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## Foreword

As Assistant Secretary for the Office of Special Education and Rehabilitative Services (OSERS), one of my major priorities has been to promote the integration of people with disabilities into all aspects of community life. OSERS' goal has been to ensure that integration begins during the school years with children being educated in the least restrictive environment (LRE). The principle of LRE means that children with the full range of disabilities can and should be integrated into regular school settings. We have supported efforts to develop educational techniques which enable an increasing number of children with disabilities to learn in the same environment as other children. For the typical student, success is usually measured in outcomes such as meaningful work, a place to live, and personal fulfillment, which includes a social network of friends and family. These goals are equally valid for students with disabilities. Education in an integrated environment is the best way of preparing students to live in integrated communities as adults.

But our efforts to ensure integration during the school years will be incomplete unless there are opportunities for community participation for persons with disabilities when they become adults. One of the greatest barriers to full inte-

gration has been the lack of employment opportunities. In response to this need, OSERS established a national priority for improving the transition from school to working life for youth with disabilities. The transition process encompasses a broad array of services and experiences during high school, the point of graduation, additional postsecondary or adult services, and the initial years in employment. We have supported the development of cooperative models among state and local education agencies. These efforts have increased our ability to help youth with disabilities in making the transition from school to work. For those individuals whose physical and mental disabilities are so severe that they do not qualify for traditional vocational rehabilitation services, OSERS developed the supported employment model. This model allows persons with severe disabilities to engage in paid employment in integrated settings and receive on-going support services.

I take great pride in the progress we have made in furthering community integration. But I am also aware of how much remains to be done. The challenge of the 1990's is to capitalize on the

progress we have made and to break down the remaining barriers to full community integration. To help meet this challenge, the Research and Training Center on Community Integration, Center on Human Policy, at Syracuse University, in coordination with the National Institute on Disability and Rehabilitation Research, within the Office of Special Education and Rehabilitative Services, convened a group of experts in the area of community integration.

The results of the group's discussions are summarized in this document. It reflects not only the progress made in community integration but recommendations for future directions. It is now up to all of us to work together to ensure that these recommendations are carried out and become realities. If we are able to do this, we will have moved closer to our ultimate goal of ensuring full community participation for persons with disabilities.

Madeleine Will

## Preface

This report is the summary of the proceedings of a Leadership Institute on Community Integration for People with Developmental Disabilities held in Washington, DC. on November 21 and 22, 1988. The Leadership Institute was designed to identify the current state of knowledge and practice in community integration and to recommend directions for future efforts in this area.

The Leadership Institute was organized around four work groups, each focusing on a different aspect of community integration for people with developmental disabilities:

- 1 Community Living
- 2 Families
- 3 School
- 4 Work

The work groups were asked to address the following issues: (1) Based on current research and practice, what do we know about community integration for people with developmental disabilities?: (2) What are the priorities for research in community integration?: (3) What are the priorities for technical assistance and training?: (4) What are the priorities for information dissemination?: and (5) What are the key concepts or ideas that should guide our thinking about community integration in the future? As a point of departure for the work group discussions, a representative of one of the major universities participating in the Leadership Institute presented a paper containing an overview of the questions the work groups were asked to address.

In presenting this summary of the proceedings of the Leadership Institute, it is important to point out that participants at the Leadership Institute included representatives of major university research and training centers, parents, people with disabilities, policy specialists, and representatives of major national developmental disability organizations as well as federal officials. Each of the Rehabilitation Research and Training Centers funded by the National Institute on Disability and Rehabilitation Research with an exclusive or major focus on people with developmental disabilities was represented at the Leadership Institute. A list of participants is included in Appendix A.

Many people contributed directly or indirectly to this Leadership Institute. First, we want to thank all of the participants for their active involvement in the Leadership Institute. We also want to acknowledge and express our appreciation of the fact that university representatives supported their own travel expenses to Washington, D.C. to participate in the Leadership Institute. Second, we wish to thank Patricia M. Smith of the Office of Special Education and Rehabilitative Services and Naomi Karp of the National Institute on Disability and Rehabilitation Research for their enthusiastic support for the Lead-

ership Institute and for their efforts on behalf of people with developmental disabilities. Finally, we want to acknowledge the contribution of Mrs. Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, whose leadership has made possible much of the progress in the field of developmental disabilities identified at this Leadership Institute.

