Looking Ahead to the Next Generation

1997 Next Generation Leadership Symposium Presentations and Recommendations August 22, 23, 1997

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Table of Contents

ACKNOWLEDGEMENTS
by Gary H. Blumenthal, Executive Director
President's Committee on Mental Retardation

PREFACE
by Kerri Melda and Tanya Dorf
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Public Policy
3 by Kerri Melda, Human Services Research Institute, Salem, Oregon

Charting the Changing Tides of Managed Care and Long Term Services
by April M. Myers, Project Coordinator, National Clearinghouse on Managed Care and Long Term Services and Supports, University of New Hampshire

What Are They Waiting For?
A Survey of Massachusetts Caregivers
Whose Adult-Children with Mental Retardation are on the State Waiting List for Residential Services?
By Dian Griffiths, M.S.S., The Heller School, Brandies University, Waltham, Massachusetts.

Leagal & Justices Issues
By Tanya Dorf, InterHab, Topeka, Kansas

People with Mental Retardation Confronting Injustice within the Criminal Justice System
By Leigh Ann Reynolds, M.S.S.W., M.P.A., Project Associate, The Arc of the United States, Arlington, Texas

Direct Support Issues
By Seth Krakauer, Rockaway Park, New York, New York

Social Action:
A Model for Community Inclusion and Self Esteem for People with Developmental Disabilities
By Ruth Levy Kahn, BS, RSW, and Shoshana Arden Rubenstein, ACSW
Independent Living Specialists, JARC, Southfield, Michigan

Housing Issues
By Sally Jochum, Johnson County Developmental Supports, Lenexa, Kansas

In Homes of Our Own: The Path Toward Self-Determination
By Louisa J. Hext, Coordinator for Special Projects, Franklin County Board of Mental Retardation and Developmental Disabilities
Columbus, Ohio

Employment
Recommendations for Realizing Meaningful and Real Work with Personalized Support
By Julia Silver, Human Services Research Institute, Cambridge, Massachusetts

Minute Man Arc For Human Services, Inc.
Own on Your Own Program
By Jim McAleer, Executive Director, Minute Man Arc for Human Services
Concord, New Hampshire

Breaking Out of the Stereotype: Rethinking Traditional Jobs for Workers with Mental Retardation
By Joy Orzechowski, Job Developer, VinFen Corporation, Cambridge Massachusetts

Education Workgroup
By Laurel Manthey-Silvio, Gaithersburg, Maryland

Early Intervention and Parenting
Support in Public School Inclusive Programs
By Heidi L. Miller Ph.D., Watertown Massachusetts

Research Issues
By Yona Lunsky, Nisonger Center, Columbus, Ohio

Reducing the Incidence of Developmental Disabilities: Building Bridges Between Research, Policy Makers and Service Providers
By Laura L. Jelliffe, Doctoral Candidate, University of California, Davis; Research Associate, President's Committee on Mental Retardation

Diversity: Redefining, Refocusing, and Restructuring Our Efforts
By Marisha Tapera, Cabin John Middle School, Rockville, Maryland

Improving the Quality of Life for People with Mental Retardation and Developmental Disabilities
The Church and Community Response
By Angela McCants, Family Advocate, University of North Carolina at Chapel Hill

Inclusion Church Communities
By Mel Dugosh, Graduate, Partners in Policymaking, Pipe Creek, Texas

Acknowledgments

As part of the mission and focus of the President's Committee on Mental Retardation (PCMR), Committee members are deeply concerned about training new leaders for the 21st century.

During the over 30 year history of the President's Committee, dramatic changes have occurred regarding the quality, location and types of services and supports available for citizens with mental retardation.

At the dawn of the Committee's formal creation in 1966, typical services and supports left a lot to be desired. Quality, if measured at all, might more likely represent numbers of individuals served in custodial settings, rather then addressing the hopes, dreams and aspirations of Self-Advocates who simply yearned to be part of their home community.

As walls of separation, segregation, low expectations, and limited options fell to integration, person centered planning, Self-Advocacy and high expectations, people with mental retardation were able to dream more, earn more and be part of everyday life.

So much more remains to be done in our field. First and foremost is building upon the successes of the last 30 plus years by continuing to ignite the fire of change to break down even more barriers that keep us apart and our futures limited.

New leaders are emerging.

That is the focus of the Next Generation Leadership Symposium. Training new leaders ranging from Self Advocates, Direct Support Professionals, Service Providers, Researchers, Agency Personnel to Family Members, will help create the energy and enthusiasm to shake the system sufficiently to allow positive change to occur.

The 1997 Next Generation Symposium, held August 22-23, 1997 was successful in meeting PCMR's goal of reaching out and training new leaders. More than 250 individuals, under the age of 35, from over 40 States and the District of Columbia joined the PCMR in passing the torch to the next generation. Participants in eight concurrent workshops were challenged to: (1) Identify and address model activities, best practices and develop strategies for future leaders in programs, supports and advocacy for people with mental retardation and, (2) Identify and address barriers that are expected to hamper progress of future leaders in their efforts to improve the lives of persons with mental retardation and their families.

The eight concurrent workgroups addressed topical issues as: Public Policy; Legal/Justice System; Direct Support; Housing; Employment; Education; Research; and Diversity.

The 1997 Next Generation Symposium culminated in this special PCMR Report entitled: *Looking Ahead to the Next Generation.*

Special thanks to Kerri Melda, Human Services Research Institute, Salem, Oregon, and Tanya Dorf, InterHab, Topeka, Kansas, for their creativity, dedication, and hard work as Co-Chairpersons of the 1997 Symposium.

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Jane L. Browning, Washington, D.C.
Robert D. Dinerstein, J.D., Washington, D.C.
Steven M. Eidelman, Arlington, Virginia
Ann M. Forts, Center Harbor, New Hampshire
Dawn Rae Hays, Columbus, Ohio
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and
Thelma Lucas, PCMR Next Generation Symposium Project Officer
Laura Jelliffe, 1997 PCMR Research Associate
Mara Kreiger, 1997 PCMR Intern
Christine Kohl, 1997 PCMR Intern

Additionally, the PCMR expresses its appreciation to Administration for Children and Families (ACF) Assistant Secretary, Olivia A. Golden and Principal Deputy Assistant Secretary, John Monahan for their leadership and continuing commitment to PCMR's initiatives.

The 1997 Next Generation Leadership Symposium
was dedicated to the memory of
Natalie Sage Hazelton Coe
a courageous and articulate advocate
on behalf of individuals with disabilities.
May her memory be a blessing
and inspire others to a life of advocacy and achievement.

Gary H. Blumenthal
Executive Director

Forward

"Do we believe all our people are entitled to an equal opportunity to live out their dreams? Do we believe our own lives are enriched when we live and work together with people of different%4backgrounds who share our values? We begin to answer these questions as young children. As Thurgood Marshall once said, 'Unless our children begin to learn together, there is little hope our people will ever learn to live together.'"

President William Clinton, September, 1997 - *reflecting on the 40th anniversary of racial desegregation at Central High School in Little Rock, Arkansas*

People with developmental disabilities have dreams to fulfill. They want to live and learn, and to work and play, just as others do. They want to be supported by their communities, as we all are. They want to contribute to their communities, as we all do.

People with disabilities want control over their daily decisions, opportunities to succeed, and the freedom to fail.

It seems so simple. Yet, at times, we have made it so difficult. Historically, it has often been the disabilities "system" itself that has isolated people with disabilities from their families and communities. Only in the past few decades have we, as a field, begun to tear down the walls, and rewrite the rules, that have for so long isolated us from being a truly integrated community.

As "young" leaders in the disabilities field, we have grown up side by side with the disabilities movement. Over the past three decades, we have experienced first hand the monumental changes in disability policy and practice. As youngsters, we welcomed children with disabilities into our schools. As teenagers, we rode the bus, we went to the movies, and we became friends with schoolmates having disabilities. And now, as adults, we fully expect people with disabilities to join us in the workforce, and as our neighbors and friends.

We have watched the "advocacy" movement become a "self-advocacy" movement. We have cheered legislation guaranteeing individuals with disabilities the same rights and protections under the law to which all Americans are entitled. And we look forward to a future that truly puts "people first" in all aspects planning, implementation, and evaluation of disability services and supports.

President Clinton posed the questions above about racial integration in America. We find these questions equally valid when considering the integration of individuals with developmental disabilities in our communities.

Best practices must become common practice. As young leaders, we came to the 1997 Next Generation Leadership Symposium to learn from one another, to share information, and to develop recommendations from our collective experiences and expertise. In the following pages, we offer our observations, our analysis, and our suggestions for better supporting individuals with disabilities as full participants in our communities.

Kerri Melda
Co-Chair, 1997 Next Generation Leadership Symposium

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Co-Chair, *1997* Next Generation Leadership Symposium

TOPIC I: PUBLIC POLICY ISSUES

Papers/Presenters:

PUBLIC POLICY

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CHARTING THE CHANGING TIDES OF MANAGED CARE AND LONG-TERM SERVICES

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WHAT ARE THEY WAITING FOR?: A SURVEY OF MASSACHUSETTS CAREGIVERS WHOSE ADULT-CHILDREN WITH MENTAL RETARDATION ARE ON THE STATE WAITING LIST FOR RESIDENTIAL SERVICES

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Next Generation Leadership Symposium
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PUBLIC POLICY

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Introduction

Public policy is a good place to start, as it encompasses all topics discussed at this year's Next Generation Leadership Symposium. Not one of us can deny that our lives are deeply and directly affected by the many policies that guide or influence our everyday lives- policies that affect our schools, our jobs, our travel, our health and safety, and our rights. These policies, established at the federal, state, and local levels, affect nearly every facet of our lives through the services and supports we receive, the laws by which we must abide, and the rules and regulations to which we must adhere. Public policy is, by definition, policies put in place for the public good.

Likewise, disability policies affect, directly or indirectly, the lives of individuals with developmental disabilities in so many ways. During the past 25 years, sweeping legislation has been enacted to improve accessibility, education, employment, housing, and rehabilitation for people with developmental disabilities. These policies, over the years, have refocused the direction of services and supports for people with disabilities- from services that are isolated and segregated to ones that emphasize full community integration; from systems that are provider or system-driven to ones that are family or individually directed; and from formal programmatic services to individualized natural or community supports. While much progress has been made in recent years, we certainly have a long road ahead. This may never change. As we continue to learn and grow about how to become a truly integrated society, we are constantly seeking new horizons and setting new goals.

Background

The developmental disabilities field is going through a tremendous change. The future direction of long-term services and supports for people with developmental disabilities is uncertain, yet change is inevitable. In fact, significant policy changes are already taking place throughout the country.

"A service system for [people with disabilities] and others in need of support will have to be a system in constant change. It has to be continuously developed, if the `customers' are not to be left behind and to become hostages of an outdated way of doing things. "
Alfred Dam; (undated), Denmark

This change is driven by two major forces. The first involves money. Over the past 15 years, funding for disability services has grown at a rapid pace. In every state, service systems have expanded. This will not continue. National leaders are looking for ways to keep down costs, and spend money more effectively. As a result, more and more states are considering "managed care" strategies to promote these changes. Some fear, however, that the coming changes will focus more on cost containment than on the quality of life for people with developmental disabilities. Second, people with developmental disabilities and their families are pushing, more forcefully than ever before, for services that provide opportunities for them to live in, participate in, and contribute to their community. But more than that, people with disabilities want choices, and a strong hand in determining the course of their own lives. (Melds, ed., 1997).

During the 1997 Next Generation Leadership Symposium, a diverse group of individuals from across the country, with and without disabilities, sat down to discuss: 1) the current thinking and practice around disability policy; 2) our vision for the future; and 3) specific recommendations toward achieving our vision. Three presenters shared with the Public Policy Workgroup some of their experiences and expertise in the disabilities field. These presenters included: 1) Donald Shumway-a proud parent, and a seasoned professional who currently serves as Co-Director of Robert Wood Johnson's Self-Determination for Persons with Developmental Disabilities Project; 2) April Myers-a young professional and self-described self-advocate serving as Project Coordinator of MCARE, a national clearinghouse on managed care and long-term services and supports at the University of New Hampshire; and 3) Diane Griiths-a doctoral student at the Heller School for Social Welfare Policy at Brandeis University. Through their insights, the group was provided a foundation for discussing policy issues of interest and concern, and was assisted in developing recommendations for future action. Below is a brief summary of the information and issues covered during the presentations which set the stage for later discussions among the entire workgroup.

Self-Determination

Laying a foundation for future discussion, Don Shumway articulated several core principles of self determination-principles highly valued by individuals with disabilities, their families and advocates:

- Freedom-the ability for individuals with freely chosen family and/or friends to plan a life with necessary support rather than purchase a program;
- Authority-the ability for a person with a disability (with a social support network of circle if needed) to control a certain sum of dollars in order to purchase these supports;
- Support-the arranging of resources and personnel-both formal and informal-that will assist an individual with disabilities to live a life in the community rich in community association and contribution; and
- Responsibility-the acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending

public dollars in ways that are life-enhancing for persons with disabilities." Shumway & Nerney, 1996).

Waiting Lists

Diane Griffiths recently conducted a survey of older families whose family members are waiting for residential services in Massachusetts. Her findings from this study provided the workgroup with important insights into the types of supports received, the types of services needed (residential and non-residential), the urgency of their service needs, and the potential implications for policy change.

- In 1996, 87,000 adults with mental retardation were on waiting lists for residential services across the country (Anderson, Polister, Prouty & Lakin, 1997).
- "In Massachusetts, over 2,000 adults with mental retardation are on a waiting list for residential services. Almost half of these individuals have primary caregivers over the age of 60.
- Overall, families place their family member on a waiting list for services because: a) they are experiencing severe family stress; b) they want a residential placement before a crisis occurs in the family; c) they want to plan for a future when they are no longer able to care for their family member; or d) they feel their family member deserves the opportunity to live independently.
- In Massachusetts, the waiting list represents real needs which must be addressed as both a short- and longterm problem.
- Even those who do not need services right away have critical needs for other kinds of support services. The waiting list is an ideal tool for planning to meet those needs. There is no excuse for the continuation of state service systems which are reactive and crisis-driven. Families should not have to continue experiencing the trauma caused by the current lack of planning." (Griffiths, 1997)

Managed Care

Managed care is a set of strategies being considered by many states faced with a need to maintain high quality services, while containing costs, and serving greater numbers of people. While managed care is a topic that has been widely discussed in recent years (primarily around acute health care), it is still relatively new to the world of long-term services and supports for individuals with developmental disabilities. April Myers, as coordinator of a national clearinghouse on managed care and long-term services and supports, provided our workgroup with an understanding of the basic concepts of traditional managed care, and the potential uses of managed care strategies in a long-term service and support environment.

- **The Political and Social Context of Managed Care**-driven by the needs to contain costs, reduce spending, meet increased needs, expand coverage, and address unmet needs.
- **Looking for Opportunities**-managed care strategies can be used to improve service systems by expanding community-based services and supports, increasing consumer control and family involvement, and promoting self-determination and consumer choice.

- **Recommendations**-people with disabilities, their families, and advocates should be involved in the development and design of any new system; any new system should be based on the principles of full inclusion and self-determination; mechanisms should be developed and implemented to assure adequate funding for long-term services and access to medical care; and all entities should be required to develop and publicize a grievance process." (Myers, 1997).

Vision

Individuals with developmental disabilities expect to be full participants in their schools, neighborhoods, jobs, and communities. As a matter of course, people with disabilities have dreams to fulfill, goals to achieve, and barriers to overcome. These expectations, dreams, goals, and barriers are no different than those imagined and experienced among all citizens. The joys of success, the risks and disappointments of failure-enrich all of our lives when offered opportunities.

Recommendations

During the course of our Public Policy Workgroup, we listed and prioritized numerous recommendations for improving or redirecting the current service and support environment. You will notice that some of these recommendations are more general or overarching in nature, while others address specific actions that we feel need to be taken.

Self-Determination

1. **Individuals with developmental disabilities make their own decisions about where they live, work, and play**. People with developmental disabilities differ tremendously, yet every person has capabilities of expressing, in some ways and to certain extents, their preferences. These may be larger decisions (such as what type of job to pursue, where to live), or smaller ones (what to wear, when to go to sleep). These decisions may be made independently, or with the assistance of a chosen helper (e.g., a family member or advocate). Most important, however, is that the individual his/herself has decision-making control.
2. **Funding follows the person**. Typically, funding flows from the finder to providers, who then offer services to people with disabilities. In this scenario, the provider agency is primarily accountable to the funder, rather than the person with disabilities. For example, a "slot" system may be used, where providers are contracted to serve a specific number of people with a specific set of services. These services may or may not meet the needs of the clientele. The individual with disabilities has little control, and little flexibility in attaining the supports that best meet their needs. Also, if a person moves or changes provider agencies, they risk losing services because the monies are attached to the agency, not the individual. Funding must follow the person needing supports, to be in alignment with the principles of flexibility, accessibility, and consumer control.
3. **Decisions are driven by individual needs, not by funding caps**. Unfortunately, the process of matching individuals with services and supports often focuses foremost on the service budget, not the person requiring support. .In some instances, we have created systems so burdened by budgetary rules and regulations that the people trying to navigate a system was which designed to

> serve them, getting lost in a labyrinth of red tape. With budgetary concerns as the focus, gatekeeping questions (e.g., Who's in?, Who's out?, Who gets how much?) can overshadow the more important questions (e.g., What do you need to live a more productive life? How can we meet those needs in the most efficient and effective manner?). In either approach, many individuals receive services and supports. However, when decision-making power rests in the hands of those requiring services, services better match the needs of the individual, and money is used more efficiently to meet those needs.

In the realm of family support services, it has been demonstrated time and time again, that when given control over how their financial assistance is used, the money is used more creatively, more efficiently, more frugally, and more effectively (in meeting the families' needs) than in comparable programs where service coordinators wield considerable decision-making power. It is imperative, as systems change, that the field recognize the expertise of individuals with disabilities (and their family members, when appropriate) in determining their goals and aspirations, and in making decisions around moving toward achievement of those goals.

