankauer, Alfred; Garrard Symposium and Workshop Conference Steering Committee. "Basic Issues," Mental Retardation; vol. 25, no. 4, pp. 227-232.

This article presents a summary of the ten basic issues which emerged at the Conference as central to the establishment of successful community health service systems for adults with significant mental retardation.

8. Erb, Robert G. "Where, Oh Where, Has Common Sense Gone? (Or If the Shoe Don't Fit, Why Wear It?)," Mental Retardation; vol. 33, no. 3, pp. 197-199.

This paper reflects the author's "politically incorrect" attitude toward services for individuals with mental retardation.

9. Ervin, Mike. "Land of a Million Elephants," Progressive; vol. 59, no. 2, p. 39.

This is the personal account by one of the participants of a disability rights protest at the headquarters of the Republican National Committee.

10. Eyman, Richard K.; Grossman, Herbert J.; Chaney, Robert H.; Call, Thomas L. "The Life Expectancy of Profoundly Handicapped People with Mental Retardation," New England Journal of Medicine; vol. 323, no. 9, pp. 584-589.

This article reports on a study of data on mortality and other factors for 99,543 persons with developmental disabilities, including mental retardation, who received services from the California Department of Developmental Services between March 1984 and October 1987.

11. _____. "Survival of Profoundly Disabled People with Severe Mental Retardation," American Journal of Diseases of Children; vol. 147, no. 3, pp. 329-336.

This article defines further the association between survival and clinical disabilities in persons who have profound mental retardation. Included in the study were 128,248 of 155,851 persons who received services from the California Department of Developmental Services between January 1980 and March 1991.

12. Eyman, Richard K.; Olmstead, Charles E.; Grossman, Herbert J.; Call, Thomas L. "Mortality and the Acquisition of Basic Skills by Children and Adults with Severe Disabilities," American Journal of Diseases of Children; vol. 147, no. 2, pp. 216-222.

This article reports on a study to determine normative data on age-related probabilities of children with severe disabilities acquiring mobility or self-feeding skills, or dying during a 5-year follow-up period.

13. Garrard, Sterling G. "Health Services for Mentally Retarded People in Community Residences: Problems and Questions," American Journal of Public Health; vol. 72, no. 11, pp. 1226-1228.

This article presents questions which need to be addressed to assess the adequacy of community health care for persons with mental retardation.

14. Hayden, Mary F. "Stories from the Belly of the Beast: Testimony from Survivors of Institutionalization," submitted to Mental Retardation for review; September 1996. (Dr. Hayden is on the faculty at the University of Minnesota, Research and Training Center on Residential Services and Community Living, Institute on Community Living, Minneapolis, MN.)

This report presents the results of a survey of survivors of institutionalization. It presents, in their own words, their opinions or observations about the differences between living in institutions and living in the community.

15. Kastner, Ted; Luckhardt, Joan. "Medical Services for the Developmentally Disabled," New Jersey Medicine; vol. 87, no. 10, pp. 819-822.

This article reviews the components of a health care delivery system to help meet the special medical needs of people with developmental disabilities.

16. Kastner, Theodore; Criscione, Teri; Walsh, Kevin. "The Role of Tube Feeding in the Mortality of Profoundly Disabled People With Severe Mental Retardation," Archives of Pediatrics and Adolescent Medicine; vol. 148, no. 5, pp. 537-538.

This paper describes the association between mortality and the presence of a feeding tube based on a statistical analysis of the data contained in the report by Eyman, et al. ("Survival of Profoundly Disabled People with Severe Mental Retardation," see above) and to suggest further lines of research using the database.

17. Kastner, Theodore; Nathanson, Ruth; Friedman, Debra L.. "Mortality Among Individuals with Mental Retardation Living in the Community," American Journal on Mental Retardation; vol. 98, no. 2, pp. 285-292.

This article presents the results of a study which described and evaluated the deaths of 14 patients from among more than 1,300 people with mental retardation who live in the community and receive their health care from a community-based primary care clinic.