A summary of the proceedings of a meeting is not the same as the proceedings themselves. While this summary" is based on presentations and work group discussions, it represents our own interpretation of the key issues addressed at the Leadership Institute. A list of papers and work group reports from the Leadership Institute available from the Research and Training Center on Community Integration is included in Appendix B.

Steven J. Taylor  
Julie Ann Racino  
Bonnie Shultz  
Research and Training  
Center on Community  
Integration  
Center on Human Policy  
Syracuse University  
February, 1989

## Introduction

In the papers and work group discussions at the Leadership Institute, four themes emerged that cut across the areas of community living, family, school, and work. First, particularly in the 1980s, major progress has been made in integrating people with developmental disabilities, including those with severe disabilities, into the community. That people with developmental disabilities can live, work, and go to school in typical community settings is not just an idea. It is a reality in a growing number of communities across the country. The policy direction of integration for people with developmental disabilities is supported by a steadily growing body of research and practical experience.

Second, as a future priority, attention must be directed to helping people with developmental disabilities to achieve full integration and participation in the community. While expressed in different ways, the importance of social integration, or community participation, was a consistent theme running throughout the two days of the Leadership Institute. The challenge today is not merely to help people with developmental disabilities to be in the community, but to be part of the community as well.

Third, a tremendous gap exists between the best practices and the practices found in most states and communities. Whether in the area of community living, family supports, work, or school, "islands of excellence" can be found across the country. Yet programs in most states and communities fall far short of the standards set by the best programs.

Finally, an insufficient policy and economic base exists to support community integration efforts. Federal and state policies and funding mechanisms continue to support segregation rather than integration for people with developmental disabilities. Medicaid was consistently identified at the Leadership Institute as a major barrier to achieving integration for people with developmental disabilities in communities, families, workplaces, and schools. Public policy lags significantly behind the "state-of-the-art" and, in many cases, threatens to circumscribe

further progress in assisting people with developmental disabilities to occupy their rightful places in America's communities, families, schools, and workplaces.

A question that seems to capture the spirit of discussions at the Leadership Institute is: "Is the glass half full or half empty?" On the one hand, states and communities have made major gains in integrating adults and children with developmental disabilities in the community. Much has been accomplished and even more has been learned. On the other hand, the potential of community integration for all people with developmental disabilities is yet to be fulfilled. There remains much more to do and to learn.

**“In summary, the general preferability of community to institution living is well documented through research on developmental change, on the amount and types of activities engaged in, on the social and family relationships and on the perceptions and preferences of parents who have seen their offspring in both community and institution settings . . . Obviously making the state-of-the-practice approximate the state-of-the-art is a major challenge for the future.”**

**K. Charlie Lakin**

The area of community living faces many new challenges. As researchers, parents, people with disabilities, professionals, and policymakers, we know that it is not enough to be merely *in* the community, but we are still trying to understand what it means to be *of the* community. We are confronted with new questions: How do we promote social relationships between people with developmental disabilities and other community members? How do we design supports around people rather than fitting people into programs? How can we enhance quality of life? How do we maximize freedom of choice and self-expression? How can we balance independence with interdependence? How can we prevent the community from becoming like the institution? While we are facing new challenges and questions, we are still confronted by the fact that roughly 95,000 people with developmental disabilities remain in public institutions and over 80,000 live at private institutions and nursing homes

#### What We Know About Community Living

- All people with developmental disabilities, including those with severe developmental, behavioral, and health impairments, can live successfully in the community if appropriately supported.
- Institutions and other large, segregated living arrangements are unacceptable places for people with developmental disabilities to live.
- Any resources available in institutional settings can be

made available in community settings.

- The evidence and experience indicate that life in the community is better than life in institutions in terms of relationships, family contact, frequency and diversity of relationships, individual development, and leisure, recreational, and spiritual resources.
- All children with developmental disabilities can be supported in natural, adoptive, or foster families.
- Both children and adults with developmental disabilities benefit from stable relationships with other people, including family members and nondisabled community members.
- People with developmental disabilities can and do make positive contributions to the life of the community.

#### Research: What Researchers Need to Study and Funders Need to Support

- Quality of Services: A range of studies that examine the quality of services provided to people with developmental disabilities, including people with challenging behaviors and complex medical needs, from different perspectives and using different methodologies.
- National Research on Institutions and Community Living Arrangements: A stable and long-term funding source for studies of demographic, population, and service characteristics of institutions and community settings and federal and state financing of services for people with developmental disabilities.