Managed Care/Funding

1. **The developmental disabilities community must develop their own definition of the term "managed care" (and/or develop a more appropriate term and definition that reflect the new support management strategies employed)**. The term "managed care" is heavily laden with perceptions of how, in the medical community, specific strategies are used to address acute health care concerns. The developmental disabilities field, however, focuses primarily on meeting the long-term support needs of individuals. Much exploration is underway, and even more is needed before we can determine how "managed care" strategies might be best applied in the disabilities arena. National projects, such as the Robert Wood Johnson Self-Determination Grants, are just beginning to mold and shape and test various theories about applying managed care approaches to long-term services and supports. It is very important that we, as a field, research the potential implications of such drastic changes in policy making before jumping in head first.

2. **Managed care, in whatever shape it takes, must be person-centered and individual-directed.** In keeping with the recommendations listed above under "Self-Determination," it is imperative that any newly designed system of services and supports put people with developmental disabilities front and center. These individuals must play a key role in influencing and determining the system's future. This control and influence must be wielded in all facets, and at all levels of system redesign (e.g., policy setting, program regulation, service and support implementation, quality assurance and evaluation).

3. **Close institutions and redirect resources to expand community services**. Nationwide, a relatively small percentage of individuals served in the developmental disabilities system reside in large institutional settings, yet a

disproportionate percentage of the developmental disabilities budget is allocated toward institutional care. For years, institutional options have come under tremendous scrutiny as beliefs and practices around integration and self-determination have evolved. Additionally, state policy makers are finding renewed interest in the downsizing and closing of institutions as community-based options demonstrate their ability to offer improved quality of care, be more cost-efficient, serve greater numbers of people, and nurture community relationships for people with disabilities. This trend must continue. Community integration and full participation have no future if we continue to support segregated and isolated residential and vocational options. People with disabilities want to live and work and learn in their communities. The developmental disabilities system should support this, by eliminating options that, by their very nature, contradict these principles.

Quality Assurance

1. **Quality is determined by meeting people's needs, and is evaluated by assessing their level of satisfaction with the supports received**. Quality assurance and performance measures must be both process and outcomes-based. People with developmental disabilities (and their family members, when appropriate) must play lead roles in all aspects of quality assurance. This includes the development of performance measures, implementation of quality assurance procedures, and in the evaluation and decision-making based on results of quality assurance efforts.
2. **Quality assurance is an ongoing process**. There should be no beginning nor end to the cycle of assuring quality in services and supports for individuals participating in the developmental disabilities service system. Quality assurance should be a continuous circle of assessment, re-evaluation of policies and practice, and improvement. Just as our beliefs around "best practices" evolve, as our communities change, and as we individually grow and develop, the methods of assuring quality services and supports must continually readjust to accommodate and enhance this growth.

Summary of Recommendations Determination

Self-Determination

- Individuals with developmental disabilities make their own decisions about where they live, work, and play.
- Funding follows the person.
- Decisions are driven by individual needs, not by funding caps.

Managed Care/Funding

- The developmental disabilities community must develop their own definition of the term "managed care" (and/or develop a more appropriate term and definition that reflect the new support management strategies employed).
- Managed care, in whatever shape it takes, must be person-centered and individual-directed.
- Close institutions and redirect resources to expand community services.

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Charting the Changing Tides of Managed Care and Long Term Services

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The Political and Social Context of Managed Care

The principles and practices of Managed Care have become increasingly attractive to state and federal policy makers. As a result of political and social pressures, state and federal governments are seeking out new avenues to contain the costs of providing social service programs for the American taxpayers while addressing the growing needs of the local communities. Additionally, communities across the country are experiencing a backlash towards welfare recipients and the tax-and-spend perception of big government.

In searching for answers to the complex question of how to best utilize our public resources, policy makers are turning their eyes to the application of Managed Care principles and practices to more service systems than just health care. While the private sector has paved the road into the health care arena for Managed Care Organizations, the path into Long-Term Supports and Service have been uncharted and the price of experimentation for people with disabilities could be extremely high.

Additionally, advancements in medical technology and the media coverage of assisted suicide have also elicited an emotional debate in our American society. This debate has surfaced many of the beliefs and stereotypes in our culture about people with disabilities, their quality of life, the price tag of meeting their needs, and their contributions to the community. In such a political and social context, Managed Care and Managed Long-

Term Services have the potential of creating an environment for setting policies and implementing practices with life and death implications for people with disabilities.

Background on the Managed Care Environment
While many people with disabilities and their families fear Managed Care, they know very little about the practices and principles that are often applied in Managed Care Organizations. Most individuals when they hear the term "Managed Care" think of HMOs (Health Maintenance Organizations). Actually, HMOs are just one form of Managed Care that individuals with disabilities and their families will need to understand in order to participate in setting tomorrow's public policies. Other examples include Health-Insuring Organizations (HIOs), Prepaid Health Plans (PHPs), Preferred Provider Organizations (PPOs), Primary Care Case Management, and Provider Service Network.

In recent years, HMOs have become increasingly popular within the private sector as a means for corporations to control the costs of providing health care benefits to their employees. Many states across the country have been also moving populations in publicly funded health programs into similar arrangements. As the numbers of individuals enrolled in some type of Managed Health Care Plan have grown, the media's interest in the quality of
services that individuals have been receiving through these plans have also increased. The majority of the media coverage of the HMO corporations have exposed many of the possible flaws in the day-to-day practices of Managed Care Plans to the American public.

While the media horror stories have justifiably elicited fear in many Americans who are concerned about their own health and the well being of their family members, most policy makers know that the quality of the services received by participating members of a Managed Care program can vary greatly from provider to provider and plan to plan. They understand that Managed Care is really a set of principles and cost-containing practices that have, in the case of the HMO's, been applied to the delivery of health care services.

State governments across the Nation are hopeful that by applying the same principles and practices of Managed Care to the area of Long-Team Services and Supports for individuals with disabilities, the American taxpayers can realize the same cost savings as businesses have in health care. Much like any other principle that have driven the service delivery system in our country, it is the specific day-to-day application of the principles and practices that have negative and/or positive implications on the quality of people's lives.

Corporations and government entities have developed and will continue to develop contracts with Managed Care Organizations for the delivery of services. The language and the specific tasks that are outlined in the contracts determine the types and kinds of services that a person who is participating in a given plan or program are entitled to receive. This is one place where individuals with disabilities, their families, and advocates can make a difference by getting informed about Managed Care and becoming involved in their state's process.

Managed Care Practices and Principles

There are generally ten common principles and practices that people will need to understand in order to work within the Managed Care policy arena. Since not all ten of the principles and practices apply to every situation and policy, some policy experts refer to the following key terms as the tools of Managed Care:

1. **Eligible Populations**-The group of individuals who will qualify to receive services by a given Managed Care Plan.
2. **Capitation**-The payment that is given to the Managed Care Entity for services to the eligible population.
3. Risk Management-The practice of trying to reduce the chance of financial loss to the Managed Care Entity since the cost of providing services to the eligible population may exceed the capitation rate.
4. Care Criteria-The standards that are used by a Managed Care Entity in determining what specific services will be available to the individual in a given plan.
5. Flow of Money-The way that the money passes from one entity to another. For example, the money often flows from the purchaser of health care insurance to the Managed Care Company then to the actual health care provider.
6. Network Management The arrangements that are made between the Managed Care Entity and the providers for coordinating and monitoring the care of individuals who are enrolled in their plans.
7. Care Coordination or Gatekeeping-When an individual or agency has the responsibility to coordinate and oversee all aspects of the individual's services under the plan.
8. Utilization Review-The process that is used to ensure that the services which are received by individual are necessary and cost effective.
9. Service Substitution-The practice of requiring the use of less costly services which are believed to be as effective as more costly services.
10. Quality Assurance-The process that is often used by a Managed Care Entity to ensure the overall effectiveness of services to individuals in a plan. This can also be a tool for a corporation to develop plans to improve theirs and their providers' performance in the future.

Application of Managed Care to Long-Term Services and Supports

While it is evident that the principles and practices of Managed Care will not be able to operate in Long-Term Services as they have in the health care delivery system, many questions remain about their specific application to Long-Term Services. Perhaps, the greatest fear is that the privatization of Long-Term Services could lead Managed Care Corporations down a path of cutting comers to ensure large profits for their shareholders. Such an outcome would not only affect the quality and quantity of services for people with disabilities and their families, but could also have life and death implications for the individuals enrolled in the plan. Additionally, any reduction in community-based services or significant changes in family support programs could increase individuals' risk for institutionalization.

A few advocates believe that by carefully applying the principles and practices of Managed Care to Long-Term Services, states could actually provide more choices to individuals with disabilities and serve additional families. For example, by applying the practice of service substitution to Long-Term Supports, a state could substitute costly institutional care for more affordable community-based supports. While this would potentially not only free up some funding to provide services to additional families, it would also greatly improve the quality of life for the individual and promote the further development of inclusion policies in the state.

Management Models

Perhaps, at the center of the question of how to apply the principles and practices of Managed Care to Long-Term Services and Supports is the issue of whether or not the funding should be "carved-in" or "carved-out." When money is carved-in to a Managed Care Plan, funding for one population or program is combined with other resources from different system(s). For instance, a state's Long-Term Supports budget for people with developmental disabilities could be added the state's resources for services to its elderly population. If funding was to remain carved-out, the services would continue to have separate financial resources to provide programs to the given population.

Some states are experimenting with new programs that integrate acute care and Long-Term Services for the elderly together while other states are exploring ways to combine developmental disability populations with elderly Long-Teen Services. The mechanism that most states are using to undertake these initiatives are the 1115 Waivers which are also known as the "superwaivers" or "megawaivers." The overall purpose of 1115 Waivers was to provide states with the opportunity to implement research and demonstration projects to test new service delivery models that would otherwise require the state to receive multiple waivers of federal laws and regulations from the Secretary of Health and Human Services.

The possible integration of acute care and Long-Term Services proposes several questions and many concerns for individuals with developmental disabilities. The first issue that comes to mind is the question of who will be in control of the new integrated system and the allocation of resources. Will an existing acute care provider, such as a hospital, begin coordinating Long-Term Services and Supports for persons with disabilities or will a nursing home corporation or home health care agency become the gatekeeper to medical services? The coordinating party for the integrated system could also be an existing Managed Care Company or a new corporation all together.

The entity that becomes the coordinator for the new integrated system would have considerable influence over the types and kinds of services that greatly impact the quality of life for people with disabilities and their families. In such an environment, it would be essential for policy makers to develop safeguards to ensure that the present funds for Long-Term Services are not drained into providing acute care. Likewise, it would be necessary to put into place mechanisms to adequately protect people's access to medical services.

As a state considers developing an integrated service system, it is critical for persons with disabilities, their families, and advocates to be involved in the development of the new system. Additionally, any Managed Care Entity that receives public funding should be required to develop a grievance procedure that involves people with disabilities and their family members in the process. It should also be mandatory for information about the grievance procedures to be widely disseminated in alternative formats and for the written materials to be easily understood.

From a universal policy perspective, the integration of services offers states the possibility of stretching funding and providing some services to individuals who are currently on waiting lists. However, by combining funding the disability community stands to lose critical supports that individuals, families, and advocates have worked hard for decades to obtain. The transition may also risk people's access to important community-based services.

Managed Care and Self-Determination

States may be able to allow a Managed Long-Term Service Entity more flexibility than has been given to traditional service providers. In the past, individuals with disabilities and their families had to accept the package of services for which they were qualified. They had little control over the kinds of services that they received. A Managed Long-Term Service Entity could potentially offer a wider range of supports to individuals and tailor their services to individualized needs and goals.

There has been increasing discussion around the country about how to move the developmental disabilities service delivery system into a new age of Self-Determination. This movement is rooted in the philosophy that individuals with disabilities and their families know best what their needs are, and should be allowed the opportunity to structure their own supports to meet their needs within a given budget. In such a system, the dollar amount associated with an individual's services would become known to the person and/or their family or advocate. Once the amount of the available funding is known, the individual and their circle of support would determine how to best utilize the money to support the person's needs, goals, and desires.

Conclusions

While the cost-containing goal of Managed Care can place individuals at risk for being denied care or receiving fewer services, it can also be an avenue to expand coverage and services to individuals who are not presently enrolled in a system. Additionally, this could be an opportunity for states and communities to redesign their service delivery system to better meet the individual needs of a very diversified population and assist individuals in reaching their personal goals.

Two important factors for people with disabilities and their families to be mindful of in a Managed Care environment are: (1) Not letting the cost-containing efforts of Managed Care become a means to deny services or care to individuals with disabilities; and (2) not allowing corporations to make large profits for their shareholders while denying services to individuals and families who are in need of support and assistance.

In today's social and political times, it will be a challenge for individuals with disabilities, their family members, advocates, and service providers to stay informed about the proposed policy and program changes. Without access to such critical information, many of the gains in the human and civil rights arena for people with disabilities may be lost and individuals will be unable to promote inclusion in federal and state policies. It is imperative that the disability community provides the necessary leadership and educational opportunities to prevent the policy trend of Managed Care from having a negative impact on the lives and welfare of individuals with disabilities and their families.

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What Are They Waiting For?

A Survey of Massachusetts Caregivers Whose Adult-Children with Mental Retardation are on the State Waiting List For Residential Services

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EXECUTIVE SUMMARY

Scope of the Waiting List Problem in the U.S.

In 1996, 87,000 adults with mental retardation were on waiting lists for residential services across the country was reported at 87,000 (Anderson, Polister, Prouty, & Lakin, 1997). Due to the fact that more adults with mental retardation are living into old age, and the baby boom generation is aging, this number will likely increase over time. A 1992 report from the University of Minnesota found that most states do not collect information from individuals on waiting lists that would allow them to plan for services. Further, despite having waiting lists, most states operate residential service systems which are crisis-driven. Individuals cannot obtain services unless there is a crisis situation in the home, like the illness or death of the primary caregiver or an abuse situation. (Hayden, 1992, p. 11)

The implications for individuals with mental retardation on a waiting list can be traumatic. If they must wait until a crisis occurs in their homes (like the death of a caregiver, or an abuse situation), then they are left with what has been referred to as a "double-trauma": that is, having to deal with the family crisis and having to adjust to an unplanned residential placement. Since over 80% of individuals with mental retardation live with their families throughout their entire lives, this scenario will likely play out for most of them (Fujiura & Braddock, 1992).

Waiting List Efforts in Massachusetts-The Formation of Family to Family

In Massachusetts, there are over 2,000 adults with mental retardation on the waiting list for residential services. Almost half of them have primary caregivers over the age of 60, and close to 5% of them are over 60 years of age themselves (Department of Mental Retardation Unserved Report, FY'97- Quarter 4). In 1996, at the recommendation of the Massachusetts Governor's Commission on Mental Retardation, a group of family members, advocates, and professionals joined to form Family to Family. Funded by the Joseph P. Kennedy, Jr. Foundation, Family to Family is working to better understand the waiting list and come up with creative strategies for eliminating it. The Department of Mental Retardation helped recruit over 500 caregivers to the project by sending *Family to Family* mailings to primary caregivers of everyone on the waiting list.

Family to Family began their efforts by first surveying the caregivers on their mailing list whose family members are waiting for residential services. They recognized that, before they could begin working on strategies to eliminate the waiting list, they needed to start by answering some basic questions about the list. The Department of Mental Retardation has not been able to provide the answers since they collect no substantive information from individuals on the waiting list. *Family to Family* sought to answer 5 questions: 1) Why do caregivers place family members' names on the waiting list?, 2) When are services needed?, 3) What kinds of residential services do caregivers envision for their family members?, 4) What formal or informal supports do families receive? and 5) Other than residential services, what kinds of supports do caregivers need?.

Major Findings of the *Family to Family* Survey

1. **Why do caregivers place family members' names on the waiting list**? Caregivers report that placing their family member's name on the waiting list was a very difficult step for their families. They gave any one of four reasons for doing so: a) they are experiencing severe family stress, including age-related problems, b) they want a residential service for their family member before a crisis occurs in the family, c) they want peace of mind that their family member will have somewhere to go when they are no longer able to care for him/her, and d) many feel their family member deserves to live independently of them.

2. **When are services needed**? 25% report their family members need residential services now, 14% need services within a year, and the rest either need services in 2-5 years or in the distant future. Those needing services within a year have more urgent family situations and are less likely to have estate plans. Many who want services in the distant future are elderly caregivers and, therefore, may actually need services sooner. Finally, 67% of caregivers say they would take a residential service for their family members if it was offered today. This is a sign that many caregivers feel desperate enough to forgo what they feel is best (continued caregiving) because they do not trust the services will be there for their family members when they truly need them.

3. **What kinds of residential services do caregivers envision for their family members?** Caregivers have extremely detailed visions of residential services for their family members, and they want to play active roles assisting their family members in making transitions to residential settings. Group homes are the most popular choice of residential setting. Only a few caregivers want their family members to live in a large facility or with a sibling

4. **What formal or informal supports do families receive**? Family members with mental retardation receive a number of formal supports, however, they provide

only a thin layer considering the 24-hour assistance that many of them need. Over half of caregivers do not have a non-paid relative or friend who can stay with their family member overnight, and few caregivers have a non-paid person who can stay with their family member for short periods, provide transportation, or arrange activities.

5. **Other than residential services, what kinds of supports do caregivers need?** Caregivers have many unmet needs besides the need for residential services. Many report that, in order to maintain their roles as caregivers, and keep their families together, they need information about the waiting list and stronger communication with the state. They also need more flexible and creative support services especially flexible respite services, aid with future planning, and services to assist their family members in preparing for residential living.

Conclusions

Unlike what many assume about waiting lists, we found that, in Massachusetts, the waiting list represents real need which must be addressed as both a short- and long-term problem. In the short-term, families with critical needs for residential services must be identified and served. We now know that even those who do not need services right away have critical needs for other kinds of support services. These needs must also be met in the short-term. In the long-term, most every adult with mental retardation will need state-supported residential services. The waiting list is an ideal tool for planning to meet those needs. There is no excuse, then, for the continuation of state service systems which are reactive and crisis-driven. Families should not have to continue experiencing the trauma caused by the current lack of planning.