18. Knobbe, Carol A.; Carey, Sean P.; Rhodes, Larry; Horner, Robert H. "Benefit-Cost Analysis of Community Residential Versus Institutional Services for Adults with Severe Mental

Retardation and Challenging Behaviors," American Journal of Mental Retardation; vol. 99, no. 5, pp. 533-541.

This article reports on a benefit-cost analysis conducted to compare services in community residences versus an institution for eleven individuals with severe mental retardation and challenging behaviors who had been moved from an institution to a community setting.

19. Landesman, Sharon; Butterfield, Earl C. "Normalization and Deinstitutionalization of Mentally Retarded Individuals: Controversy and Facts," American Psychologist; vol. 42, no. 8, pp. 809-816.

This article examines the sources of the controversy over normalization with the objective of clarifying the limits of knowledge about treatment [in 1987] and opening the possibility of theory-based evaluation of service delivery.

20. Lindeman, Alice K. "Resident Managers' Nutrition Concerns for Staff and Residents of Group Homes for Mentally Retarded Adults," Journal of the American Dietetic Association; vol. 91, no. 5, pp. 602-604.

This article reports on the results of a needs assessment and the recommendations for staff training, menu design, and nutrition references presented to administrators at each of eight group homes and to a dietician working with the homes.

21. Malmberg, Bo; Zarit, Steven H. "Group Homes for People with Dementia: A Swedish Example," Gerontologist; vol. 33, no. 5, pp. 682-686.

This study evaluated four group homes in Jönköping, Sweden, and concluded that both staff and residents were satisfied with the set up (a social model in which the residents participate in everyday activities in a home-like setting) which was developed as an alternative to traditional institutional care.

22. Miller, C; Eyman, R. "Hospital and Community Mortality Rates Among the Retarded," Journal of Mental Deficiency Research; vol. 22, no. 2, pp. 137-145.

This paper reports on a study which contrasts mortality factors between persons with mental retardation and living in hospital settings with those living in community placements.

23. Minihan, Paula M. "Planning for Community Physician Services Prior to Deinstitutionalization of Mentally Retarded Persons," American Journal of Public Health; vol. 76, no. 10, pp. 1202-1206.

This is the report of a study that assessed the need for physician services among a group of institutionalized individuals with mental retardation in anticipation of their transfer to community residential facilities and subsequent management of their care by community-based physicians.

24. O'Brien, John. "Down Stairs That Were Never Your Own: Supporting People With Developmental Disabilities in Their Own Homes," Mental Retardation; vol. 32, no. 1, pp. 1-6.

This article discusses the historical and current meanings and dimensions of "house" and "home" for persons with developmental disabilities.

25. O'Connor, Susan. "Supporting Families: What They Want Versus What They Get," OSERS News in Print; vol. 5, no. 1, pp. 7-11.

This article discusses the discrepancy between what families feel they need versus what they get from the human service system with special emphasis on the impact of culture in receiving services.

26. Owen, Margaret Tresch; Mulvihill, Beverly A. "Benefits of a Parent Education and Support Program in the First Three Years," Family Relations; vol. 43, no. 2, pp. 206-212.

This study describes an evaluation of a parent education and support program offered to all parents of newborn children regardless of socio-economic status in three independent school districts. Potential benefits to the parents and the children were examined over the 3-year course of the program.

27. Parsons, Marsha B.; Cash, Victoria B.; Reid, Dennis H. "Improving Residential Treatment Services: Implementation and Norm-Referenced Evaluation of a Comprehensive Management System," Journal of Applied Behavior Analysis; vol. 22, no. 2, pp. 143-156.

This article reports on a study conducted to evaluate the extent and quality of treatment services provided in residential living units (Experiment 1) and to evaluate a comprehensive management system designed to improve such services (Experiment 2).