- Social Relationships. Social Integration, and Social Networks: Quantitative and qualitative studies of social integration, including comparative studies of people with developmental disabilities and nondisabled people, studies of the relationship between formal and informal support systems, studies of the impact of community integration on families, studies of how community integration impacts on women and members of racial and ethnic minorities, and case studies of individuals, families, communities, and agencies.
- Legal and Policy Research: Studies of the impact of law and policy on people with developmental disabilities and their families, including comparative studies of states.
- Implications of Community Integration for Diverse Groups: Research on the meaning and nature of community integration for members of minority groups, urban populations, elderly people, and people with the most severe disabilities.
- State and Local Agency Administration and Practices: Studies of state administration and funding of services, quality assurance systems, especially nonregulatory approaches, consumer driven service approaches, and agency administration and staffing issues.

### **Technical Assistance and Training: The Assistance that States, Communities, Families, People with Disabilities, and Professionals Need**

- Training for Policymakers: Training, workshops, study tours, and policy institutes for policy officials at the state and local levels and for elected and appointed state officials, including representatives of state legislatures, counties, and executive departments.
- Large-Scale Demonstrations: Long-term, well-funded community living demonstrations, including states or communities that face special challenges by virtue of poverty, urban problems, and similar issues.

- Interdisciplinary University Training: Undergraduate and graduate training programs that integrate disability studies with studies in other disciplines; for example, aging, policy studies, family studies, urban studies, and women's studies.
- In-depth Technical Assistance: Long-term technical assistance to assist states and communities to integrate people with developmental disabilities into the community.
- Training for Families, People with Developmental Disabilities, and Service Providers on Critical Issues: Conferences and workshops for families, people with developmental disabilities, and service providers on critical issues such as citizen monitoring, self-advocacy, generic resources, and social relationships.

### **Information: What Information Needs to be Available, Accessible, and Usable by Diverse Audiences**

- Develop Multi-Media: Disseminate information through a variety of media, including films, videotapes, and general distribution publications.
- Reach Diverse Audiences: Develop and disseminate information targeted to diverse audiences, including families, minority group members, direct care providers, generic service providers, journalists,

community members, and policymakers.

- Address Policy Implications: Disseminate information on the public policy implications of research findings.
- Synthesize Research Findings: Prepare research summaries, bibliographies, and reviews for the use of different audiences.
- Document Successful Examples of Community Integration: Document and disseminate information about successful examples of community integration on the individual, family, community, agency, or state level.



**“We are at the beginning of a new venture into the community for a person with multiple handicaps and we know it can work. There are, however, some important quality-of-life learnings already emerging.**

**“For professionals: Bureaucracies are run by well meaning people who often are caught in rules, procedures and ways of doing things that other well-intentioned people have put in place. When rules stand in the way of full citizenship, they can be adapted, modified or changed. Think always with creativity and innovation, and above all, start by focusing on the**

**individual rather than the system . . .**

**“For families: Become aware of your child’s preferences. Plan for the future. Trust your vision. Help agencies design individual support systems. Band together with other families and create your own community network. Always keep your son or daughter the focus of brainstorming.**

**“Communities are filled with people who will connect, if the opportunities are offered. Our children can be truly valued, important, participatory community members.”**

**Cory and Ralph Moore**

## Families: To Realize Dreams

### What We Know About Families

The experience of the past decade, in particular, calls into question traditional assumptions underlying services to people with developmental disabilities and their families. Public policy and services for families of people with developmental disabilities must reflect revised assumptions about: perceptions of disability (from viewing the person with a disability as a burden to seeing the person as a contributing member of the family and community); family member roles (toward reflecting individual family members' preferences and choices); family-person-professional partnerships (from viewing families and people with disabilities as passive recipients of services to respecting them as equal partners); professional services and informal supports (toward striking a balance between formal programs and informal supports); and family support services (toward helping families "dream" or form a vision of a desirable future for their son or daughter).

- A person with a disability can be a valued and contributing member of the family and the society.
- Society and its reactions to disabilities impose stresses and pressures on families.
- All people need positive and enduring relationships with their families.
- All children, regardless of severity of disability, can be supported in natural, adoptive, or foster families.
- Families know best about what they need to support a member with a disability.
- Family support services in practically all states and communities are inadequate and in many cases inappropriate for most families.