What Are They Waiting For?

"... waiting lists can become permanent indicators of our society's inability or unwillingness to respond to the needs of individuals. At their worst, waiting lists are indicators of system crisis and failure, but we can use [them] as meaningful tools for planning and policy development. " Hayden, 1992

Text of paper presented at the President's Committee on Mental Retardation, Next Generation Leadership Symposium, Washington, DC, August 22-23, 1997.

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Good afternoon, today I will be discussing what is considered a national problem in the field of mental retardation: waiting lists for adult residential services. First, I am going to review some facts and figures around waiting lists nationally. Then, I will describe the waiting list problem in Massachusetts. My focus will be on the efforts of Family to Family, an advocacy group in Massachusetts focused entirely on the waiting list issue. I will present results of Family to Family's survey of several hundred caregivers whose adult-children with mental retardation are on the state's waiting list for residential services. These results will allow us to understand the meaning of waiting lists from the perspective of families.

Scope of the Waiting List Problem in the United States

The first comprehensive look at mental retardation waiting lists in states across the country was published in 1992 by the University of Minnesota. At that time, there were over 60,000 adults with mental retardation, who were living at home, and who were on waiting lists for residential services (Hayden, 1992). In 1996, the number had grown to 87,000 (Anderson, Polister, Prouty, & Lakin, 1997).

The 1992 University of Minnesota report found that most states maintain some kind of waiting list for individuals who have a need for residential services, but for whom the state does not have the funds to serve. They also found that few states collect anything other than basic demographic information from individuals on waiting lists. Therefore, they are unable to plan for the residential needs of those individuals. Finally, the report found that most states maintain some priority system for ranking the residential service needs of individuals on the list; however, "these procedures are typically centered around crisis situations." (Hayden, 1992, p. 11). Crisis may involve illness or death of the primary caregiver or abuse situations.

The implications of these findings for individuals with mental retardation on a waiting list can be traumatic. If they must wait until a crisis occurs in their homes (like the death of a caregiver, or an abuse situation), then they are left with what has been referred to as a "double-trauma": that is, having to deal with the family crisis and having to adjust to an unplanned residential placement. Since over 80% of individuals with mental retardation live with their families throughout their entire lives, this scenario will likely play out for a vast proportion of them (Fujiura & Braddock, 1992). These will also be issues for the unknown numbers of individuals who are not documented on waiting lists.

The Waiting List in Massachusetts

In Massachusetts, there are over 2,000 adults on the waiting list for residential services. Almost half of them have primary caregivers over the age of 60. Close to 5% of them are over 60 years of age themselves (Department of Mental Retardation Unserved Report, FY'97-Quarter 4). Officially, the numbers represent adults who need services within one year. The reality in our state, however, is that the vast majority of individuals on the waiting list will not receive services until a severe crisis occurs in the home, even if they have then identified as needing services within a year. When a crisis does occur, the state is still reluctant to provide services. Often they attempt to persuade siblings to take over caregiving.

As in other states, there is a fiscal crisis around mental retardation services in Massachusetts. Funding for residential services weighs disproportionately on institutionally-based services. Massachusetts continues to Aperate seven institutional facilities at rates as high as $500 per day (Braddock & Hemp, 1997). Despite these meets, the Legislature tends to be split over whether institutions should be downsized, closed, maintained as they or filled back up. Powerful interest groups have pushed for years to maintain the institutions. This issue circles back to the waiting list because these groups contend that re-opening institutional beds to individuals on e-maiting list would solve the problem. Their solution, of course, implies that individuals on the waiting list liftild choose to live in institutions.

In general, the Legislature in Massachusetts has been reluctant to increase funding for residential services at that would eliminate the waiting list. This reluctance may stem from basic unanswered questions that still in our state regarding the kind of need represented by the waiting list ... questions like: "Is the waiting list made up of individuals who are in crisis or who need services within a year?", or "won't most families just these care giving responsibilities on to the next generation?", or "couldn't we just re-open institutional beds most in need?" The questions may feel uncomfortable to us, but they are the very questions which disagreements over strategies to reduce the waiting list in Massachusetts.

Formation of Family to Family

In 1994, the Massachusetts Governor's Commission on Mental Retardation held a public hearing on the waiting a result of this hearing, the Commission published a report recommending, among other things, that a should form to connect families of individuals on the waiting list. (Governor's Commission on Mental 1994). Responding to this recommendation, a group that included mostly family members of adults retardation, advocates, and professionals formed a group called *Family to Family* with funding from Joseph P. Kennedy, Jr. Foundation. The goals of the group were to gain a better understanding of the waiting problem, and work together on creative strategies to reduce the list. The Department of Mental Retardation recruit caregivers to the project by sending *Family to Family* mailings to primary caregivers of everyone waiting list. Over 500 families are now part of *Family to Family*.

The group began their efforts by first surveying caregivers whose family members are waiting for residential They recognized that, before they could begin working on strategies to eliminate the waiting list, they to start by answering the basic questions which were plaguing policy-makers. The Department of Mental ion, after all, has not been able to provide the answers since they collect no information about individuals list other than basic demographic data.

Family Needs Survey: Posing Unanswered Questions

In what was called the "Family Needs Survey," we sought to answer five questions:

1. Why do caregivers place family members' names on the waiting list?
2. When are services needed?
3. What kinds of residential services do caregivers envision for their family members?
4. What formal or informal supports do families receive?
5. Other than residential services, what kinds of supports do caregivers need?

In March of this year, Family to Family mailed the "Family Needs Survey" to 400 caregivers on our mailing list whose family members were on the waiting list for residential services. Of these, 250 caregivers completed the survey.

Description of Respondents

1. **Why do caregivers place their family member's name on the waiting list**?
   Despite the pervasive role that caregiving plays in the lives of the parents we surveyed, they are not eager to discontinue this role. In fact, some admit that placing their family member's name on the waiting list is the hardest thing they have ever done. One woman writes, "This having to find a residence for our son is the most traumatic thing for us and our son that has happened in our lives!"

   There are four basic reasons caregivers give for placing their family member's name on the waiting list. Most list more than one of these reasons. Some caregivers describe issues which cause severe family stress, including age-related problems. One man writes, "Our family has endured our daughter's temper tantrums for over 20 years. Three of us are being treated for stress-related disorders. One of us left the home for over a year to get away from the situation." Other caregivers said that they want a residential service for their son or daughter before a crisis occurs in the family. A parent writes, "Primarily we want to avoid our son having a double trauma (once when we die, twice when he moves)." Another writes, "My feelings are that people like my daughter need to be taught to live away from their parents when they are still young enough and it is part of growing up, not when they are in their 40's and their parents are sick or dead. It should be when their family is still able to help them." Some caregivers want peace of mind that their family member will have somewhere to go when they are no longer able to care for him/her. These parents write, "We're in no hurry but would like to be assured that, should the need arise tomorrow, he would have a good place ready for him." Finally, many caregivers feel their family member deserves to live independently of them. One mother says, "He needs male companionship- not an old lady! We can't wait much longer. I don't want to drop dead in front of him!"

These reasons run contrary to the belief that only individuals in urgent need for services are on the waiting list in Massachusetts. The responses give needed depth to our understanding of how families perceive the service system. It seems that many of them know the system is in crisis, and that they may not get services for awhile. Placing their family member's name on the list, then, is part of a larger planning process (Essex, Seltzer, & Krauss, 1997).

2. **When do caregivers need residential services for their family members?**
Most of the caregivers we surveyed are not yet ready to give up their roles as caregivers today, or within the next year. 25% of caregivers report their family members need residential services right now. Another 14% need services within a year. The rest either need services in 2-5 years, or in the distant future.

First, we compared the caregiving situations of those who say their family members need services within the year with those who need services later. We found that caregivers reporting a need for services within a year are no older than those needing services later. However, they are in poorer health and their family members with mental retardation have significantly more behavior problems than those needing services later on. It is clear then, that caregivers needing residential services sooner have some critical issues in the home which may be influencing the urgency of their for need for residential services. What is also notable is that fewer caregivers needing services within a year versus later have estate plans or guardians designated in their wills. In other words, those with the most urgent need for residential services are also less likely to have taken care of essential planning tasks.

When we focus in on the group of caregivers who say their family members do not need services within the year, there is one fording I would like to highlight. -. Those who report needing services "in the distant future" tend to be elderly caregivers who feel their family members will only need residential services when they, the caregivers, become too disabled to continue care giving. Due to their age, a portion of these caregivers may need services for their family members a lot sooner than they want them, especially if they experience sudden illness or death.

Finally, when we asked caregivers whether they would accept a residential service for their family member if it was offered to them today, sixty-seven percent of caregivers say yes, they would take it. This finding indicates that some families feel a sense of desperation over the availability of services. Even though we found that most caregivers do not want to give up their caregiving roles right now, they would do so anyway, for fear that their family members may never get another chance.

3. **What kinds of services do caregivers envision for their family members**? One parent writes, "My son ... would like to live in the semi-rural town where he has lived for the last 15 years, and he wants to be physically near his church." Another family gives considerable detail concerning housemates for their son: "We feel our son would appreciate 2 or 3 housemates who are of a cheerful temperament, who like to be sociable, to sing and dance, watch decent sitcoms, enjoy musical entertainment ... go swimming in the summer, [or] go to camp ... Our son also likes his quiet time when he can be by himself and think his own thoughts and relax."

   The responses to this question tell us that caregivers have very clear visions of residential services for their family members. Overall, they want clean, cozy, safe environments in their current or surrounding towns with comprehensive supports provided by well-trained, experienced support staff. Caregivers also wish to play active roles in establishing and maintaining residential placements for their family members, including approving housemates and staff.

   Finally, when asked to choose among twelve residential settings for their family members, the majority of respondents (84%) want either a group home or an apartment for their family members (groups homes are the most popular choice). Almost three-quarters indicate a setting with full support staff (versus partial or none).

   Only 4 caregivers say they would consider a larger institutional facility for their family members. Eleven caregivers indicate that a sibling will take over care giving in the future. So, here are two more myths around the waiting list that we can dispel. Caregivers with family members on the list do not want institutional placements for their family members, and, on the whole, they do not expect to pass on care giving responsibilities to siblings. The take-home message here is that almost everyone on the waiting list will need services from the State.

4. **What formal or informal supports do families receive**? Caregivers report that their sons and daughters are receiving a number of formal support services-

usually income support, case management services, a daytime vocational program, and respite services. Remember, however, that these services provide only a thin layer of the supports which most of these individuals need to survive. Caregiving parents and families do the rest.

In terms of informal supports, we asked caregivers whether any non-paid relative or friend provides caregiving assistance. In one question, we ask whether anyone stays with their family member when they go away overnight. Over half say that no one ever does this. They take their family members with them everywhere they go. Even fewer caregivers have an informal, un-paid support person to stay with their family member for short periods during the day, provide transportation, or arrange activities or services for them. This scarcity of informal support means that many caregivers must balance their responsibilities alone. For some, this can become overwhelming. One woman writes, "I can't do this much longer. I've been single for 25 years. I have no other children. My relatives live out of state. I am tired!" One father wishes he could have gotten help during a temporary crisis. He says, "I could have used some help when I came home from the hospital. I was so weak, I couldn't take care of him. If only I had someone for that time."

5. What Supports do Caregivers Need? We felt it was important to ask caregivers not only about the residential services their family members need, but also the kinds of caregiving supports they need, even if their family members are not ready for residential services in the short-term. Caregivers report a variety of needs which, if met, would assist them in maintaining their caregivng roles and, keeping their families together. In general, they need more information and communication with the state, combined with more creative and flexible support services.

Better Information and Communication

Caregivers in our sample report that they are given very little information concerning the waiting list. They want to know how the waiting list is organized and prioritized. They want verification that their family members are on the list and some idea of when their family members will receive services, even if it is ten years down the road. They would like information on the services that are available, both residential and support services. They also want to know exactly what actions the state will take if they suddenly become ill or die.

More Flexible and Creative Support Services

Many caregivers report that their respite services are inadequate. They need respite services that are flexible and that are available on short-term notice. Families request other support services as well, like transportation, allied health, recreational, and estate planning. The need for future planning services is also crucial to these families. Almost a third of the sample do not have anyone in mind who will look after their family members' needs in the future. Two-thirds have not established a legal guardian for their family member in their wills, nor begun the process of estate planning.

Families have a creative vision of future planning services which includes more than just guardianship and estate planning. Caregivers want themselves and their family members with mental retardation exposed to the world of residential living. They want opportunities to visit residential settings. They want residential skills training programs for their sons and daughters (to prepare them for residential living), opportunities for their family members to "practice" living in a residential setting away from home, and many suggest setting up housemate matching programs. Some write that they the Department of Mental Retardation should be required to gather information from their family regarding their residential plans in the future. Finally, there were families interested in learning more about private funding options, or family partnership projects.

Summary of Results

To summarize, the results of the survey allow us to answer some of the basic questions which have haunted efforts to deal with the waiting list in Massachusetts. We re-affirmed that the waiting list includes individuals who have urgent needs for services that must be addressed immediately. However, we now know that a large portion of individuals on the list do not have critical needs for residential services. Many caregivers have no intention of giving up their roles as caregivers yet. They do, though, have critical unmet needs for information and support services which would assist them in maintaining their caregiving roles.

Many caregivers think of the waiting list as an initial step in future planning and realize that, since the need is so great, they better make themselves known to the state now rather than later. Further, caregivers are rightfully in fear of what will happen to their sons and daughters if crisis arrives unexpectedly. They are not content to wait until a crisis occurs before their family members move to residential settings, and they want to assist their family members in making smooth transitions to new homes. Another thing is also clear from this survey: re-opening institutional beds or passing caregiving responsibilities on to siblings are really not options for these families.

Condusions

The waiting list is both a short- and long-term issue. In the short-term, the residential needs of individuals in crisis must be met, in addition to meeting the critical planning and support needs of those who do not need residential services right now. In the long-term, virtually every individual on the list will need state-supported residential services. The need for residential services among individuals on waiting lists is clearly real and it is not going away. If anything, the number in need "will most likely continue to increase, rather than decrease over time' (Hayden, 1992, p. 11). Many more individuals with mental retardation are now living into old age and the baby boom generation is also aging. For the short- and long-term, the crisis-driven nature of the system needs to acknowledged and challenged. Families should not have to continue experiencing the trauma caused by the current lack of planning. So far, waiting lists represent a missed opportunity for meaningful planning.

Even if these findings do not surprise, you, it is important to remember that they will surprise some of the policymakers in our state who hold inaccurate assumptions about the waiting list, but who make real decisions regarding the allocation of resources. By starting from the beginning, and answering the most basic questions about the waiting list, the group Family to Family is now in a better position to advocate on behalf of individuals the waiting list and their families. Thank you for listening.

Table 1
Sample Characteristics (N=250)
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Care 'vin Respondents		
Who Responded?	Mothers	50%
	Fathers	10%
	Mothers & Fathers	40%
	mean	62 ears
	range	44-87 ears
Race	% white	94%
Marital Status	% married	72%
Caregiver Health Status	% good/excellent health	62%
Family Members with Mental Retardation		
	mean	32 ears
		22-60 ears
Gender	% female	47%
Level of Retardation	% mild or moderate	74%
Behavior Problems	% with at least 1 problem	46%
	average number	2 behavior problems

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TOPIC II: LEGAL/JUSTICE SYSTEM ISSUES

Papers/ Presenters

LEGAL/JUSTICE ISSUES

Tanya Dorf
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PEOPLE WITH MENTAL RETARDATION CONFROTNING INUSTICE WITHIN THE CRIMINAL "JUSTICE" SYSTEM

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LEGAL & JUSTICE ISSUES

BY TANYA DORF
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In a ceremony on the White House lawn, President Bush signed the Americans with Disabilities Act (ADA), which guarantees all Americans, regardless of ability, equal opportunity and access to employment, education and public places. It also guarantees that people with disabilities will no longer be discriminated against on the basis of their disabilities.

The first piece of legislation of its kind in the world, the ADA catapulted the disability movement into a full fledged civil rights movement. It did more to solidify the rights of people with disabilities than the Constitution, the Bill of Rights, or any other actions of the United States government during the previous 200 plus years. Dramatic changes have occurred since that historic day in 1990. People and businesses are now much more aware of people with disabilities and of their needs, and they are becoming much more accepting of the abilities of people with disabilities. But there is still a long way to go, especially in the area of justice.

"If we are to achieve a richer culture, we must weave one in which each diverse human gift will find a fitting place." In saying this, Margaret Mead recognized the importance of each individual to society. She pointed out that only when all people are included in society, and when all are looked at as equally important to society, will we have a rich, vibrant culture.

Mead is also famous for saying, "Never doubt that a small group of thoughtful, committed people can change the world, indeed it is the only thing that ever has." The disability movement is a relatively new one and as it grows older, it grows in numbers. Most of the progress made so far in the movement was made by small groups of people, though. This movement has proven that Mead was right: a small group of committed people can, do and have changed the world.

A contemporary of Mead's, Eleanor Roosevelt, also recognized the power of a small, committed group. Eleanor Roosevelt was not only the wife of one of the greatest presidents this country has ever known, she was also the wife of a person with a disability. She, like Mead, knew that it only takes a small group of thoughtful, committed and motivated people to change the world and make it a better place. After all, she was there when her husband and his advisers brought this country out of despair and made it a better place to live. And she knew from personal experience that a person's disabilities have nothing to do with what he or she can contribute to the world. Both women understood that it takes each person, regardless of ability, to weave the strong fabric of our society.

Margaret Mead's notion of a small group of people changing the world was the impetus behind the 1997 Next Generation Leadership Symposium, especially behind the work groups. The President's Committee on Mental Retardation recognized that young people, just entering the disabilities field, are the future of the field and that they must be empowered to take the field to the next level and to change the world.

The legal/justice issues work group seized the opportunity afforded them to take the first steps toward changing the world. The group made a list of all of the legal/justice issues which they believe need attention and then made a series of recommendations for the issues which they felt were most urgent.