28. Racino, Julie Ann; Heumann, Judith E. "Independent Living and Community Life: Building Coalitions Among Elders, People with Disabilities, and Our Allies," Generations; vol. 16, no. 1, pp. 43-47.

This article describes societal responses to elders, people with disabilities, and people with mental retardation; highlights independent and supportive living for people of all ages; discusses the issues of housing, personal assistance, and independent living centers; and recommends steps to meet the challenge of maintaining the right for all people to live and participate in community life.

29. Schloss, Patrick J.; Alper, Sandra; Jayne, Donna. "Self-Determination for Persons with Disabilities: Choice, Risk, and Dignity," Exceptional Children; vol. 60, no. 3, pp. 215-225.

This article presents a rationale for including self-determination in special education curricula. The article describes a framework for providing choices, based on an analysis of risk and benefits and offers assessment approaches and teaching strategies.

30. Strauss, David; Kastner, Theodore A. "Comparative Mortality of People with Mental Retardation in Institutions and the Community," American Journal on Mental Retardation; vol. 101, no. 1, pp. 26-40.

This paper compares the risk-adjusted mortality rates in institutions and the community in California from 1980 through 1992 with the aim of improving the understanding of the capacity of the community health system to support deinstitutionalization.

31. Taylor, Steven J.; Bogdan, Robert. "On Accepting Relationships Between People with Mental Retardation and Non-Disabled People: Towards an Understanding of Acceptance," Disability, Handicap and Society; vol. 4, no. 1, pp. 21-36.

This article outlines the sociology of acceptance, a theoretical framework for understanding relationships between people with mental retardation and people without disabilities.

32. Taylor, Steven J.; Lakin, K. Charlie; Hill, Bradley K. "Permanency Planning for Children and Youth: Out-of-Home Placement Decisions," Exceptional Children; vol. 55, no. 6, pp. 541-549.

This article advocates the extension of the basic protections of "permanency planning" to all children and youth, including those with severe disabilities.

33. Traustadottir, Rannveig. "Mothers Who Care: Gender, Disability, and Family Life," Journal of Family Issues; vol. 12, no. 2, pp. 211-228.

This article is based on a study of families of children with disabilities which examined the role of gender in caring for a child with a disability.

34. Trent, James W., Jr. "Suffering Fools," Sciences; vol. 35, no. 4, pp. 18-22.

This article comments on the efforts in the 20th century to change the definition of mental retardation. These efforts opened opportunities to improve the treatment conditions of people with mental retardation and have included the move for deinstitutionalization and proposals to stop using IQ tests for measuring a person's intelligence.

35. Vandergriff, David V.; Chubon, Robert A. "Quality of Life Experienced by Persons with Mental Retardation in Various Residential Settings," Journal of Rehabilitation; vol. 60, no. 4, pp. 30-37.

This article reports on a study conducted to assess the quality of life of persons with mental retardation residing in a variety of residential settings.

36. Walker, Pam. "Promoting Individualized and Integrated Recreation and Leisure Experience," Exceptional Parent; vol. 23, no. 4, p 54.

This article presents strategies for developing the supports that will enable people with disabilities to participate in regular community programs, activities, and settings and for moving away from special recreation and leisure programs.

37. _____. "Where There Is a Way, There Is Not Always a Will: Technology, Public Policy, and the School Integration of Children Who Are Technology-Assisted," Children's Health Care; vol. 20, no. 2, pp 68-74.

This article discusses issues of educational and Medicaid policy regarding payment for school health care services for children who use assistive technology.

38. Walker, Pam; Edinger, Betsy. "The Kid From Cabin 17," Camping Magazine; vol. 60, no. 7, pp. 18-21.

This article tells the story of Chauncey's summer camp experience and the lessons learned about the integration of children with severe disabilities.