**"... The family research literature is replete with information on the stress created for families with a member with a disability; however, almost no mention is made of positive contributions. The notion of focusing on positive has a tremendous potential for destigmatization and enhancement of social status and individual dignity ...**

**"... Family decision-making about needs and priorities is obviously strongly influenced by the nature of expectations. Many**

**families are confused about what to expect with respect to integration (they are still experiencing 'deinstitutionalization jet lag'), and they are still 'carrying baggage' from lowered expectations generated at various points of their lives and by various professionals, policies, and public attitudes. A concerted effort at raising family expectations can substantially increase the nature and extent of integration ..."**

**Ann P. Turnbull and  
H.R. Turnbull**





### **Research: What Researchers Need to Study and Funders Need to Support**

- **Family Perceptions:** Studies of how families view their members with a disability, how family recognition of the positive contributions of the person with a disability can be increased, and how societal attitudes and public policy impact on family perceptions and expectations.
- **Family Members' Roles:** Research on family relationships, especially the roles of mothers and siblings, and on how public policy can support or interfere with family ties.
- **Person-Family-Professional Partnerships:** Studies of practices for developing effective partnerships, especially with families from minority groups.
- **Professional Services and Informal Supports:** Research on the benefits and limitations of both professional services and informal supports, on family preferences, and on practices for helping families to make connections to the community.
- **Family Support Services:** Studies of how different kinds of support services impact on families, including families from minority and other traditionally under represented groups, and on families' dreams for their children.

### **Technical Assistance and Training: The Assistance that Families, States, Communities, Professionals, and People with Disabilities Need**

- **Training on Changing Assumptions:** Families, people with disabilities, professionals, and policymakers need training on changing assumptions about families and people with disabilities.
- **Technical Assistance for States and Service Systems:** States, service systems, and local agencies need in-depth technical assistance on implementing promising practices for supporting families.
- **Technical Assistance for Policymakers by Families:** Technical assistance provided to policymakers should include training from family members and people with disabilities.
- **University and Professional Training:** All training needs to incorporate information on new practices and new ways of thinking about families and people with disabilities.

### **Information: What Information Needs to Be Available, Accessible, and Usable by Diverse Audiences**

- **Use Multi-Media:** Information needs to be disseminated through various means, including films and videotapes, tailored to different audiences and communities.
- **Develop Practical Information:** Families need practical information written without jargon.
- **Prepare Information sending Positive Images:** Information that portrays positive images of people with disabilities and families needs to be provided to the media and policymakers.
- **Document Successful Examples:** Families, people with disabilities, and service providers need information on successful examples of community integration and family supports on the individual, family, community, and state levels.
- **Reach New Audiences:** Information on families needs to be prepared and disseminated to new audiences including judges and attorneys, trust officers in banks, and others.

## School: Supported Education

With the enactment of Public Law 94-142, the Education for All Handicapped Children Act, many thousands of children with developmental disabilities attended school for the first time. Since Public Law 94-142 was passed, attention has gradually turned to the quality of education provided to students with developmental disabilities. The concept of "Supported Education" provides a direction for efforts to enhance the quality of education for students with disabilities and indeed for all students. Supported Education means bringing the supportive services needed for the student with developmental disabilities into the regular class-

room, and entails the following: schools as inclusive communities; all students attending local schools; a team approach for staffing allowing flexibility and creativity in meeting students' individual needs: special educators as a resource to regular educators; administration based at the local school; integration of all services; accountability for services and resources; fiscal incentives to integrate students with disabilities; and a philosophical commitment to accepting students with developmental disabilities as capable learners who can achieve, and who belong with their typical peers.

### What We Know About Schools

- All students with developmental disabilities, including those with severe disabilities, can attend the same public schools they would attend if not disabled.
- All students with developmental disabilities can participate in regular school programs at the preschool, primary, and secondary levels.
- The qualities and practices necessary to make integration work for students with developmental disabilities are the same qualities and practices that characterize effective schools for all children.
- No prerequisite skills are required for students with developmental disabilities to be integrated into regular classes and local schools.
- Classroom integration can be achieved at the preschool, primary, and secondary levels.
- Integration of students with disabilities positively affects the school environment for all students and staff.
- State and local education agencies vary tremendously in their commitment and the degree to which students with disabilities are integrated into regular classes and schools.