The issues the work group identified as important fell into two basic categories: civil and criminal justice. Among the civil justice issues are guardianship, risk and liability, and monitoring community services. Criminal justice issues included educating law enforcement officials, lawyers and self advocates, providing services to the forensic population, fully implementing policies and procedures, tracking the number of people with disabilities in the criminal justice system, supporting people with disabilities after they are released from prison, and identifying and researching diversionary programs. As they began to craft solutions, the work group focused on education, guardianship and monitoring. Fo1lovwing are the work group's recommendations in each of these areas.

Education

The key education problem is that it is difficult to utilize all of the available resources to educate people about the justice system and disability. Leigh Ann Reynolds, presented research and ideas about the inadequacies of the justice system's treatment of people with disabilities.

Reynolds proposed developing a National Clearinghouse on criminal justice and developmental disability issues. This Clearinghouse would promote the use of existing training programs, and it would provide a central location where information on criminal justice and developmental disabilities can be gathered, organized and disseminated.
The work group recommended creating this National Clearinghouse to become the "one-stop center" for information on justice issues for people with disabilities.

The National Clearinghouse would house and disseminate materials to train law enforcement officials, attorneys and judges about the uniqueness and the needs of people with disabilities. Anyone in the country could access materials to train their local officials and justice workers. Many training materials of this type already exist, but there is no central repository for easy access.

Another type of information that would be found at the National Clearinghouse is information to train self advocates about the justice system. Many people with disabilities become victims of the justice system because they do not know what their rights are. People with disabilities are often taught to be very respectful of authority. While we all respect authority, we also know that there is a line between respecting authority and knowing what our individual rights are. The Clearinghouse would contain materials to teach people with disabilities about their rights as citizens, as well as about how the justice system works. They also need to understand that in some cases their disability is relevant to the charge against them, and sometimes it is not. The information available in the Clearinghouse will help people understand the difference between these situations. When people with disabilities are more informed about how the justice system works and their rights within it, they will be less likely to be either inadvertently or purposefully abused by it.

The ADA guarantees that information be available to anyone in a variety of formats upon request, including Braille and large print. The Clearinghouse would certainly make accessible formats of its materials available, but it would also go one step further. It would make sure that materials intended to help self-advocates understand the justice system are written clearly and in simple English.

The final problem the National Clearinghouse could address is diversionary programs. Currently there is a distinct lack of diversionary programs for people with disabilities. A common alternative sentence is work release. People with disabilities who are not offenders work very hard to get jobs in the community and to tear down attitudinal barriers about them. The fact that this movement is still struggling points to another fact: it will be difficult to sustain a good work release program for offenders with disabilities. The Clearinghouse could do research into the VA= of diversionary programs available for the general population and then work on modifying them as necessary for. people with disabilities. Ideas for new programs could also be researched and developed by the Clearinghouse. After these programs are developed, they must be implemented nationwide, taught to law enforcement officials across the country and sustained over time. By taking these steps, it will become easier to keep people with disabilities from becoming repeat offenders and from becoming trapped in the justice system.

Within the educational issues category, our group also identified law enforcement training as a problem. Police departments are not required to have disability education included as a part of their training programs for officers. The work group recommends that the national accreditation program for all police departments require disability awareness education as a part of all training programs. Robert Perske, who is a nationally recognized disability advocate, has devoted much of his time in recent years to helping people with disabilities who are caught in the criminal justice system. In 1991 he wrote a book called Unequal Justice, which chronicles many stories of people with disabilities, whether they are guilty or innocent, who are sadly defenseless when they become caught in the justice system. The book is filled with stories of what happens to people with disabilities when the justice system fails to understand them. In one story, Perske described the trial of a man who had an IQ of 49 and who had confessed to a murder. The following is part of the conversation from the witness stand:

"Jerome, did you assassinate President Lincoln?",
"Yes" Jerome said.
"Did you assassinate President Kennedy?" ,
"Yes" Jerome said.

It seems obvious that Jerome's competency is a central issue in this case, but his was never addressed in court, and he was executed for the murder to which he confessed. A case like this might not have gone so far if the police officers had better understood people with cognitive disabilities.

Guardianship

The problems centered around guardianship concerned the level of dependence on guardians. Often there is too great a dependence on guardians and that sometimes there is too little. The work group felt that there are some things over which guardians should have little control. Among these are deciding where to live. As more and more people with disabilities move out and live on their own, it is important that their decisions be respected. Frequently guardians are against either the decision to move or the location of the new residence, simply because they are not familiar enough with their wards. It is extremely important that guardians are in touch with their wards on a regular basis. When they stay in regular contact with their wards they will understand them well and know what they are like. The work group feels that guardians must be required to have regular contact with their wards. When they know their wards very well, they will be in a better position to offer constructive help when big decisions like moving need to be made. The decision itself, however, should still rest with the person who wants to move.

An additional guardianship problem involves people with disabilities who become their own guardians. A growing trend in the disability movement is that people with disabilities become their own guardians. It is never possible to know when a serious medical problem will occur for someone, so when self-advocates experience major medical problems, there may not be anyone available to make medical decisions for them. As a preventive measure, there should be a procedure by which people with disabilities can go to a judge or some other legal entity to find or identify someone who can serve as a medical guardian in the event they become seriously ill. By instituting a procedure like this, the sanctity of a person's right to be his or her own guardian can be preserved, while their safety and health is still be protected.

Monitoring

It is extremely important to monitor the work of organizations that provide services for people with disabilities to assure that no abuse, neglect and exploitation (ANE) violations occur. People with disabilities are among the most vulnerable to abuse, neglect and exploitation, so their safety is of the utmost importance. Most people who work in a setting in which they provide services for people with disabilities have only the best interest of the people they serve at heart. The human services field attracts people who want to help others and want to do their part to make the world a better place. Sometimes, though, a few bad apples slip in. It is important to have a system by which regulatory agencies monitor the work of the service organizations to ensure that the safety of the people they serve is a top priority. Frequently regulatory agencies charged with monitoring for ANE violations announce the time of their visits to the very organizations they are charged with monitoring. It is very unlikely that they will find ANE violations when those being monitored are ready and waiting for them. The legal/justice issues work group recommended that monitoring visits for ANE violations be unplanned and unscheduled. Only by surprising those who may possibly commit such atrocities, can offenders be caught. It may not seem ethical to stage unplanned visits, but it is a way to ensure that a true picture is taken of the activities of service organizations.

There is one further monitoring issue, regarding people with disabilities being supported as prisoners and exconvicts. Little support exists for people with disabilities when they are incarcerated, are participating in diversionary programs, and are released from jail or prison. Our work group recommended that as soon as people in the prison and jail system are identified as having a disability, they be assigned an advocate by the state's advocacy and protection agency. People with disabilities frequently become trapped in the justice system because there is a lack of services for them once they enter that world. There is a better chance of them making it back out of the criminal justice world when they are offered appropriate services and are properly supported when they are still in it.

The Work Goes On

Robinsue Frohboese, of the U.S. Department of Justice's Civil Rights Division, opened our work group's meeting on the first day by talking about the disability movement as a civil rights movement. She explained that civil rights is an evolving process. It is not something that is suddenly achieved. Strides are continually made, and rights are continually achieved, but the ultimate goal will only be achieved through many, many years of hard work. The civil rights movement of the 1960s has certainly put in many, many years of hard work to assure that African-Americans are treated as equal citizens. That movement has seen much success, but, thirty years later, even that famous movement has not achieved its ultimate success. The work already done and the Civil Rights Act of 1964 have been great strides forward, but it will take more years of work to finish tearing down old attitudinal barriers about African-American people. Likewise, it will take more work and more commitment from those already in and those just joining the disability movement to finish tearing down attitudinal barriers about people with disabilities.

People with Mental Retardation Confronting Injustice within the Criminal Justice System

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Wbo Cares to Confront?

Confrontation is a carefully learned skill which many people, both with and without disabilities, may never learn 'do. Yet, it is a skill that is vitally necessary when asserting and defending one's rights. Webster's dictionary fines confrontation as "facing something, especially in a challenge." This is certainly a challenging time for both ople with disabilities who get involved in the criminal justice system, as well as for those advocates who attempt provide some form of assistance for such individuals. Those with disabilities who have lived in institutional Clings, group homes or in their own homes with parents or caregivers who did not encourage their independence ve traditionally not been given the opportunity to make their own decisions or taught how to recognize or stand ,against injustices perpetrated against them. Injustices can happen, and do happen, whether the person with a ability has been victimized, unjustly accused of a crime (and possibly facing a life sentence or execution) or ed as a scapegoat to carry out criminal behavior.

People without disabilities who have generally been given more opportunities to learn how to confront and are equipped with some confrontation skills offer little help when it comes to advocating on behalf of individuals with ital retardation who become involved in the criminal justice system. Such issues involving criminal justice and tl advocacy are not too important to the vast majority of people UNTIL the person who becomes involved in criminal justice system is a child, a family member, a spouse, a friend, a co-worker, a neighbor or some other significant other. Advocates who do get involved feel overwhelmed, helpless, alone and inadequate to provide the (stance required due to their inexperience with the complicated criminal justice and court systems.

There are so many pressing issues facing people with mental retardation that it is difficult to justify spending time i energy discussing criminal justice matters. After all, how often do disability advocates rally to advocate for re diversionary programs created to assist defendants with mental retardation and other criminal justice-related advocacy services? Not very often, if at all. Many fighting for the rights of people with mental retardation, including self-advocates, are already overwhelmed with the task of fighting for basic needs, such as health and long-term care, fully integrated educational opportunities, supportive work and home environments and other vitally important needs. Although these issues demand constant attention and vigilance, we can no longer risk minimizing the issues people with disabilities face when they become involved in the criminal justice system. The longer we put off dealing with these issues, the greater the risk of unnecessary or inappropriate placement of people with mental retardation in jails and prisons. ALL people deserve a chance to receive basic rights within the criminal justice system, such as the right to a fair trial, to be taken seriously when testifying and to be heard. Yet for people with disabilities, these rights are often denied.

Overall, perhaps the most serious challenge facing self-advocates in achieving equal access to justice is the lack of a strong, committed and unified voice. This would allow individuals with disabilities the opportunity to speak for themselves about injustices. It would also give advocates without disabilities the ability to draw attention to the grave seriousness of this problem. Many with disabilities who find themselves in the criminal justice system often have not learned how to use their voice or do not have a voice to speak up about injustices, whether through a parent, advocacy group or other representative that could provide a wake-up call for the community. Fortunately, there are some services and programs available for people with mental retardation. Such advocacy services have shown to be helpful in providing alternatives to incarceration. However, even as this paper is being written, many people with mental retardation who are in the criminal justice system will have no one to help them navigate their way through this confusing process of "justice."

Because of this lack of accountability within the criminal justice system and disability community, injustices (whether perpetrated directly or indirectly) against people with mental retardation continue to be a routine part of their lives. This paper will first discuss the broad range of issues creating these injustices, then narrow the focus to three issues followed by possible solutions that can be used in creating future policy recommendations.

Looking At "The Big Picture"

A vast array of criminal justice issues impact people with mental retardation on a daily basis. These issues range from concern about whether or not the death penalty should be prohibited for people with mental retardation to how to identify those entering a jail or prison who have a disability to educating judges and attorneys that people with mental retardation who are victimized can provide credible testimony. Scholars, policy analysts, researchers, service providers, advocates and others concerned about criminal justice issues are often forced into grappling with only one tiny segment of the entire criminal justice system in a brave effort to effectively create positive change in a system that is generally punitive toward those it encounters. Unfortunately, looking at specific issues on a one-by-one basis has created a rather narrow perspective among criminal justice and mental retardation experts resulting in narrow solutions to a problem which exists in a much larger context than is often considered. The global picture of people with mental retardation in the criminal justice system must be shaped, defined and thoughtfully considered before attempting to provide solutions that have a significant impact.

By looking at the big picture, a framework can begin to be developed that provides direction when deciding which issues need the most attention at a certain point in time. This is especially important in a field where very little empirical research is conducted due to lack of funds or interest in the issue. One example of this need is provided by Dolores Norley, the first person to develop training curriculum for police officers on mental retardation, who stated in 1994 when attempting to survey states to find out who has diversionary programs for defendants with mental retardation that "a national picture is imperative before we can expect federal attention to a country-wide problem." Unfortunately, her words of wisdom have gone largely unheeded and many questions remain in the minds of criminal justice and disability experts as to what exactly needs to be done. How can criminal justice issues be defined and prioritized or can they? In using a systems view, (looking at the big picture, as well as each individual part) we can begin to define these issues so that possible solutions can emerge.

The "big picture" issues can be categorized into the following categories:

Lack of Clear Direction

Without an accurate definition of a social problem, it is virtually impossible to develop possible solutions. Defining and carefully articulating an issue takes valid and reliable data that can be used to construct strategies to the problem. Unfortunately, this data is often difficult to obtain due to the lack of research and the non-existence of significant statistics. Research is one of the most crucial needs within the field of mental on and criminal justice if comprehensive and lasting changes in policy and practice are to occur. Much of the research in the area used to demonstrate that a problem does exists is not consistent (Reynolds, 1995). For le, some studies have found that 10 percent of people with mental retardation are in the criminal justice while other studies cite only 2 percent (Noble & Conley, 1992). This variation in the number of people y involved in the criminal justice system presents a problem since policy makers and funding bodies who y fund important research initiatives are unconvinced that a problem exists. Research must be emphasized in order to create standards of measurement in each area of the criminal justice field. Such areas but are not necessarily limited to: 1) measuring the success of training programs for police, court el and self-advocates, 2) measuring the success rate of

various diversionary programs for offenders with retardation, 3) surveying the current knowledge of attorneys, judges and other court personnel who defend adjudicate people with mental retardation, 4) measuring the actual number of times a police officer encounters e with mental retardation and defining the outcome, i.e., is the person arrested, detained or released, 5) uring the success of training programs for self-advocates (looking closely at ability to understand their rights arrested) and 6) measuring the number of people within state and jail populations who have mental on.
Research is needed to provide answers to questions such as:

- How many programs for offenders with mental retardation are now in existence and how is their success measured? This has been attempted in various studies or projects in past years, but a comprehensive study is still needed.
- What crimes are people with mental retardation usually charged with committing? Some research has shown that most offenders are arrested for committing misdemeanors and other less serious felonies while other research conducted in New York found that sexual offenses are most common (White & Wood, 1986) (Sundram, 1990).
- What are the characteristics of people with mental retardation in the criminal justice system? Statistics have documented differing conclusions. Specifically, it would be helpful to know what is the average IQ and does the person have anyone able to provide advocacy on his or her behalf?

There simply is no substitute for valid and reliable research. Research is, in fact, the only thing that can provide the clear direction so desperately needed at this time in the mental retardation and criminal justice field. It is imperative to answer some of the underlying questions, such as the ones mentioned above, before moving forward in attempting to create policy that is not short-sighted, but comprehensive in scope.

Lack of Accountability

The creation of a strong voice that will speak clearly with and on behalf of people with mental retardation is paramount in achieving equality in the criminal justice system. Who is ultimately accountable for ensuring people with disabilities are treated fairly within the criminal justice system? No one has defined who should be held accountable, causing many individuals to slip through the cracks with respect to advocacy services. DeMoll states, "Overall, very few advocacy programs have been established in this country for defendants with mental retardation" (DeMoll, 1992). Although this observation is a few years old, it remains a stark reality even today. One example is the Protection & Advocacy agencies directed to provide legal services for people with mental retardation in each state. These agencies are generally able to provide advocacy services involving civil, not criminal law. Therefore, this agency is not accountable for serving a person with mental retardation involving criminal matters since they do not have the resources or expertise to do so.' This lack of response to injustices against people with disabilities happens in every aspect of the criminal justice system. Police officers feel this is a problem for the social/human service system, while the social service system feels this is a problem law enforcement officials should handle. No one system is taking responsibility for these individuals because many working in the system do not feel qualified or able to do so.

This lack of any one system taking responsibility results in part from little to no communication between and throughout systems which interact on behalf of defendants, victims and witnesses with mental retardation. The state of South Dakota recognized this problem in 1994 when the University Affiliated Program (UAP) developed a handbook of recommendations specifically for human service and criminal justice personnel to improve communications between these specific systems. The first key recommendation given was that, "The human services and criminal justice systems must work closely together to assure citizens with developmental disabilities are treated fairly and appropriately throughout their involvement in the criminal justice system" (Scheinost, 1994).

Creation of such a resource demonstrates the need for more accountability in a system where people with disabilities can easily become lost with little to no hope of obtaining any help from advocates "on the outside" (of the jail or prison system).

Misunderstanding the Disability of Mental Retardation

Mental retardation is still largely misunderstood by the general public, as well as those who also happen to be police officers, defense attorneys, prosecutors, judges and jury members. Moreover, these individuals only consider visible disabilities, such as blindness or Down syndrome, as being significant enough to warrant their attention. Many people are still unaware that approximately 89% of all people with mental retardation are mildly affected, meaning their disability is often not immediately recognizable upon outside appearance alone (The Arc, 1993). This lack of identification and understanding of the disability of mental retardation may cause problems in many areas of that person's life, such as in the educational, health care or social service system.

However, this problem of misunderstanding is especially dangerous and threatening to those who become involved in the criminal justice system. The consequences of being arrested, taken to court and detained in jail or prison are much different from the consequences of being placed in a segregated educational system or being denied medical treatment based on having a disability. While the latter situations are certainly unfair and can result in serious consequences, a person with mental retardation who becomes involve& in the criminal justice system faces consequences that are potentially more threatening (even to the point of losing a one's own freedom and life) due to the nature of the criminal justice system and lack of advocacy available. .

One frightening example is Johnny Lee Wilson, a man with mental retardation who spent almost a decade of his life in prison for committing a crime (murder) which he did not commit. He was forcefully guided by investigators to "confess" to the creme duivng a leagony and kwy Vaemfiil questioning period. 'the Gzovemar finally pardoned Wilson when the actual murderer confessed. Dr. Denis Keyes is a psychologist and special education professor with the University of Charleston at South Carolina who I have had the opportunity to work with on a federal death penalty case involving a man with mental retardation in Texas. He's conducted psychological testing on several defendants with mental retardation facing the death penalty. According to Dr. Keyes, *"What helped convict Johnny Lee Wilson was that he is mentally retarded. People with mental disabilities effectively come to the criminal justice system unarmed and ill-equipped. .. [they] are taught that the police are our friends, that they are the people we should trust to help us when we need help, and when you've got a problem, who do you call?"* (Atchison & Keyes, 1996).