39. Weidlich, Thom. "A Bureaucracy Lays Siege to Group Homes," National Law Journal; vol. 18, no. 11, p. A1, col. 1.

This news article reports on Judge Elizabeth O'Neill LaStaiti's criticism of officials and lawyers in Massachusetts' Department of Mental Retardation over their treatment of the Providence, RI, Judge Rotenberg Educational Center. Judge LaStaiti accused department officials of making false claims and abusing discovery practices to shut down the center (formerly known as Behavior Research Institute, Inc.).

40. Weisman, Mary-Lou. "When Parents Are Not in the Best Interests of the Child," Atlantic Monthly; vol. 274, no. 1, pp. 42-56.

This article describes the programs at several residential treatment centers where children with behavior disorders receive treatment.

41. Woodward, Harold L. "One Community's Response to the Multi-System Service Needs of Individuals with Mental Illness and Developmental Disabilities," Community Mental Health Journal; vol. 29, no. 4, pp. 347-359.

This paper describes some of the barriers individuals and communities confront in developing new or expanding existing services to meet the needs of people with mental illness and mental retardation. It then describes how one community initiated multi-system collaboration in its delivery of crisis intervention services, community mental health center services, and specialized short-term residential living.

42. Ziring, Philip R.; Kastner, Ted; Friedman, Debra L.; Pond, William S.; Barnett, Michael L.; Sonnenberg, Edward M.; Strassburger, Kathryn. "Provision of Health Care for Persons with Developmental Disabilities Living in the Community," Journal of the American Medical Association; vol. 260, no. 10, pp. 1439-1444.

This article describes the program of health care services established by the New Jersey Department of Human Services to supplement the existing generic system of medical care. The supplemental program was developed when the generic system was not able to provide all necessary services to the large number of individuals transferred from state residential facilities to the community.

III. SITE VISIT REPORTS

1. Hulgín, Kathleen; Searl, Julia A. Job Path: Shifting the Focus Beyond Just Work. Syracuse, NY: Center on Human Policy, Syracuse University; 1996.

This report describes how an organization in New York City began to develop alternative day services for people with severe disabilities.

2. Racino, Julie Ann. "People Want the Same Things We All Do": The Story of the Area Agency in Dover, New Hampshire. Syracuse, NY: Center on Human Policy, Syracuse University; 1992.

This report describes a visit to a site in New Hampshire that strives to support people to work, live, and have leisure in the same ways as other community members.

3. Rogan, Pat. Toward Integrated Employment for All. Syracuse, NY: Center on Human Policy, Syracuse University; 1993.

This report describes the development of employment services at Monadnock Developmental Services in Region V of New Hampshire. It includes discussion of system change strategies, practices being used to support people in jobs, and current issues and dilemmas.

4. Shoultz, Bonnie. "Like an Angel that Came to Help Us": The Origins and Workings of New Hampshire's Family Support Network. Syracuse, NY: Center on Human Policy, Syracuse University; 1993.

This report describes New Hampshire's innovative family support services. It details the legislative history of the program as well as its implementation throughout the state, and draws lessons for others interested in developing family-centered programs.

5. Walker, Pam. Coming Home: From Deinstitutionalization to Supporting People in Their Own Homes in Region VI, New Hampshire. Syracuse, NY: Center on Human Policy, Syracuse University; 1993.

This report describes the efforts of the Area Agency for Developmental Services in Region VI, New Hampshire, to shift from supporting people in group homes to supporting them in their own homes. It offers important lessons for agencies/regions facing the dual challenge of institutional closure and promoting quality of life in the community.

IV. OTHER RESOURCE MATERIALS

1. General Accounting Office. Medicaid: Oversight of Institutions for the Mentally Retarded Should Be Strengthened. Washington, D.C.: GAO; 1996.

This report discusses (1) deficient care practices occurring in large Intermediate Care Facilities for the Mentally Retarded (ICF/MR), (2) whether state survey agencies identify all serious deficiencies in these institutions, and (3) weaknesses in Health Care Financing Agency (HCFA) and state oversight.

2. Hagner, David C. The Social Integration of Supported Employees: A Qualitative Study. Syracuse, NY: Research and Training Center on Community Living, Center on Human Policy, Syracuse University; 1989.