**"Inconsistency in the availability of integration is a national phenomenon . . . One of the lessons to be learned from the situations of (individual students) is that where a student lives has a lot to do with whether he or she attends a regular school . . . a few states, notably Oregon, Hawaii, Arkansas, and Iowa, segregate hardly any students in**

**separate schools. . . American education is still a long way from making the promise of integrated schooling universally available. Further, even if we are able to integrate all students into typical schools, we must also be concerned about insuring the quality of the integrated education."**

**Douglas Biklen**



**Research: What Researchers Need to Study and Funders Need to Support**

- Case Studies: Qualitative case studies of successful integration on the school, school district, and state levels
- Outcomes: Research on the student outcomes of integration.
- Organizational Practices: Studies of practices on the school, district, or state levels used to integrate students with disabilities, including staffing issues, transportation, administrative strategies, funding, and policy implementation.
- Fiscal Practices: Research on promising funding practices and fiscal barriers, and incentives to support integration.
- Impact on Families and Nondisabled Students: Studies of the impact of integration on families of students with disabilities and on students without disabilities. Impact on Staff: Studies of the impact of preservice and inservice training, collaboration between staff, and other areas.

**Training and Technical Assistance: The Assistance that States, School Districts, Schools, Professionals, and Family Members Need**

- Demonstrations: Systems change projects to implement Supported Education in a variety of local schools and at district levels.
- Training for Regular Education Policymakers, Officials, and Leaders: Institutes, conferences, and workshops on integration and Supported Education.
- Technical Assistance: Indepth assistance and consultation to states and school districts on integration and conversion to Supported Education.
- Parent Training: Conferences and workshops on integration and Supported Education for all students with developmental disabilities.
- Teacher Training: Preservice and inservice training on Supported Education, including "master teacher" programs for experienced teachers.
- Training for Non-Special Educators: Preservice and inservice training for regular educators, educational administrators, related services personnel, and hearing officers on school integration and Supported Education.

**Information: What Information Needs to be Available, Accessible, and Usable by Diverse Audiences**

- Use Common Words: Information needs to be presented in common language for policymakers, educators, and families.
- Employ Nonstigmatizing Language: Information needs to avoid the use of unnecessarily stigmatizing labels.
- Describe Successful Examples: Information on promising practices and successful examples needs to be disseminated widely to policymakers, state and local officials, regular and special educators, and families.
- Document Positive Outcomes: Research findings on integration outcomes need to be disseminated to audiences beyond researchers.
- Reach Minority Audiences: Information needs to be accessible to members of minority groups and other traditionally underserved groups.

## Work: From Good Practices to Public Policy

People with all types of disabilities can work and are working. Many people who were considered unemployable a few years ago now hold paying jobs. Research and practice have shown that supported employment is feasible, desirable, and cost-effective. Yet despite the widespread success of supported employment programs, major policy and fiscal barriers—Medicaid, inadequate funding for supported employment from vocational rehabilitation agencies, work disincentives imposed by the administration of Social Security programs, inadequate incentives for industry, and a lack of interagency collaboration—stand in the way of expansion of supported employment programs and in some cases threaten the continuation of existing programs. Now that supported employment has proven itself, policy changes need to be made to insure that people with developmental disabilities have the opportunities to contribute to their communities through work.

### What We Know About Work

- People with developmental disabilities, including severe disabilities, can work,
- Supported employment is feasible and cost-effective.
- The vast majority of people with disabilities are unemployed, with unemployment the highest among women, members of minority groups, and people with severe disabilities.
- Among people with disabilities who do work, severe underemployment exists in terms of hours worked.
- Schools seldom provide appropriate vocational training to prepare students with developmental disabilities to be employed.
- In virtually every state and community in the country, a crisis exists in the capacity of service providers to provide post-school services to adults with developmental disabilities.
- Major disincentives to supported work exist on the federal and state levels.