'The P&A in California is unwilling to support legislation that would prohibit the death penalty for people with mental retardation claiming the lack of evidence of how many people with this disability are on death row.

Once a person becomes involved in the criminal justice system as a defendant, it is not easy to get out of the System and virtually impossible to receive any type of advocacy or rehabilitation services. Even if the person is recognized as having a disability, there are rarely specialized programs for offenders with mental retardation that pan ensure a safe and appropriate placement while imprisoned.

On the other hand, if the person becomes involved as a victim, the person is much less likely than a person without a disability to be seen as a credible person to provide "reliable" testimony. Because of the district attorney's misunderstanding of mental retardation, he or she may assume that because a client has mental retardation, there is little to no chance of prosecution. Giving people with disabilities the opportunity to voice injustices perpetrated against them is a major area of concern since research has found that people with disabilities are about twice as likely as others to be victimized (Sobsey & Doe, 1991). Whether a victim or .aspect, a person with mental retardation faces insurmountable obstacles to a fair hearing. If accused of a crime, At individual faces a greater risk of being found competent to stand trial and found guilty of the charge, whether or, not the person is guilty. If victimized, the person seems to face a greater risk of being found incompetent to `stand trial and given no opportunity to provide testimony.

People with mental retardation must be given more opportunities to learn how to protect their rights and themselves whether they are accused of a crime or victimized. Such instances of training and education rarely Um until the person is forced to learn by becoming directly involved in the criminal justice system. There continues to be little availability of training materials for self-advocates on these issues. Many advocacy groups)who desire to provide such training may find it difficult to find curricula that is easy to use and affordable. It is 'fair and unrealistic to place all of the responsibility on self-advocates to be trained and to be able to confidently front police officers and others in authority, but neither should their abilities be underestimated in protecting :l* own rights when necessary. Providing self-advocates with education about what to do if arrested, how to how who to trust and how to know when they are victimized is essential in preparing such individuals for a life of independent living in the community.

Likewise, all sectors of the criminal justice system require a constant flow of training on mental retardation. ~4fficers, much like the average member of society, do not have a good understanding of what mental retardation 'it. They may assume a person with mental retardation is drunk or on drugs when the person has mental won and, possibly, other related disabilities that gives this appearance. Police officers are on the front-line of the criminal justice system and have the ability to prevent unnecessary incarceration when appropriate. For reason, the training and educating of officers about mental retardation should be an ongoing activity 4wdertaken by local law enforcement, advocacy groups and other disability-related organizations throughout the country.

Courtroom personnel, specifically judges and attorneys, need training as well. If a police officer fails to identify ~*at the defendant who is charged with a crime or that a victim of a crime has a disability, a judge or attorney can maize the disability and make appropriate accommodations. In fact, the court, defense counsel and prosecutors have required by law to raise the competency issue whenever there is any suspicion that a person may have a mental disability (Pate v. Robinson, 1966). This law holds little purpose if people with mental retardation who go ,Is court are not being identified as having a disability. Defendants with mental retardation are generally not referred for competency evaluations because attorneys (both public defenders and prosecutors), judges and 'sic clinicians either do not recognize the disability or do not believe the disability is severe enough to require further investigation (Keyes & Edwards, 1996). Fortunately, some training materials have been created to educate self-advocates, police and court personnel. The following section will explain these efforts in greater dew.

The Arc of California recently surveyed probation officers, prosecutors and the courts to find out their desire for training on mental retardation and found that not one prosecutor felt there was a need for such training. Mental retardation is not only misunderstood, it is not even identified because many prosecutors do not feel someone "mildly" effected truly has a disability.

Past and Current Initiatives to Confront Injustice

Various projects have attempted to deal with the issue of people with mental retardation in the criminal justice system as far back as 1971 when the first training effort of significant importance (sponsored by PCMR) was held in Newport, Rhode Island. A conference was held consisting of law enforcement and mental retardation professionals to educate individuals in both systems about each other and defendants with mental retardation. A number of projects have followed focusing on various topics such as training of juvenile justice judges, development of screening tests to screen for adolescents with mental retardation in a Florida detention center, development of comprehensive model for coordinating services to adult offenders with developmental disabilities in a local jail setting, formation of statewide task force in New York and surveying UAP's to find out who was providing training in the area of criminal justice (Messinger & Davidson, 1992).

There are currently a number of excellent projects underway to combat the injustices faced by people with disabilities. These are highlighted and clearly defined in an effort to discover what is needed at this time within the mental retardation and criminal justice field.

The National Advisory Group for Justice (NAG) is funded through the Administration of Developmental Disabilities (ADD). Its goal is to prevent discrimination against people with developmental disabilities in the criminal justice system and does this by educating self-advocates about the criminal justice system, advocating for specific individuals through circles of friends and providing legal advocacy for people with disabilities who are arrested.

The Justice Now! project located in Texas is another initiative funded through ADD which is producing multiple training curricula specifically designed to allow self-advocates the opportunity to provide training to other selfadvocates, as well as criminal justice personnel. A disability screening tool was also developed to help accurately identify people with mental retardation entering the criminal justice system in Texas.

Temple University's Equal Justice project at the Institute on Disabilities/UAP in Pennsylvania is addressing the need for information and training by developing two sets of curricula for criminal justice professionals and people with disabilities, as well as trying to implement the topic of mental retardation into their law school curriculum. It also offers a statewide network of leaders in the areas of law, psychology, law enforcement, corrections advocacy and self-advocacy for those assisting people with mental retardation in the criminal justice system. They are writing a bi-monthly newsletter and a listing of resources which will be placed on the Internet.

The Arc of the U.S. has been involved in criminal justice issues for some time. The organization developed a position statement, "Access to Justice and Fair Treatment Under the Criminal Law for People with Mental Retardation" which specifies some of the major roadblocks to justice people with mental retardation face on a continual basis. The Arc obtained a one-year grant in 1994 from the U.S. Department of Justice to develop materials for self-advocates, police officers and court personnel to help each population understand what to do when in contact with one another. The Arc also developed a national resource list in the attempt to begin gathering all of the most current resources in the field, including "model" programs for offenders with mental retardation. At the national level, The Arc provides support and technical assistance for members and other individuals seeking practical advice when someone they know becomes involved in a criminal justice situation. Chapters of The Arc are also active at the state level. State chapters monitor statutes which impact individuals with developmental disabilities and many operate programs or conduct initiatives to protect the legal rights of such individuals. Chapters in New Jersey, New Mexico and California provide outstanding examples of how The Arc is making an unequivocal impact.

The Arc of New Jersey operates the Developmentally Disabled Offenders Program (DDOP), one of few programs nationwide that provides alternatives to incarceration for defendants with development disabilities. The program, directed by an attorney with a background in criminal defense law, serves as a clearinghouse for information about offenders with developmental disabilities and acts as a liaison between the criminal justice and human services systems. The DDOP, through the use of a Personalized Justice Plan (PJP), offers the court alternatives to incarceration for people with developmental disabilities. PJPs identify community supports and provide least restrictive, community-based alternatives for offenders, while holding them accountable for their ~dions. The PJP is presented to the court as a special condition of probation or parole. If it is accepted by the Judge and the offender is placed on probation or parole, DDOP then monitors the PJP until the person completes * or her sentence. Additionally, the program provides technical assistance to attorneys who represent people With mental retardation, educates individuals with developmental disabilities about confusing aspects of the criminal justice system and immediately intervenes on the client's behalf when necessary.

The Arc of New Mexico operates a similar program called The Justice Advocacy Project (JAP). JAP provides advocacy services statewide to adults and juveniles with developmental disabilities who are detained by the police i who are accused or convicted of crimes. They provide individual advocacy and a coordinated system of follow-up or aftercare. JAP also provides systems advocacy by actively supporting legislation that promotes improved treatment, habilitation and the development of specialized programs for offenders with developmental disabilities. People with disabilities are educated about individual rights, rights when arrested, what constitutes illegal behavior and consequences for breaking the law. Specialized training is also offered to law enforcement, the judiciary, and probation, correctional and parole officers. Currently, JAP is advocating for a change in the Criminal Competency Code for persons with mental retardation so that an individual who is being confined, Waiting to see if he or she becomes "competent to stand trial," would be capped at one year.

The Arc of California formed the Criminal Justice Task Force for Persons with Developmental Disabilities in 1995 to address the problem of increasing numbers of people with developmental disabilities entering the criminal justice system, and to promote better coordination between criminal justice and mental health/mental retardation agencies. The task force convenes a number of committees that cover a wide array of topics, including victims of crime, incarceration and community resources. Included on these committees are self-advocates, psychologists, attomeys, and police officers. The goal of the task force is to identify specific problems in California and propose solutions in the form of legislative, policy and procedural reforms. The task force is currently involved in creating materials for public defenders who represent clients with developmental disabilities.

By looking closely at past and current attempts to successfully handle problems of people with mental retardation in the criminal justice system, it becomes evident that there are some excellent strategies already taking place. Such models of practice must be further analyzed in order to pinpoint what works and why. Without any true measurement of what makes a program successful, there is little hope for continued funding for these necessary programs.

How To Confront - Three Proposals for Policy Implementation

After speaking with leading experts in the field who have devoted themselves to years of careful study and relentless advocacy efforts, it has become clear that many of the same problems we were facing fifteen to twenty years ago within the field of criminal justice and mental retardation are the same problems we face today. PCMR's Report to the President on Citizens with Mental Retardation and the Criminal Justice System written in 1991 mirrors this truth. Recommendations included having a national focus, conducting research and increasing awareness of mental retardation (PCMR, 1991). These suggestions for change remain much the same today, however, the strategies to reach these goals need revisiting.

We should be embarking on new challenges, focusing more attention on prevention efforts. Yet, as it stands, we continue to pragmatically focus more of our attention on those individuals with mental retardation who are already in the criminal justice system since these individuals seem to require the most intense advocacy efforts. For example, individuals with mental retardation facing the death penalty typically receive greater attention than a person with the same disability who is on the verge of entering into the criminal justice system simply by hanging around "the wrong crowd" and being arrested for petty theft.

How can we organize ourselves to provide a well-thought out plan of advocacy in the interest of ALL people with mental retardation, whether the person is facing the death penalty or charged with a misdemeanor, whether the person is poor or wealthy, whether the person is a minority or Caucasian, whether the person's IQ is 60-70 or 4050, whether the person has good communication skills or is non-verbal? This is the challenge criminal justice and mental retardation experts have not yet addressed or confronted completely. Someone or organization must be held accountable to consider the "big picture" in order to ensure that justice is distributed equally among those with disabilities. Providing services based on anecdotal information instead of research is a waste of time, money and, most of all, a waste of human potential in those the policies are created to serve.

In attempting to analyze the issue of people with mental retardation in the criminal justice system in its entirety, which is an incredible challenge, three possible solutions seem likely to produce the greatest positive impact at this time. The primary areas of change are focused on 1) making research a priority, 2) creating a Federal Criminal Justice Accountability Council and 3) developing a national clearinghouse on criminal justice/developmental disability issues

Make Research A Priority

In order to create a clear direction for future policy, research must be the top priority within the criminal justice and mental retardation field. In a field where the existence of research is usually the exception rather than the rule, it is difficult to attempt to pinpoint with a strong degree of confidence what areas of research is most needed at this time. However, the following have been selected in order to provide a basis on which future research may be conducted.

- Conduct a national survey on all programs which serve (as their primary client) offenders with mental retardation.

  A comprehensive survey has never been done before. Residential programs have been surveyed statewide; however, community-based programs were not included in the survey. When developing materials for The Arc's Access To Justice project which included identification of model criminal justice programs throughout the country, I heard from judges, attorneys and other criminal justice personnel about the lack of specialized programming for offenders with mental retardation. Providing training for criminal justice personnel to consider alternatives to incarceration is useless because there are not enough diversionary or other types of programs available for offenders with mental retardation.

This study could provide a solid estimate of how many programs are in existence (demonstrating the lack of programs available) which could ultimately help states pose convincing arguments to their funding sources of the need for more programs. Agencies may then be more inclined to provide funding for specialized programming for offenders with mental retardation. Once this information is gathered, it should then be made available to police officers, court personnel (specifically probation and parole officers) and others who can use this knowledge to prevent inappropriate placements of people with disabilities in unsafe prison or jail settings.

The U.S. Department of Justice conducted two different studies in 1989 that serve as a model for possible use in gathering this information. The first was a national study prepared by the National Institute of Corrections (NIC) to help citizens, policy makers and criminal justice personnel identify referral sources (Foote & Sivilli, 1989). Information was obtained through a national mail survey of residential community correction facilities. One category in the survey was "Services Regularly Available to Residents." Under this category are those facilities which offered any type of mental health services, which is described as "group counseling, individual counseling, family counseling or psychological screening/testing." This category would need to be changed to show if a program offers services or programs specifically for people with mental retardation. The second study prepared for the NIC by the Institute for Economic and Policy Studies identified "model programs" throughout the country serving adult offenders with mental retardation (Coffey, Procopiow & Mller, 1989). Combining the first and second studies would provide a comprehensive overview of programs serving people with mental retardation in the United States.

- Conduct research that would identify specific number of people with mental retardation who are involved in the criminal justice system, how they became involved, who (if anyone) provided any type of advocacy services, their ages, race and income level.

The U.S. Department of Justice already collects information on inmates with regard to sex, age, race, region and other basic identifying factors that are helpful in creating reliable criminal justice policy. A category should be added to include whether or not the person has mental retardation. This will be a challenge since each state has different ways which they define this disability (according to the type of testing used and how mental retardation is defined). Therefore, the method of how the information is obtained should be explained in the study. Such information could be obtained through an already existing study conducted by the

> Bureau of Justice Statistics (BJS), which regularly conducts highly informative surveys on criminal justice-related topics. Another option, which would yield much more information, is for BJS to conduct a completely separate study focusing only on people with mental retardation in the criminal justice system. This study should include how the person became involved in the criminal justice system, who (if anyone) provided any type of advocacy services during the time of criminal involvement, the age, race and income level of the person. Such information should be used to guide federal and state policy makers in deciding where to concentrate their efforts in preventing crime involving people with mental retardation, as well as deciding what type of advocacy service is most effective in serving people with disabilities.

Create a Federal Criminal Justice Accountability Council

This council would be responsible for researching, thoroughly investigating and carefully analyzing possible organizations who could be held accountable to provide advocacy and other related services for people with retardation and other developmental disabilities who become involved in the criminal justice system. The council should consist of experts in the field of mental retardation/criminal justice and include one representative each state. First, the council would need to identify all systems possibly involved whenever a person rs the criminal justice system, including mental health/mental retardation centers, police departments, assistance programs, courts, probation/parole offices, human service departments, self-advocacy groups, rofit organizations and other significant bodies. Next, the council should decide to what extent each of these ies is involved and how.

After obtaining a good understanding of the above, the council can begin to brainstorm and develop suggestions of possible organizations/individuals who can be held accountable for ensuring the safety of people with mental on in their respective states/communities. The council should consider those who already have a le amount of expertise or resources to provide such accountability. Some organizations that are mandated to assist defendants with mental retardation include Protection and Advocacy Systems, Councils on Developmental Disabilities, University Affiliated Programs, Client Assistant Programs and ional Rehabilitation programs.

The organization that seems best situated to provide assistance is the statewide network of Protection and Systems (P&A's). P&A's were mandated by Congress in 1978 to protect and advocate for the legal human rights of persons with developmental disabilities. They are authorized to use the legal system in order ensure the protection of such individuals. Unfortunately, DeMoll states that, "some state protection and systems have shied away from significant involvement in the area of defendants with developmental disabilities, for fear that the demand for services could drain their resources" (DeMoll, 1992, p.193).

This fear on behalf of P&A's to get involved in criminal matters demonstrates that there is a need for advocacy services for people with disabilities that is not being met. After being hired by The Arc of the United States to direct a federally-funded criminal justice project, I began taking a number of criminal justice-related inquiries from chapter members, attorneys and other interested persons seeking practical advice and helpful resources. In my experience, P&A's generally were (and still are) unable to provide assistance in criminal matters. The council should investigate further this issue and consider how P&A's may be given more resources to provide adequate services for these individuals on a consistent basis. The council should appoint specific individuals and organizations to provide assistance for self-advocates and other advocates who are unable to find assistance elsewhere. This network of criminal justice/developmental disability advocates could consist of staff persons with P&A's, national non-profit organizations, such as SABE (Self-Advocates Becoming Empowered), PCMR, AAIVIR, The Arc of the U.S. and other national, advocacy-related organizations.

Develop A National Clearinghouse on Criminal Justice/Developmental Disability Issues

A clearinghouse would serve to accomplish several important initiatives currently lacking within the criminal justice/developmental disabilities field. These include:

- Promote the use of already existing training for 1) self-advocates (to have a better understanding of criminal justice issues whether a defendant or victim), 2) law enforcement (including probation/parole officers, correction officers and others who work both within and outside of the prison/jail facilities) and 3) court personnel (including judges and lawyers to increase awareness of the requirements of the ADA as it relates to people with various developmental disabilities).

- Provide a central location where information on criminal justice/developmental disabilities can be gathered, organized and disseminated as needed. The information to be obtained should include: 1) a comprehensive database of past and current research findings to provide criminal justice policy makers with factual data with which to make important policy decisions, 2) a national listing of experts with experience in the fields of both mental retardation and criminal justice systems that can be used for referral purposes and to identify new leaders in the field who can play pivotal roles in continuing advocacy efforts on behalf of people with mental retardation in the criminal justice system, 3) a national listing of programs and resources serving people with mental retardation who are offenders or victims.