This study examines the social interactions that occur within supported employment settings, between workers with disabilities and nondisabled co-workers, and the job

supports at work settings, including the relationships between formal and informal job supports.

3. Hulgín, Kathy; Walker, Pam; Fisher, Ellen; Handley, Mary; Shoultz, Bonnie. Housing for People with Severe Disabilities: A Collection of Resource Materials. Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, Syracuse University; 1995.

This information package provides an introduction to housing strategies and resources to promote home ownership by people with disabilities and parents, to make housing more accessible to all people, and to increase the development and use of integrated housing options.

4. Lutfiyya, Zana Marie. Affectionate Bonds: What We Can Learn by Listening to Friends. Syracuse, NY: Research and Training Center on Community Living, Center on Human Policy, Syracuse University; 1990.

This report describes a study of friendships between people with and without disabilities, including how they met, characteristics of their friendships, and implications.

5. O'Brien, Connie Lyle; O'Brien, John. Making a Move: Advice from People First Members Helping People Move Out of Institutions and Nursing Homes. Syracuse, NY: Research and Training Center on Community Living, Center on Human Policy, Syracuse University; 1990.

This document shares the perspective of about 40 People First members on how People First members can help people move from institutions and nursing homes.

6. O'Brien, John. Designing Policies in Support of Inclusive Community: Questions for Decision Makers. Syracuse, NY: Research and Training Center on Community Living, Center on Human Policy, Syracuse University; 1989.

This paper presents questions for policy makers to examine the effects of funding priorities and service policy decisions on the capacity of communities to include people with disabilities.

7. _____. Getting the Job Done: Learning to Expand the Social Resources Available to People with Severe Disabilities at Work. Syracuse, NY: Research and Training Center on Community Living, Center on Human Policy, Syracuse University; 1992.

This paper presents ideas on how everyone involved can work together to support people with severe disabilities at work.

8. _____. Supported Living: What's the Difference? Syracuse, NY: Research and Training Center on Community Living, Center on Human Policy, Syracuse University; 1993.

This paper discusses the differences between supported living and the traditional ways of providing residential services, based on discussions among representatives of supported living agencies.

9. _____. Working on...A Survey of Emerging Issues in Supported Employment for People with Severe Disabilities. Syracuse, NY: Research and Training Center on Community Living, Center on Human Policy, Syracuse University; 1990.

This paper presents the common perspectives and themes of groups in seven states concerned with improving the quality of supported employment.

10. O'Brien, John; O'Brien, Connie Lyle. Assistance with Integrity: The Search for Accountability and the Lives of People with Developmental Disabilities. Syracuse, NY: Research and Training Center on Community Living, Center on Human Policy, Syracuse University; 1993.

This paper is a discussion piece, intended to stimulate controversy and dispute, about support for people who rely on service providers for 24-hour assistance. It addresses the field's concerns about such issues as safety, quality, and the potential for abuse, and calls for major reorganization of the current system of service provision.

11. _____. More Than Just a New Address: Images of Organization for Supported Living Agencies. Syracuse, NY: Research and Training Center on Community Living, Center on Human Policy, Syracuse University; 1991.

This paper presents a discussion on the changes agencies must make in moving to a "supported living" approach to community living, and is based on in-depth work with a number of agencies and individuals across the United States.

12. Searl, Julia. Community Integration Policy and Practice Abstracts. Syracuse, NY: Research and Training Center on Community Living, Center on Human Policy, Syracuse University; 1996.

This is a compilation of abstracts of recent journal articles relevant to community integration for people with developmental disabilities and includes topics of education, employment, policy, communication, and supported living.

13. Silverman, Wayne P.; Zigman, Warren B.; Silver, Ellen Johnson. "Adults with Profound Mental Retardation and Multiple Handicaps: Factors Associated with Mortality," in Community Living for People with Developmental and Psychiatric Disabilities. Baltimore, MD: Johns Hopkins University Press; pp. 82-93; 1992.