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**“In closing, it is probably fair to say by most standards, wonderful progress has been made in implementing supported employment nationally. Yes, the idea is eloquently simple: place persons who have never worked competitively before into real work settings, provide training at the job site, and then provide long-term maintenance in the form of job coaches, attendants, coworkers, volunteers, or whatever type of support service seems to work. However, the actual implementation is quite difficult**

**because it is markedly different from what professionals had done previously. In considering that literally thousands of programs are providing supported employment, many for the first time, it is remarkable indeed that we are making the progress we are. The true fruits of these systems change efforts will be shown in the years which follow.”**

**Paul Wehman**



**Research: What Researchers Should Study and Flinders Should Support**

- Policy Initiatives and Service Approaches: Research on administrative and programmatic practices for supported work, including approaches for the conversion of segregated services to supported work, the integration of supported work with special education, personnel recruitment and training, and alternative training approaches.
- Social Support and Community Participation: Studies on informal supports and social relationships in the workplace.
- Employment Statistics for People with Disabilities: Research on the trends and needs in employment for people with disabilities.
- Economies of Supported Employment: Studies of the costs and benefits of alternative approaches, including studies of the economic consequences of converting from segregated services to supported employment and the economic consequences for employers.
- Labor Market Trends: Research on labor market and employment trends relevant to people with disabilities.

**Training and Technical Assistance: The Assistance that States, Communities, People with Developmental Disabilities, Families, Professionals, and Employers Need**

- Preservice and Inservice Training: Training on supported employment for rehabilitation professionals, administrators, educators, and supported employment staff.
- Technical Assistance to Providers: In-depth training and technical assistance to new and current providers who are providing supported employment or are converting from segregated services.
- Technical Assistance to Employers: Consultation and assistance to employers on restructuring jobs and employment settings to accommodate people with disabilities.
- Training for Parents: Conferences and workshops for families on increasing expectations for their sons and daughters and on supported employment, including parent-to-parent and consumer-to-parent training.
- Coordination With Special Education and Rehabilitation Counseling: Include supported employment in state comprehensive personnel development plans and certified rehabilitation counseling

**Information: What Information Needs to be Available, Accessible, and Usable by Diverse Audiences**

- Increase Public Awareness: Inform the public, the media, and employers about the potential of people with disabilities through various media.
- Disseminate Research Findings: Disseminate information to policymakers, service providers, families, people with disabilities, and educators on the practical applications of research findings.
- Reach National and State Leaders: Develop information for policymakers on the national and state levels.

examinations.

- Family and Consumer

Involvement in Training and Technical Assistance: People with developmental disabilities and family members should be involved in planning and providing training and technical assistance.



## Conclusion: Concepts to Guide the Future

Concepts and ideas can help us get from one place to another, to move closer to a vision of a society in which people with developmental disabilities assume their place alongside their non-disabled peers. The concepts that have dominated

the field of developmental disabilities for nearly two decades are giving way to a new set of ideas. The following are some of the concepts emerging at the Leadership Institute that will help set a direction for the future:

**dreams for the future**  
**complete school**  
**interdependence**  
**respect**  
**reciprocity**  
**unobtrusive support**  
**community building**  
**future planning**  
**supported education**  
**positive contributions**

**full citizenship**  
**partnership**  
**informal support**  
**equity**  
**empowerment**  
**diversity**  
**regeneration**  
**autonomy**  
**choice**  
**friendship**



## **Appendix A. list of Participants**

Leadership Institute Coordinators: Bonnie Shoultz and Naomi Karp

### **Community Living**

#### ***Presenter:***

K. Charlie Lakin, Ph.D.  
Research and Training Center on Community Living  
University of Minnesota

#### ***Facilitator:***

Julie Ann Racino  
Research and Training Center on Community Integration  
Center on Human Policy, Syracuse University

#### ***Other Participants:***

David Braddock, Ph.D.  
University Affiliated Program in Developmental Disabilities  
University of Illinois at Chicago

Rob Horner, Ph.D.  
Research and Training Center on Non-Aversive Behavior  
Management  
University of Oregon

Cory Moore  
Parent

Tom Nerney, Director  
National Society for Autistic Citizens

Esther Lee Pederson  
Research and Training Center Consortium on Aging and  
Developmental Disabilities  
Cincinnati Center for Developmental Disorders. University  
of Cincinnati

Charles Rhodes  
Beach Center on Families and Disability  
University of Kansas

Steven J. Taylor, Ph.D.  
Research and Training Center on Community Integration  
Center on Human Policy, Syracuse University

H. Rutherford Turnbull, III, Parent  
Beach Center on Families and Disability  
University of Kansas

Robert Williams  
Association for Retarded Citizens, D.C.