These activities create opportunities to provide a consistent flow of education to all those involved in the mental retardation, criminal justice and court systems. Implementation of these strategies would not be too difficult since some of this information is already in existence. The Arc of the U.S. has already began the task of identifying programs serving people with mental retardation and The Arc of California's Criminal Justice Task Force has developed a somewhat comprehensive listing of experts. As mentioned previously, ADD-funded projects are currently developing training for self-advocates, police and attorneys. Another benefit to having a national clearinghouse is to identify which educational materials are still needed. For example, one possibility that I have seen the need for is a handbook for parents, service providers, caseworkers and other advocates to help them become their own expert (to the extent possible) when advocating on behalf of someone with mental retardation in the criminal justice system. Advocates often seek information on the basics of criminal law, what to expect when going to court and how to best advocate on behalf of the individual who has been accused or victimized. The National Alliance for the Mentally Ill (NAMI) has discovered the same need and responded by creating a handbook specifically on mental illness issues for advocates. This book should be replicated with the focus being on issues specific to mental retardation. Providing this information to advocates increases the chance that someone with mental retardation will not have to face the criminal justice and court systems alone.

Conclusion-Confronting On A Global Scale

A number of excellent past and current efforts have demonstrated that attention to this problem is worth our limited resources, time, effort and money. Individual projects, programs and (a few) research initiatives provide a solid foundation for which to begin developing new strategies to confront injustices in the system against people with mental retardation. Yet, one or two federally-funded programs a year is not going to bring significant change. A statewide network of interested, passionate and highly motivated advocates that can be held accountable for ensuring equal access to justice for people with mental retardation must be created in order to better understand the far-reaching implications of this nationwide problem and to respond effectively. The past inability to see the big picture issues within the mental retardation/criminal justice policy arena has resulted in recurring problems that could have been more adequately handled had the entire system been considered during program and policy development. A number of large systems interact to provide services for these individuals, yet few people actually receive the kind of advocacy required to ensure equal and safe treatment in America's system of justice. Facing this harsh reality head-on by successfully confronting injustices suffered by people with mental retardation can happen only when a global perspective of the multifaceted issues is taken into account.

NOTE: A FULL SET OF APPENDICES ARE AVAILABLE FOR THIS PAPER UPON REQUEST. PLEASE CALL 202-619-0634 FOR MORE INFORMATION.

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TOPIC III: DIRECT SUPPORT ISSUES

Papers/Presenters:

WORKGROUP REPORT: DIRECT SUPPORT ISSUES

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SOCIAL ACTION: A MODEL FOR COMMUNITY INCLUSION AND SELF ESTEEM FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

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Direct Support Issues

By Seth Krakauer
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PCMR's Next Generation Symposium in just one short year has shown its vision by giving direct support issues its own platform for young leaders to influence policy and practices which affect the lives of people who support people with disabilities. Though people with disabilities have more opportunities for services than ever before, the services provided lack staff stability. Partnership and collaboration between staff and consumers is needed for the best possible outcomes. Some of the issues resulting in instability are as follows:

Nearly 10% staff shortages.
- A tumover rate of 50-70%.
- An average hourly wage of only $5.97 an hour.
- A high rate of staff being fired (15 % within first 12 months).
- Very high recruitment costs (6 million a year in Minnesota).
- A national and personal feeling of low status and value.

Clearly this results in a lack of continuity and support in the lives of people served. Next Generation clearly supports the ideal of assisting and challenging persons with disabilities to pursue quality lives. An integral part of this initiative also means supporting the staff intimately involved in their everyday activities. This includes advocating for better wages, training and recruitment for qualified people.

It is difficult to recruit and keep people who have a college education because of the low wages. Though it is hard to determine exact demographic information about direct support professionals, it is believed that 80% are women between 18-36. This lack of diversity is alarming. Additionally, only 33% have a BA or an Associates degree; 53% have some college; and 21% are currently students.

Entry level requirements into the field are similar to those in a fast food delivery job. An applicant simply must have no felony convictions and a valid driver's license. It is no wonder that many newly hired have little to no understanding of the hard work and dedication it takes to serve people with special needs. Ironically, agencies helping the disabled are one of the fastest growing industries. There is such a desperate need for staff that in Minnesota, for example, a whopping 53 % of all applicants are hired.

During the Next Generation Symposium on Direct Care Professionals, these challenges were discussed. Following are some of the priorities established to better support employees in the field:

- Reduce turnover through better initial screening processes and more stringent required qualifications.
- Offer better training programs for supervisors and direct care staff. Mentoring programs where seasoned staff train and support new staff have shown much success.
- Educate the community through media press releases and improved relationships with local businesses.
- Work to discover ways to increase job satisfaction. Ask staff directly about their needs.
- Pursue efforts to offer higher pay and better benefits. For example, offer information to staff regarding day care and housing load opportunities. Consumer and staff could participate in inservices or some college courses together.
- Ensure staff and consumer representation on all decision-making boards and committees. Encourage better communication between direct support professionals and administration. Ensure team collaboration on writing goals and objectives (i.e., Self-advocates chair their own goals/needs meetings and ensuring the inclusion of direct care staff.).
- Offer more opportunities for conference/trade show participation. Encourage management to fill in for direct support workers in their absence. Allow the formation of local committees with initiatives similar to PCMR's on a local level.
- Pursue ways to get more young people interested in the field. Encourage agencies to participate in volunteer
- Encourage collaboration between agencies.
- Individuals should lobby for more flexibility in state requirements.

Although the goals are clear, the potential barriers to change loom large. Many fear that middle management would not support these initiatives. More empowered direct care staff might somehow result in a reduction in mid programs (Youth groups, Fraternities, High Schools, etc.). Offer high school and college internships.dle management's power or status. Therefore, there must be support for these goals at all administrative levels. Even more important to the success of these initiatives is the procurement of funds to support increased wages and benefits. Currently, most agencies are unable to offer increased pay and benefits, especially costly pensions and on-premise employee childcare.

These recommendations need to be advocated not just by staff, but by consumers and their families; the community; and local, state and national leaders. This collaboration will lead to a win-win situation. The millions of dollars wasted on current practices can be funneled to increase the numbers of long-term competent staff who satisfy consumer and family needs. This will not happen by keeping silent. We as direct support professional need to be, along with consumers, diplomatically assertive until a top down mindset realizes the benefit to having all involved. We do believe that this is slowly occurring and are excited about the 21st century.

This report could not have been presented without the hard work of direct support professionals, staff agencies, state leaders, self-advocates and families. I would like to thank Amy Hewitt for her research; self advocate and 1997 Elizabeth Boggs award recipient, James Meadours for his heart felt personal experiences; Shoshana Rubenstein, also a Elizabeth Boggs award recipient, for her presentation of 21st century ideas that she has been instituting for years; Beth Pittinger for her mentoring; the entire Direct Support Issue Workgroup; PCMR Staff; and finally Hoong Yee Lee Krakauer for her intense support of her Direct Support Professional husband and recording of this topic.

Social Action:
A Model for Community Inclusion and Self Esteem for People with Developmental Disabilities

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The Direct Support Challenge: Community Inclusion With Dignity

The barriers to community inclusion for persons with developmental disabilities are vast with lingering effects. Too often, adults have been greeted with child-like interactions and expectations. Adults with developmental disabilities have been viewed exclusively as recipients of goods and services, when in reality, every person has the potential to be a productive member of society. It is not uncommon to encounter those in the community who want to "do something for the kids", when referring to adults. These attitudinal barriers have negatively impacted the self-esteem of those with disabilities, isolating the individuals and creating diminished self-concepts. This results from feeling dependent, insignificant and on the fringes of society.

While we have each been created with unique qualities, we also have similarities. Individuals with developmental disabilities, just as you and I, have the capacity to give to the community, in their own unique way. The greatest source is the human heart and the desire to give of oneself. Supports to actualize one's dreams must be given in a manner that provides dignity to every individual.

As direct care workers, we have been involved with activities of daily living, such as cooking, budgeting, personal care, employment, education, legal, social and quality of life issues. We have been relatively successful in offering supports as directed by the recipient via person-centered planning (PCP) to create an immediate environment that enhances self-esteem. Perhaps, we have also played a role in building a positive atmosphere at the workplace or the local pharmacy or other establishments. However, "the community" is a much larger place than one's hometown. It includes local, national and more global settings.

The challenge remains: to foster community inclusion of persons with developmental disabilities in all aspects o life. As Albert Einstein said, "A person first starts to live when he can live outside himself. .. we are here to d good and make this world a better place ... Life is a gift, and if we agree to accept it, we must contribute in return.' The social action model was chosen to overcome these challenges.

Social Action Model Objectives

1. To educate the community through personal contact by focusing on common goals and similarities, talents, abilities and contributions.
2. To build feelings of self-esteem and self-worth by being on the giving end.
3. To enhance empathy through opportunities to see others' needs.
4. To improve the social independence of Social Action Committee members (hereafter referred to as SAC) through opportunities to demonstrate leadership skills, make social contacts, work cooperatively with others and be recognized for their efforts.
5. To provide a truly meaningful service by meeting community needs.
6. To enhance community integration by providing opportunities to form natural relationships with other community volunteers as they work side by side as equals.

The Journey of the Heart-The Beginnings

Although the idea of starting a SAC had floated around for a couple months, it was difficult to determine how to start. It was a new experience for all involved. The role of the supports staff person was more involved initially, but as the numbers grew (from a handful, to eventually 50 participants) and experiences expanded, SAC members took on more of the leadership role. Support staff and committee members worked side by side, stepping into the project with both trepidation and anticipation. Little was known at that time of the challenges, growth, social changes, pride, tenderness and bonding that would come from the simple notion of giving to those in need. "It is in giving that we receive" (author unknown) became the foundation of the group.

The Projects

The following stories will serve to illustrate SAC's journey to become a model for inclusion, as well as the role of the direct care or supports staff, the changes and the implications.

The Cannery: The First Venture

TV news flash: "Several trucks were stolen from the local food bank, each carrying food for needy families ... the intended recipients would go without.." This news story was the spark that lit the fire for the birth of SAC. The food bank was contacted to offer help packing and canning food to replace the stolen goods. The initial response was positive. However, when it became known the volunteers were individuals with developmental disabilities, the response changed to obvious reluctance. The reasons given were : "they will be slow" and "they won't be able to keep up" with the packing. It was also mistakenly assumed the SAC was requesting food, since, after all, it was a group of people with disabilities. It became quite apparent that a major priority of the project would be educating the community and breaking down the stereotype of the person with a disability as "helpless" and the "needy recipient" which seemed to be so prevalent.

Once the project was identified, the staff role was to recruit volunteers. For this initial project, 13 volunteers agreed to participate. Flyers were sent to each volunteer confirming participation, confirming all essential information (date, time, suggested attire, summary of the project, transportation information, etc.) and offering words of encouragement and gratitude in advance for their upcoming efforts. (Note: Interestingly enough, it was later learned that the flyers were kept by several SAC participants as a means of recording their achievements.) This project (as well as all subsequent projects) were photographed by the staff support person. Volunteers were each given a photo album and photos of their participation in this initial and subsequent projects. Following the project, it was clear that social action participation had a definite effect on self-esteem. SAC members shared their experience with family members and friends with a great deal of pride. This offered family members the opportunity to see the special gifts and achievements as the central attributes as opposed to the "disability".

Social skills were also evident as participants were able to converse with ease about their experience and capture eager audience with the subject matter.

The group packaged food and canned several thousand items. For many, this was their first volunteer experience. e volunteer who has severe rheumatoid arthritis, scoliosis and Lupus, spent hours labeling cans. She wanted to the electronic canning machine, but felt she didn't have the physical strength to do so. She spotted another C member, who also experienced numerous physical challenges, operating the machine, and felt encouraged to try. She stated: "If she can do it, I can too! I am happy that I am able to help others, as many have helped me in life, too. I feel good knowing that we will help make a difference." Quite obviously, the SAC members inspire one another.

Following the project, volunteers lunched together, conversing about their experience, their feelings, their effect on others and how the day impacted them on a personal level. One volunteer shared that he felt good that he could be of the larger picture ... an active, productive member of society who is able to give the best he has to others in meaningful and uplifting way. Another volunteer, who actually receives food bank resources to supplement his limited income, commented "I am glad I can give back to show my appreciation for what I was given."

Clearly, the staff support role beyond initial organization of the project, community education related to inceptions/stereotypes and providing transportation, is one of providing opportunities. The opportunity for actual participation as well as the opportunity to "debrief' are equally important. The staff role is one of facilitator.

The SAC members who participated in this project gained skills in working as a team on an assembly line, an experience which most had not had (an opportunity to know success as a "team"), feeling a part of something bigger. Volunteers shared feelings of empathy for those in need, looking beyond themselves and their own needs. s particular piece is significant, as unfortunately the stereotype model of persons with disabilities being the recipients (as opposed to the givers) has given rise to a "welfare mentality". To realize one's capacity to act and "me" when "give me" is what has been reinforced most of one's life, is quite an accomplishment.

The SAC was invited back several times, in efforts to package and ship goods to Rwandan refugees and preparing packages for shelters for homeless persons. Quite obviously, the initial perceptions/stereotypes had changed! Each project offered opportunities to learn more about others' plights; in a sense, these were catalysts -for becoming a part of a more global community. This was only the beginning.

The Valentine Project

As the SAC gained momentum due to members enthusiasm and desire to be involved, the support staffs role was to facilitate exploration of potential future projects. A decision was made by individuals in the group to give Valentine remembrances to a homeless shelter so individuals/families there would know they had not been forgotten. The SAC decorated and stuffed 250 gift bags with 35 pounds of candy and hand-written messages. While involved in the project, several volunteers mentioned that they chose this idea because they were usually forgotten on Valentine's Day when they were growing up. The packages, when completed, were delivered to a local homeless shelter. When a 50-year-old volunteer was asked if the operation could be hosted at his apartment, he was very reluctant. He eventually agreed. He expressed his fears related to never having guests and not knowing how to host. Staff support allowed him the opportunity to express his fears and to meet the challenge. He successfully hosted a fabulous project (making cards and packaging candy), cleaning his apartment, purchasing snacks and welcoming each guest with grace. Fifteen projects later, he stated that the Valentine project was his favorite as he built confidence in himself, was the leader of the group and had since had many guests to his home.

Homeless Shelters

Each year, local temples shelter and feed the homeless, typically around Christmas time. SAC members agreed that they would like to join hands with this existing project. The first year SAC was involved, the volunteers were invited to put lunches together in an assembly line. While every part of the project was valuable and necessary, it appeared that we were assigned this particular task, once again, due to some misconceptions related to abilities.

By the third year of participation in this project, the challenge was met. The volunteer members of SAC planned, shopped, cooked, hosted and served the meal. Many people wished to participate, but for a variety of reasons could not be there. Their donations of money and baked goods were just as significant. Everyone came to realize that giving comes in all forms: financial, hands-on work, a smile, an open ear, a tender touch ... The

SAC volunteers worked hard to prepare a five-course meal, and with a great deal of warmth, easily reached out to touch another human being. The recipients of the meal brought tears to the eyes of some of the SAC members involved when the comment was made that in the past, they had never been served appetizers. The idea of being treated with dignity and the value of this seemingly small act was easily identifiable by committee members who understand all too well that dignity is important to all of us.

As the support staff facilitated discussion amongst participants, the social significance of homelessness was explored. The full impact of homelessness was brought home to some volunteers when they had the opportunity to talk and play with families with young children who were homeless. Circumstances which create homelessness were also explored. Once again, volunteers gained information and a comfort level which has translated into improved social skills in making conversation. A SAC member in her 50's, who spent most of her life in an institution, actually leant a very attentive and empathetic ear to individuals who were homeless. She expressed experiencing a bond ... a knowledge of what it feels like to have no home of your own.

Martin Luther King Day
Each January, SAC members march and participate in community-wide events honoring Reverend King and learn about civil rights. The SAC members are side by side with people of all backgrounds, races and faiths. The volunteers were initially afraid to venture out and expressed fears about being with individuals who did not have developmental disabilities. When asked to elaborate as to why they would feel more secure with others "just like them," comments were made that individuals with developmental disabilities would not make fun of them. Many members related stories of how they were called cruel names, laughed at and degraded. The support staff role here was clearly to facilitate a discussion related to "equality for all," the embodiment of the civil rights movement. Discussion moved on to how SAC members could be self-advocates in such situations. The support staff was able to facilitate a deeper introspective look, whereby individual members became aware that they too, were labeling groups of people instead of seeing others as individuals with their own thoughts, ideas, interests, etc.

By looking at their own feelings of isolation when labeled and lumped together by a single trait (disability), as opposed to their more numerous unique attributes, SAC members came to understand the barriers created by such thinking.

The Purim Parcel Project
Note: the holiday of Purim, observed by Jews, commemorates the rescue of the Jews of Persia in the fifth century B.C E. One of the customs of this holiday is to send gigs and goodies to friends and neighbors

Each year, a local agency spearheads a community-wide project to package and distribute these food parcels to seniors, hospice patients, and other isolated individuals just prior to the holiday of Purim. Some years ago, SAC members were the recipients of these luscious packages. The involvement of the SAC in this project, first and foremost, served to meet a community need. In addition, through the involvement of members of SAC, the host agency acquired quite a different perspective on persons with developmental disabilities. The SAC is now an integral part of the committee that plans and implements this annual community event. Moreover, several members of the SAC sit on the planning board for this activity, side by side with other leaders of community agencies as equals. The SAC involvement has increased to at least three annual community-wide efforts each year. One SAC member who now sits on the planning board stated , "We don't want a disability to be in our way. We have so many things we can offer the community. It opens other people's eyes to people with disabilities and what we can do."

Clearly, at one time the perception of persons with disabilities as the receivers rather than the givers was held by the host community agency. Not only has their perception changed, but a greater opportunity became available to the SAC members. With prominent positions on the planning board for several annual community events, SAC members have the opportunity to interface with other community leaders as equals, to role model for their peers, to offer encouragement to parents of children with disabilities, not to mention to shine in their own right as persons committed to their communities.

Bosnia: Sweets For The Soldiers And Children

In response to the suffering in Bosnia, the SAC organized a special campaign in which they baked and shipped out thousands of cookies, candies and cards to the American soldiers in Bosnia and to the Bosnian children. They hoped these packages would bring a touch of home and let them know that they are supported and appreciated.