This chapter reports on a study designed to examine survival in a group of adults with disabilities (profound mental retardation, minimal adaptive competence, virtually no expressive language or independent mobility, and a history of medical problems) while they were living either in a large service-intensive facility or small residences integrated within the community.

14. Stancliffe, Roger J.; Lakin, K. Charlie. Analysis of Expenditures and Outcomes of Residential Alternatives for Persons with Developmental Disabilities. Syracuse, NY: Research and Training Center on Community Living, Institute on Community Integration, Syracuse University; 1996.

This manuscript, recently submitted for review, examines the expenditures, staffing, and outcomes for 116 adults with severe or profound mental retardation, who moved from

state institutions in Minnesota to various community settings, and a comparison group of 71 persons who remained institutionalized.

15. Traustadottir, Rannveig. Supported Employment: Issues and Resources. Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, Syracuse University; 1991.

This information package includes an overview article; three articles which offer different perspectives on employment: a consumer perspective, a parent perspective, and a gender perspective; and an annotated bibliography.

16. _____. Supports for Community Living: A Case Study. Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, Syracuse University; 1991.

This study examines in detail the supports provided to one individual with severe disabilities and the role this support has in enabling him to become a part of community life.

17. Walker, Pam. Selected Issues in Family Support: A Compilation of Materials and Resources. Syracuse, NY: Research and Training Center on Community Integration, Center on Human Policy, Syracuse University; 1995.

This information package focuses on selected issues in family support, including: family support principles; limitations of family support programs (related to race/ethnicity, culture, poverty, women, etc.); permanency planning; and state-level systems change advocacy. It contains various articles and annotated references relevant to these issues.

18. Wyden, Ron. "Residential Programs for the Mentally Retarded: Poor Quality Care, Waste and Theft of Millions in Public Reimbursement; Dangerously Inadequate Oversight by Federal, State, and Local Authorities," before the U.S. House of Representatives, Committee on Small Business, Subcommittee on Regulation, Business Opportunities, and Technology, March 29, 1993.

This is a transcript of Rep. Wyden's (Oregon) opening statement to the Subcommittee. Also included is a Subcommittee Staff Memo which presents the results of a year-long investigation of providers of assisted and independent living arrangements for persons with mental retardation.

V. NEWSBULLETINS

1. These bulletins were published through the Impact series of the Institute on Community Integration (UAP) and the Research and Training Center on Residential Services and Community Living at the University of Minnesota:

- A. This "Feature Issue on Institution Closures" (Winter 1995/96) contains national information as well as a variety of articles on closing institutions written from the perspectives of self-advocates, professionals, parents, researchers, and policy makers.
 - B. This "Feature Issue on Supporting Diversity" (Summer 1996) focuses on services for persons with developmental disabilities that support the whole person by acknowledging, respecting, and incorporating aspects of identity such as race, ethnicity, religion, sexual orientations, gender, age, and class.
 - C. In this "Feature Issue on Supported Living" (Autumn 1995), many leaders in the development of supported living describe the challenges and rewards in this new relationship between those who need assistance and those who provide assistance.
2. This newsbulletin was published by the Research and Training Center on Community Integration, Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University:
- A. "Community Living for Adults" (November 1989) highlights promising practices, issues, and resources in supporting adults with disabilities in living in the community.
3. This newsletter is published by the Research and Training Center on Residential Services and Community Living, Institute on Community Integration (UAP), University of Minnesota:
- A. "Policy Research Brief" (July 1996) summarizes the results of a survey of 32 states concerning training and certification requirements for direct service workers supporting people with developmental disabilities in residential settings.
4. This newsletter is published by the National Association of Protection and Advocacy Systems (NAPAS):
- A. "P&A News" (November/December 1996) presents success stories of supported living--excerpts from people with disabilities who have lived in institutions and now live and thrive in the community.