### **Families**

#### ***Presenter:***

Ann Turnbull, Ed.D., Parent  
Beach Center on Families and Disability  
University of Kansas

**Facilitator:**

Bonnie Shoultz  
Research and Training Center on Community Integration  
Center on Human Policy, Syracuse University

**Other Participants:**

Molly Cole, Parent  
Pediatric Research and Training Center  
University of Connecticut  
Sharman Jamison, Parent  
PACER Center, Inc., Minnesota  
Naomi Karp  
National Institute on Disability and Rehabilitation Research  
Ralph Moore  
Parent  
Betty Pender  
Parent  
Karen Shannon, Parent  
Kennedy Institute, Maryland  
Fran Smith, Parent  
United Cerebral Palsy Associations, Inc.

**School**

**Presenter:**

Douglas Biklen, Ph.D.  
Syracuse University

**Facilitator:**

Susan Lehr, Parent  
Technical Assistance for Parent Programs  
Center on Human Policy, Syracuse University

**Other Participants:**

Mary Beth Bruder, Ph.D.  
Pediatric Research and Training Center  
University of Connecticut  
Barbara Buswell, Parent  
PEAK Center, Colorado  
Larry Butcher  
Parent  
Barbara Cunningham, Ph.D.  
Parent  
Katty Inge  
Rehabilitation Research and Training Center  
Virginia Commonwealth University  
Celane McWhorter  
The Association for Persons with Severe Handicaps

Elizabeth Rouse  
Joseph P. Kennedy, Jr. Foundation

Wayne Sailor, Ph.D.  
California Research Institute  
San Francisco State University

Marti Snell, Ph.D.  
The Association for Persons with Severe Handicaps  
George Zitnay  
Joseph P. Kennedy, Jr. Foundation

**Work**

**Presenter:**

Wendy Parent  
Rehabilitation Research and Training Center  
Virginia Commonwealth University  
(Paper by Paul Wehman, Ph.D., Virginia Commonwealth  
University)

**Facilitator:**

Colleen Wieck, Ph.D.  
Minnesota Governor's Planning Council on Developmental  
Disabilities

**Other Participants:**

Robert Bruininks, Ph.D.  
Research and Training Center on Community Living  
University of Minnesota  
Susan Goodman  
Community Services for Autistic Adults and Children  
Michael Kennedy  
Research and Training Center on Community Integration  
Center on Human Policy, Syracuse University  
Frank Laski  
Public Interest Law Center of Philadelphia  
Paul Marchand  
Association for Retarded Citizens - U.S.

**Participants in Several Groups:**

Patricia McGill Smith  
Office of Special Education and Rehabilitative Services  
Karen Faison  
National Institute on Disability and Rehabilitation Research

## **Appendix B. List of Additional Papers and Reports From The Leadership Institute**

The Center on Human Policy would like to make available the complete proceedings of the Leadership Institute by work group or as a complete document.

### ***Complete Proceedings: Leadership institute on Community Integration***

(Includes an introduction, four papers presented at the Institute, and detailed proceedings of all work groups.)  
Cost: \$15.12

### ***Leadership Institute: Community Living***

(Contains a paper, titled "An Overview of the Concept and Research on Community Living," by Charlie Lakin, and the proceedings of the work group on Community Living.) Cost: \$6.32

### ***Leadership Institute: Families***

(Contains a paper, titled "Families and Community Integration," by Ann P. Turnbull and H.R. Turnbull, and the proceedings of the work group on Families.) Cost: \$2.40

### ***Leadership Institute: Education***

(Contains a paper, titled "Integrated Education," by Douglas Biklen, and the proceedings of the work group on Supported Education.) Cost: \$1.68

### ***Leadership Institute: Employment***

(Contains a paper, titled "Supported Employment: Toward Equal Employment Opportunity for Persons with Severe Disabilities," by Paul Wehman, and the proceedings of the work group on Employment.) Cost: \$2.88

To order any of the above, please send the amount to Rachael Zubal, Center on Human Policy, 200 Huntington Hall, Syracuse, NY 13244-2340.

Upon request, The Center on Human Policy will make available enlarged copies or an audiotape of this document.

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## **From Being in the Community to Being Part of the Community**

**Summary of the Proceedings and Recommendations of a Leadership Institute on Community Integration for People with Developmental Disabilities**

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