SAC members from group homes and independent living programs all became involved, side by side with staff and their family members. (Note: the SAC members overwhelming response and enthusiasm sparked involvement of general agency staff in the SAC project). SAC members baked and contributed items they purchased. A conference room was turned into a massive cookie decorating and candy packing event. Some individuals volunteered to write notes/cards to accompany the packages.

A World War II veteran addressed the group, and brought home the point that mail call was the day's highlight during his overseas experience. SAC members heard firsthand that their valiant efforts would surely be appreciated, warming hearts even under the most bleak circumstances.

The far-reaching effects of this project were evident:

1. The global gateway was opened. SAC members touched the lives of others on the other side of the world. A connection was made with a much larger community. SAC became part of the international community, where their actions and words had a direct impact on others' lives.
2. Members were recognized for their individual and collective efforts not only by the guest speaker, but by the recipients of these packages. A copy of a soldier's letter of gratitude was sent to all SAC members.
3. SAC members realized their leadership qualities as they developed and orchestrated this project completely on their own.

4. In selecting this project, SAC members learned about other countries, about war, politics and humanity. The more one learns about others, the more one learns about oneself, about his/her capacity to give, to be empathic and understanding. SAC members now felt confident and joined in conversation when the subject turned to war, Bosnia, etc. Members reported, prior to this, feeling alienated and uninformed when news topics were discussed. Many members reported seeking out further information from the media, which had previously been intimidating.
5. SAC members said they "felt so good knowing they could help so many people." One individual said he felt "rich inside, like he was a goodwill ambassador."

Detroit Historical Museum City-Wide Birthday Party

This particular project was a bit different in terms of the origin of the SAC involvement. A former JARC staff person, very much aware of the SAC efforts, requested SAC participation in this massive effort. The SAC members reputation for commitment and enthusiasm would be an asset to this effort.

For this project, numerous art, social and civic groups gathered to celebrate Detroit's history, community and diversity. Our SAC ran the children's activity booth. One member described how meaningful this project was to her: "I got along with people from so many different backgrounds. I used to be scared to come to large events, especially if they were in the city. I guess I had my own prejudices and misconceptions, because I was misinformed. Today was so special to me because I got to teach others. Children asked me for advice and how to spell certain words. I couldn't believe it. That was the first time that anyone ever asked me for advice. It gave me a wonderful feeling."

Make A Difference Day 1996

In August of 1996, a van carrying 17 residents from a nursing home in Detroit, had a tragic accident. Many of the elderly residents were thrown from their wheelchairs onto the road, causing numerous injuries and several deaths. Some of their peers who didn't go on this outing were very shaken up when they learned what occurred and too frightened to venture out. SAC hoped to bring a little joy to the residents of that home and a reprieve from their painful memories.

Following an initial meeting with the Activities Director of the nursing home, the scope of the project was determined. SAC members would visit the residents, arrange for entertainment and bring refreshments, in the hopes of offering support, comfort and sunshine inside, when outside there was broken glass, debris, graffiti and deserted buildings.

In October, members of the group assembled, armed with hundreds of dietetic baked goods (baked by many volunteers), gifts, cheese and crackers, soft drinks and parry supplies. The volunteers visited with the residents and exchanged hugs, food and conversation for several hours. The staff support person was able to arrange for a group of singers and musicians to put on a lively show at the nursing home. The performers ended with Amazing Grace, which brought full participation and tears to many eyes. It is difficult to recapture in words the warmth and glow in the nursing home at that moment, a far cry from the dismal setting first encountered where bags of donated clothing not fit to be worn, were the first thing we saw.

SAC members were moved by both the warmth and determination of the residents. It was truly touching to see the joy in their eyes as they, too, sang and held out their hands. SAC members who had fears of being around elderly persons were able to put those fears aside and reach out and touch another human being who was isolated and afraid, feelings with which they could identify.

Changes And Outcomes Attained By Sac

1. Significant volunteer manpower is provided to both the local and global community. Aside from the above-mentioned projects, the members have contributed money to AIDS projects, created home-made get well cards for hospitalized children, and helped to paint and rebuild homes in the inner city, etc.

2. Self-esteem and self-image have improved substantially in committee members. The SAC enables those who have been accustomed to being on the "receiving end" to be on the "giving end". Confidence builds and the feeling of making a difference in someone else's life elevates self-worth. Positive changes have been noted in many aspects of committee members' lives, from social interactions to attitude and energy. In addition, leader-ship and organizational skills are built as committee members take on more significant roles in planning, organizing and executing projects.

   After each project, SAC members fill out a Social Action Participant's Survey. The members have an opportunity to discuss how they felt being part of the project, the impact of the project, ideas for future projects, etc. The staff support person has an opportunity, through this forum, to facilitate meaningful discussion amongst volunteers related to emotions, assessing the success of the project, etc. It is a very empowering process.

   During one of the debriefing sessions, the members described the skills they have gained, how being a member of SAC has effected them and why they keep coming back. "I learned that I get along well with people. I didn't know that before because I feared groups of people that I didn't understand. I avoided them, just as others might avoid someone with a developmental disability. It's important to see others as individuals."

   "I see myself in a different way now. I can be a leader and get a job done. I can also make people laugh and smile. When I grew up, people laughed at me. It hurt me and caused me to be afraid. Now I feel very proud of what I do."

   Another member commented:"I want to dispel rumors about disabilities. I am a good example. It's so important to give back to the community. I feel that SAC gives me an opportunity to meet new people, learn about the world, socialize, be part of the larger community. I do not want to be shown favoritism or treated like a child.I am an equal and I can help others as well as anyone..."

Yet another member said that she felt appreciated and important. She also commented that working with SAC "makes me feel like a human being." This particular individual felt she had been excluded from "mainstream society" for so long that she did not feel a part of the community. Clearly, presenting her with an opportunity to be part of the community was all it took. .

3. Society's perception of people with disabilities is changed. The mere involvement of the committee in organized volunteer events contributes to changes in public perception. As committee members showcase their own abilities through participation via SAC, or independently, their abilities become the prominent feature in their identities. It is no longer the disability that attempts to serve as the identity.

Members of this committee are working side by side with other volunteers, building a relationship and contributing to a better community. As noted previously, members now sit on a planning board for community volunteer events. Their participation is requested for major charitable events. Volunteers have also volunteered to mentor other individuals with disabilities, again increasing their visibility as positive role models. One SAC member stated that his efforts have motivated individuals who do not have a disability to get more involved in their communities.

Budgetary Issues

For the first three years of operation, JARC received no outside funding for the SAC. In 1996, we applied and were fortunate to receive a $5,000.00 grant from the Widman Foundation to expand SAC. These additional funds have allowed JARC to provide the staff time and transportation expenses to increase the number of committee members, as well as expand the number and scope of projects to be initiated by the committee itself.

This has provided increased planning and coordinating opportunities for the members. It is critical to bear in mind that SAC was successful in its infancy without specific funding. Depending on the projects selected, costs can be limited to existing staff and transportation. Volunteers may be sought to drive SAC members at no cost. It is possible to join hands on existing projects, whereby no cost would be involved. Donations can be sought for goods and services to complement efforts. BUDGET SHOULD NOT BE A BARRIER!

Future Directions/Recommendations

As individual committee members begin to identify favorite projects, staff support personnel can assist that individual in making a project their own. Support staff can explore options and assist in problem solving a project that a particular member may choose to execute on his/her own on a one-time basis or as an annual effort. An example that could be realized is the Valentine Project. The individual for whom this was his most meaningful project, could, with very little support, identify a small group of friends who could each come armed with a bag or two of candy and a heart of gold. This particular individual who is very proud of his newly developed computer skills (on a donated computer with donated teaching time) might choose to make Valentine cards to go with the packages. Once the cards/packages are done, he could drive them to a homeless shelter himself, along with his friends. This could potentially be **his** project.

SAC members might participate in more community leadership training/social action training, which could give way to greater opportunities and greater community visibility in a positive light.

An awards recognition program for volunteer participation might encourage even greater participation.

Ultimately, creating a community where SAC no longer needs to exist is the real challenge. Community inclusion will be achieved when individuals with developmental disabilities are welcomed as neighbors and taxpayers, participating fully in every aspect of community life they choose. Larger communities usually have many social action groups. Through visibility, persistence and heartfelt efforts, volunteers with disabilities will be included, eventually, along with everyone else.

Background

JARC (Jewish Association for Residential Care for persons with developmental disabilities) is a 501(c), nonsectarian organization dedicated to providing quality services which support men and women with developmental disabilities as valued and integrated members of our community. JARC today operates 16 homes and 4 independent living programs serving 150 individuals. JARC is funded primarily by the Michigan Department of Community Health and Oakland County Community Mental Health Services Board. One-third of JARC's $5.4 million annual budget, or $1.8 million is raised from individuals, foundations and businesses. JARC is governed by an active, dedicated and knowledgeable 45 member Board of Directors. Over 300 volunteers enrich the lives of people JARC serves and improve the productivity of its administrative operations. JARC is proud that 90.7% of its budget is used for program services; 5.6% for management and general; 3.6% for fundraising. Joyce Keller, executive director for the past 19 years, serves on the President's Committee on Mental Retardation.

The Social Action Committee (SAC) is coordinated by Shoshana Arden Rubenstein, who has a Masters Degree in Social Work from the University of Pennsylvania and has over 14 years experience in the human service field. Ms. Rubenstein has worked at JARC for the past 4 years as an Independent Living Program Specialist. In addition to her case management responsibilities to 12 adults with developmental disabilities living independently, Ms. Rubenstein developed SAC. (Note: SAC members participate on a voluntary basis and are not limited to persons living independently. Persons living in group homes have participated, and depending on the project, individuals participate in a number of ways as you have seen in the examples throughout the paper). Her role as staff support to this committee is as follows:

- to serve as role model for both the participants and other community members. Ms. Rubenstein role models positive, adult interaction.

- to provide education/exposure to SAC participants in relation to community needs, whether these needs exist in our local community, a neighboring community or are of a much more global nature, such as Bosnia or Rwanda..
- to provide opportunities to build leadership skills.
- to provide opportunities for decision-making beyond ones' own activities of daily living.
- to provide opportunities to plan and carry out the various tasks involved in each project.
- to provide opportunities for both project and self-evaluation.
- to coordinate and guide the process/activity on an as needed basis (dependent upon the project and the skills of the individuals participating)

Ruthe Levy Kahn has a BS in Special Education from Wayne State University and is a Registered Social Worker with the State of Michigan. She has worked with individuals with developmental disabilities for 33 years, beginning with volunteer work at the age of 13, teaching special education, doing job placement, case management and a great deal of advocacy work. Ms. Kahn has been at JARC for 10 years where she currently supervises the DeRoy Independent Living Program and provides supervisory support to Ms. Rubenstein and the SAC.

NOTE: A FULL SET OF APPENDICES ARE AVAILABLE FOR THIS PAPER UPON REQUEST. PLEASE CALL 202-619-0634 FOR MORE INFORMATION.

TOPIC IV:
HOUSING ISSUES

Papers/ Presenters:

HOUSING ISSUES

Sally Jachum
Johnson County Developmental Supports
Lenexa, Kansas

IN HOMES OF OUR OWN: THE PATH TOWARD SELF-DETERMINATION

Louisa J. Hext
Coordinator for Special Projects
Franklin County Board of Mental Retardation and Developmental Disabilities
Columbus, Ohio

HOUSING ISSUES

By Sally Jochum Johnson
County Developmental Supports
Lenexa, Kansas

Background
The topic of housing is one that effects every person with mental retardation and their circle of support. The search is on for housing that is adequate, safe, affordable and accommodating for those who are coming home to their communities in which their family and friends live. Consumers desire and should be allowed a choice in where they live and improved opportunities to afford housing in neighborhoods they chose to live in.

At the 1996 conference, the housing issues workgroup discussed the decline of large public institutions, The Home of Your Own Alliance, the Fannie Mae "Home Choice" underwriting experiment and continued barriers and disadvantages consumers face in finding homes of their choice.

This year, the housing issues workgroup chose to focus on specific issues important to housing challenges faced by consumers today, with the goal of improving the housing access process for consumers. The housing issues workgroup was made up a diverse group of people: family members, self-advocates, direct support professionals, and administrators.

The combined perspectives of two senior presenters in the field of mental retardation, Michael Smull, Support Development Associates, and Gary Smith, National Association of State Directors of Developmental Disabilities Services gave the work group several issues to consider in terms of how housing issues are conducted at present and the direction in which it needs to go.

In addition, a junior presenter, Louisa Hext, presented similar issues and gave a touching account of a consumer's story on her pursuit of housing. Housing issues were examined in terms of new age thinking; person-centered planning, housing assistance; opportunities and challenges, and supports; self-determination.

1. **New Age Thinking; Person-Centered Planning**: According to Michael Smull, when dealing with housing issues the focus needs to be on what the consumer needs and desires in their choice of a living environment. The person-centered planning process asks the consumer many questions that will help aid in the final decision on where this person would like to live. These questions may be centered around where they want to live, if they want a roommate, any home modifications needed, what can they afford, and what kind of supports are needed to assist them

in living in the most independent environment they can. The consumer is also shown different living situations and environments to make an informed choice. The circle of support for the consumer needs to listen, be consistent, show action, be realistic, and don't make promises they can't keep. The idea of person-centered planning is the commitment to act on what you learn for people with mental retardation now working with the person-centered planning concept the quality of life is sure to improve keeping in mind the whole focus of person-centered planning being the consumer's wishes that are acted upon. According to Gary Smith, it's important for people to have a home of their own. Independence is nothing else if not being able to decide where one lives.

2. **Housing assistance; Opportunities and Challenges**: Assisting people with mental retardation to obtain the housing they want in their communities poses various challenges. During 1970s and 1980s, housing and services were welded together. Group homes and other living arrangements controlled by provider agencies defined "residential services." The person-centered support principles led to supported living. Supported living holds that services and supports should be brought to the individual in a living arrangement he or she controls. Slowly but steadily the number of people with mental retardation and other developmental disabilities who receive supports in a home of their own is growing.

   The old way of funding residential services was to combine funding for housing and services. This funding was not portable-if a person left a group home, he or she could lose the funding. For supported living to succeed, new ways of thinking about funding and related aspects emerged. There are four elements of successfully supporting people with mental retardation to live in a home they can call their own:

Supports. Supports need to be brought to the person. The Medicaid home and community based waiver program is a particularly effective way to pay for these supports. Waiver services need to be tied to a facility. Waiver funding has played an important role in aiding funding for services and supports to be separated from housing. It aided many states in getting supported living off the ground. But, not all states have taken advantage of the flexibility afforded by the waiver program.

- **Income**. If people are to live on their own, then they will have to have the dollars to pay for rent and living expenses. Individuals usually are eligible to receive income assistance payments and other public benefits to help meet these costs. Helping individuals obtain a job is another important part of their having the dollars they need to meet their living expenses. Usually, the amount of assistance needed is modest. However, other states make it difficult for individuals to live on their own by taxing their income at high rates to off set the costs of services.

- **Housing Assistance**. There are many opportunities for people with mental retardation to obtain assistance through the public and private sectors to buy or lease a home of their own. In some of these programs, parents can help with the down payment. Gary Smith shared an idea (Individual Opportunity Accounts) to change federal SSI policies to enable individuals to save for a home of their own. Taking advantage of housing assistance opportunities in important because it makes housing more affordable for people with mental retardation.

- Helping Agents. Frequently, it is complicated to pull together all that's needed to help a person find, obtain and pay an affordable home. Thus, it makes sense to provide helping agents to provide assistance to individuals who need it in navigating the various opportunities. Complements to traditional case management services have emerged in various states to provide this assistance.

As supported living has grown, the "technology" for addressing these elements has matured. There are fewer barriers today than in the past in assisting people with mental retardation and other developmental disabilities to secure a place they can call their own and still have receive the supports they need. In several communities around the country, all people-regardless of the severity of their disability-are living in homes of their own while receiving the supports they need from public programs, their families, friends, and fellow citizens. They are included in their communities, have the security that comes with having a homes of their own rather than being dependent on service system housing, and thereby enjoy real independence and citizenship.

Still and all, despite many successes, only about one individual in seven who receives publicly-funded residential services and supports lives in a home of their own (cite is the University of Minnesota 1997 residential services report). There is still a long road ahead in creating the opportunity for every person to live in a home they call their own.

3. Supports; Self-Determination: The issue still remains on people being able to meet the financial and support requirements of obtaining an apartment or home of their own. The important component to keep in mind is the need to give thought on what supports do they need in their home? Many people are leaving large state facilities and coming home to their communities and need services.

   According to the Residential Services for Persons with Developmental Disabilities: Status and Trends Report through 1996 about 75% of the states (38) have either closed a large state MR/DD facility or are planning to do so by the end of 2000. Fifteen states plan to close at least one large state MR/DD facility between 1997 and 2000. Overall, 21 of 216 remaining large state-operated MR/DD residential facilities are currently projected for closure in Fiscal Year 1997-2000. The total decrease in populations of large state MR/DD facilities between 1980 and 1996 was 71,152 average daily residents.

With the closing of large state facilities this poses the need for service providers to meet the needs of the persons with MR/DD in their home communities as well as persons already in the community living with family for friends that desire a residence of their own. According to Louisa Hext, individuals must be given the opportunity to identify where and with whom they want to live. These choices should not be determined by funding sources, but rather driven by personal choice. The concept of Supported living, presented by Louisa Hext, separates housing from services, therefore allowing people to have more power and control over where they live and how they choose their lives. Supported living allows individuals, regardless of their disability, to live in typical housing in residential neighborhoods, alone or with person of their choice, and with a strong and complementary community-based system of supports. The principles of supported living encourage individuality, selfdetermination, independence and the opportunity to assume responsibility and control over one's life. The focus desire is to support one person at a time and not compare one individual with another to determine overall equity. The control over their own money can be achieved by working with the person-centered planning support individuals and with technical assistance. Costs can be reduced by empowering individuals to be more creative with their individual allocations while remaining accountable for those dollars spent.

Recommendations

1. **Funding is portable**. The expressed desire by the housing issues workgroup was the strong need for the individuals with MR/DD to have individualized budgets, controlled by the individuals and flexible to go with the person from service area to service area as they choose. Pulling the funding streams together to meet their whole need rather than the control being with the funding sources and agencies in the states, counties, regions and provinces that provide the services. The important aspect to focus on is that supports need to be brought to the person. The Medicaid home and community based waiver program is an effective way to pay for these supports. In addition, waiver services need not be tied to a facility. Funding needs to be flexible and portable. The continued availability of HCBS waiver will aid in the funding for services and supports to be separated from housing.

2. **Affordable housing**. The need for affordable housing is great. Often individuals are left on waiting lists for Section 8 housing and other assistance programs for years and then later find out that they do not meet the financial requirements to obtain even these housing assistance programs. The "Individual Opportunities Account'(IOAs) is a recommended solution to this problem. The other assistance programs such as FannieMae and Home of Your Own programs also need the continued support to fulfill the housing needs of consumers. Supporting and forming allies in home communities, allowing tax breaks and offering financial control to go with the person are all ways of achieving the desired outcome of affordable housing.

3. **Assessable and safe housing**. Often is the case that individuals on fixed incomes are directed to unsafe, substandard accommodations for housing. We recommend the continued support and enforcement of the ADA law and Fair Housing Act, and the support of educational programs on ADA to service providers, families, communities, and business owners. The emphasis is recommended to educate and enforce these laws.

4. **Real choices provided**. Our recommendation is to support the education of providers on what informed choice is for the person with mental retardation.

Increase opportunities for self-determination. According to Lousia Hext, often times individuals are encouraged to make difficult choices with limited personal experience and knowledge of how these decisions might impact their lives. To increase opportunities for selfdetermination, individuals should be offered the necessary support to make informed and responsible choices. Informed choice is necessary to truly fulfill the opportunity to make safe and adequate choices and take responsibility for these choices. The support and practice of person-centered planning is the cornerstone of success for real choices being provided.

5. **Develop natural supports.** Natural supports is not just a new key phrase but a real direction we must take to be successful and creative with the supports for people with mental retardation. It is also an area that needs to be approached with caution as to not eliminate needed supports or allow someone to provide supports that is not adequately trained to offer needed supports. The person-centered planning approach should allow a person to design their support network. The conflict comes when there is not a separation of supports from housing. An example is if a person needs supports and the requirements of a program is that the person has to live in their residential facilities provided otherwise the person is not eligible for services if they choose to live elsewhere in a place of their own choosing. These rules created by systems may allow the individual to become lost in the system. This approach provides limited choices by companies owning properties, providing supports and require minimal choice opportunities. We recommend individuals be given the opportunity to identify where and with whom they want to live. These choices should be driven by personal choice and natural supports are created as an outcome of these choices.

Summary of Recommendations

- Funding for consumer services should be portable and flexible. The consumer controls the funding by choosing the services that best meet their needs. Support needs are brought to the person.
- Housing for individuals with mental retardation should be affordable. Tax breaks and financial savings plans would enable a person to better afford a home of their own.
- Enforcement and education required of the ADA law and Fair Housing Act to assure assessable and safe housing options.
- Informed choice is necessary and a citizen's right. Necessary supports need to be maintained and encouraged to allow a person with mental retardation the opportunity to make an informed choice based on opportunities of experience and to develop knowledge of choices and responsibilities they have.
- Developing natural supports would allow an individual successful and creative ways of support. The support of the person-centered planning process would allow natural and timely transitions of persons and their support needs to tangible and developed supports in the community.

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In Homes Of Our Own:

The Path Toward Self-Determination

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Historically, people with mental retardation and related disabilities were protected and corrected by the service delivery system. Professional staff typically "cared for" and "did for" individuals rather than providing them with opportunities to make independent, informed choices. Similarly, while families provided the impetus for many changes, they tended to shelter and isolate individuals. Such practices resulted in limited encouragement or support for individuals to lead autonomous and proactive lives.

Positive changes have occurred since the early 1970's. People with disabilities are being viewed with increasing value and given more opportunities to lead satisfying lives. This trend has emphasized inclusion rather than segregation, increased opportunity for informed decision-making and promotion of independence rather than dependence. Despite progress, individuals have not always received support in assuming these new challenges and corresponding responsibilities.

During the 1980's, *supported living* has emerged as an alternative way of doing things which allows for greater autonomy in life choices for individuals with disabilities. Supported living as a concept separates housing from supports, therefore allowing people to have more power and control over where they live and how they choose their lives. More specifically, supported living evolved to allow individuals, regardless of their disability, to live in typical housing in residential neighborhoods, alone or with persons of their choice, and with a strong and complementary community-based system of supports and services.

Supported living has created a powerful vision for the future. While compelling and desirable, it has also introduced significant risks and challenges. People have begun to experience increased power and control and have been instrumental in defining lives that make sense to them. Life is no longer confined to a "program" but according to how individuals determine their life quality. It is successful when an individual "experiences a sense of place, when they or their agent control their home and the support necessary to live there, and when they occupy the valued role of homeowner or tenant and thus build equity or credit through rent or purchase payments" (O'Brien, 1991).

The increasing gap between the defined principles and actual practices of supported living has profoundly impacted ways people are supported according to their preferences and desires. With reference to housing, and *supported living* philosophy, some individuals are directed to unsafe, sub-standard accommodations to demonstrate that they are living in their own homes. In reality, this practice does not constitute home ownership, nor choice and control of where these persons live. Similarly, when facilities are simply relabeled as the person's home, or non-profit housing associations lease to individuals under the guise of home ownership, the dimensions of supported living and it's guiding principles are compromised. Commitments must be made to ensure that philosophy becomes consistent with practice. Key stakeholders must be encouraged to consider current practice and envision positive, desirable futures, identify and discuss the challenges and barriers, and determine what it will take to support people to live quality lives as defined by the individual.

Professionals, practitioners, scholars, families and self-advocates have raised endless questions such as:

1. Given the inevitability of more restrictive funding sources and the onset of managed care, can we support people effectively?
2. Given the diversity of each person's disability, can we support all individuals?
3. Given each person's abilities, preferences, desires together with their challenges and needs, can we create outcome-based, quality supports for everyone?
4. Given professional, family and public opinion, can we provide effective, equitable, flexible supports which respond to these concerns?
5. Given the significance of personal choice, how will systemic and personnel issues maintain their balance while encouraging individuality, initiative and innovation for those people we support?
6. Given the importance of offering supports, which define the person holistically, how can we guarantee a reasonable balance between choice, health and safety, the provision of supports, which are equitable and cost-effective, and those, which do not impinge on the person's defined quality of life.

The overall vision is to lay out a path that makes sense to the individual, a path which is pro-active, realistic and outcome-based. Issues surrounding existing policies and procedures, equity, costs, health and safety, often prevent us from making the requisite commitments, experiencing accomplishments and creating change. Often, simply open communication and willingness to discuss visions and challenges, hopes and fears can lead to a more successful and flexible approach to supports for persons who experience disabilities.

Now responding to individual needs and preferences and supporting people in their own homes has become the verbalized norm, yet practice does not always demonstrate the true acceptance of these principles. Supported living as practice continues to grow in response to a variety of financial incentives. The most significant impetus has come from the recognition that individuals have the right to choose how they prefer to live, who they live with and who will support them. This vision challenges the traditional service delivery system. Housing is not always considered separate from the supports provided to individuals. Typically, operators of residential facilities place "residents" into structured ways of living which reflect policy and procedure. On the other hand, the supported living principles challenge this by complementing each individual's unique vision. These principles encourage individuality, self-determination, independence and the opportunity to assume responsibility and control over one's life.

Despite some success in supporting individuals in more flexible ways, funding is becoming increasingly limited at the federal, state, and local levels. Most states are moving toward a managed-care approach to supporting individuals with long-term disabilities and health-care needs. Traditionally, managed health-care entities have operated will supporting individuals with short-term disabilities. As individuals who need long-term supports are funneled towards a managed-care approach to service delivery, individual support plans must be developed which clearly articulate how money will be spent. Key stakeholders must think more creatively about spending which will lead to positive outcomes which are equitable, affordable, and desirable. It is also imperative that individuals and their circles of support have the opportunity to develop useful decision-making skills so they can be empowered to control dollar allocations.

The individual and their support network must trigger and direct the design of their supports. Consonant with supported living philosophy, all individuals should receive the supports which can lead to independent, quality lives. In certain situations individuals have been considered too expensive or not eligible for services, and therefore, have been refused supported living dollars. If the principles of supported living are embraced, each person's needs must determine what it will take to make their life meaningful. Moving slowly and supporting one person at a time will provide opportunities to make changes for larger numbers of individuals over time. Certainly, supports must be cost-effective and equitable, however, if individuals are compared with one another to determine overall equity, the core principles will be threatened. Initial investment in people's lives will create savings further down their support path. Rather than paying close attention to entire budgets within supported living programs and dispensing monies according to perceived need, individual allocations should be calculated for individuals with their support network. Together with technical assistance and person-centered planning individuals can then assume control over their money. Overall, costs will be reduced by empowering individuals to be more creative with their individual allocations while remaining accountable for those dollars spent.

Liz's Story: No Way Out!

Liz is a young woman in her thirties who resides in her own condominium in a suburb of Columbus, Ohio. Liz lives close to family and friends and receives daily assistance from her chosen support circle. At this time Liz is very happy and leads a quality life created with the support of her family, friends, direct support professionals and others who care about her. Following an automobile accident in 1980, Liz suffered a significant brain injury. Consequently, Liz's plans to attend university as an art major and pursue her dreams as an artist were postponed. Following her rehabilitation she began to receive services from the local county board of mental retardation and developmental disabilities together with monies from a federallyfunded waiver. Over time, Liz began to voice concerns that the "system" was not responding to her preferences and needs. Initially, Liz had lived with her family and received supports in her home. She was later given the opportunity to move to a house leased by a non-profit housing association. The process provided many opportunities for choice-making including which side of town she wanted to live on, the type of house she wanted to reside in and whom she wanted to live with. She was also involved in the development of her individual service plan. While these were significant opportunities to make choices, a number of conditions and restrictions were imposed. Liz had to choose two housemates from a list of individuals who were eligible for services and each person had to agree on the same provider. Liz asked to bring her own support person with her. It was decided that an exception could be made, and Liz moved into her house with two other women, a common provider and her own support. She lived there for three years.

Over time, Liz did not feel at ease with her housemates. She expressed difficulty relating to them feeling that her disability was quite different from theirs. She began to ask people to listen to her frustrations. Few people took the time to empathize with her and encourage her hope to move to a place of her own. This was in part due to the policies of the supported living program. While it encouraged individuality and independence, most opportunities were not separate from the non-profit housing association and most of the funding was directed towards this housing. While people were encouraged to make choices, they were not given other residential options such as leasing off the open market, buying a home, living alone or sharing with individuals who do not receive services from the county board.

Given Liz's frustrations, she chose to participate in a self-enrichment program which allowed her to articulate her hopes and wishes and to create a plan of action. Liz clearly indicated her desire to move, yet again the "system" did not listen to her. Her wants and preferences did not appear to coincide with the menu of opportunity offered by the supported living program. As Liz became more frustrated, she directed her dissatisfaction towards her housemates by shouting and hitting them. Though it was unfortunate that Liz chose this way to communicate her preferences, she felt there was no way out; that this was the only way to be heard. Her negative actions clearly had a significant impact on the opportunities which became available to her. During this time, Liz also responded positively by developing a circle of support to help her define her path. Her circle pursued a variety of home ownership options. Finally, Liz and her family identified their desire to buy a condominium close to her sister's home. Since Liz received waiver supports, she could choose where she wanted to live and still bring her supports with her. She wanted to buy her own residence, make it accessible to her needs, afford to live and still maintain her benefits. The circle communicated their hopes to the supported living program which then agreed to assist Liz if she could come up with a reasonable plan. Liz was asked to consider ways to reduce her cost to support herself over time. She was offered a rent subsidy and a loan to make her condominium accessible and provided with the opportunity to think creatively about what it would take to make her vision a reality.

Liz's family purchased the condominium to protect Liz's social security benefits. Considerable discussion was given to making the condominium accessible to Liz so she could increase her independence and in so doing reduce the amount of daily support she needed. The initial investment required $10,000, money Liz did not have. The supported living program loaned Liz the money to complete these accommodations and a re-payment plan was established over a five year period. Liz was able to reduce the amount of money she required for her rent subsidy, which allowed her to reallocate money towards her loan. In addition, she reduced the amount of formal supports through the establishment of a natural support network of family and friends, defined periods of time she chose to spend alone, and established an emergency contact plan. All of these supports have offset the need for extensive professional services. Liz is already saving money in comparison to her previous support costs.

Liz has found more time to pursue her artistic talents. She is currently considering ways to generate income to support herself more effectively and to be less reliant on assistance. Liz recently hosted an art show at a local coffee shop which created new relationships in her neighborhood. She has networked with peer artists and has found people are very interested in her work. This interest triggered her desire to start her business selling notecards and prints. In addition, she has found more time to involve herself in local community events facilitating the development of even more community connections.

Thinking creatively and allowing the flexible allocation of funds, the "system" finally responded to Liz's own vision of a desirable life. This solution has proven to be cost-effective. Some may consider this an inequitable way to spend resources, but it has proven to be an investment which has allowed an individual to live according to her own identified outcomes. While more expensive initially, costs will diminish over time. Liz herself is committed to re-paying the loan and making monthly rent payments to her family. This form of best practice can be replicated. Liz's story offers a vivid example of the importance of asking people what they want and demonstrates the creativity that can be afforded in effectively supporting individuals, rather than expecting people to fit into pre-defined programs and limited options.

Prescription for Change

Liz's story highlights ways to enable people to start on a path towards a self-determined, quality life. Her story offers hope that individuals can be supported in ways which acknowledge, respect and build personal visions for positive futures. More generally, we learn from Liz the benefits of supporting individuals to:

1. define their own quality of life;
2. choose how, where and with whom they live;
3. select their own supports and providers of service;
4. direct the planning, and implementation of these supports;
5. have the opportunity to increase personal life experiences by moving towards their desired goals;

6. lead life and choose supports based on individual and personal need;
7. increase the flexibility and control of the financial resources available; and
8. assume the dignity of risk and responsibility for aspects of this life.

Individuals with disabilities have the same dreams and desires as those who do not have disabilities. The only difference is they require assistance to identify and work towards these dreams. Notions of quality are often affected by the presence of disability. "Systems" have typically pictured lives of persons with disabilities as quite different than the lives of others. The standard held for quality of life should be consistent and not compromised because of disability or for any other reason. Overall, people do not rely totally on professional services and supports, yet this is the backbone of service delivery for individuals who experience disabilities. Generally, people reach out to one another through mutual support networks. Individuals with disabilities should be encouraged to do the same. Direct support professionals should help to connect individuals with other community members. The hope is for support professionals to become companions rather than supervisors and ensure a connection with unpaid community members, together with families and friends.

To help people achieve self-determined futures, and to respond to the supported living principles, the following strategies should be considered:

1. **Increase Opportunities for Self-determination**-Individuals now have an unprecedented range of choices in their lives. Often they are encouraged to make difficult choices with limited personal experience and knowledge of how these decisions might impact their lives. To increase opportunities for self-determination, individuals should be offered the necessary support to make informed and responsible choices. Provided with opportunities to make valuable contributions, individuals will begin to assume increased responsibility in their lives and in the development of their service plan. At the same time, it is crucial that individuals understand their roles and related responsibilities when making decisions. Support should be offered so that individuals can make realistic and informed choices, and assume the risks associated with each option. As individuals become more comfortable identifying what is important to them, and participate actively in the process, the supports developed will reflect more desirable and meaningful outcomes. Individuals should be afforded opportunities to choose people to assist them to participate in a circle of support. Circles of support happen when groups of people get together and brainstorm what it will take for the individual they care about to reach their visions and dreams. Families, advocates, friends and direct support professionals are encouraged to become active participants in support circles. Furthermore, these advocates should be empowered to help people plan and to define their vision of a desirable future.

2. **Use Circles of Support and Build Personal Networks**-Individualized planning and support can maximize the individual's voice together with support from people closest to them. Active support networks offer individuals the opportunity to develop skills to speak out and to be heard and respected. Each individual

should be assisted to develop a support circle which can define, plan for and realize an individual's hopes, dreams and preferences. It should be proactive and future-oriented, helping to develop positive, realistic and responsible images of desired futures. Family, friends, advocates and direct support professionals should be encouraged to participate in circles to the extent desired by the individual.

The circle of support should be considered a complement, and thus a component of, the individual planning process. In this way the individual service plan can be driven by the individual and those people important to them. Individuals will be encouraged to cultivate their gifts, and talents and use them to define and implement their life plans. Furthermore, the circle of support, together with the individual should be afforded the opportunity to access resources utilizing individualized budgets which will be spent according to consensus of an individual's needs. In essence the circle assists with problem solving and supporting individuals to achieve a desired life-style.

It is routinely assumed individuals with disabilities are reliant on structured, professional supports in order to lead quality lives. This implies that individuals with disabilities lead lives which are unique and different than other individuals. But everyone relies on personal networks to some extent. Natural support networks should assist people plan their lives with people who care about them. Personal relationships will vary by situation, need and intensity of involvement, and can help to build community belonging and facilitate an individual's participation in their communities to the extent and level desired.

3. **Support Individual Choice of Housing and Housemates**-Individuals must be given the opportunity to identify where and with whom they want to live. These choices should not be determined by funding sources, but rather driven by personal choice. Individuals should be offered the assistance to make informed decisions pertaining to this. Individuals should not be expected to live with various people assigned to waiting lists. They should be encouraged to select people whom they value, respect and are prepared to live with. By developing their own vision, including such options as living alone or with housemates, buying or leasing property independent from non-profit housing associations, individuals will assume the basic freedoms associated with self-determination.

   Leasing from housing associations is a viable option for some, although it occasionally limits individual choice, and does not always reflect creativity and flexibility in the design of housing and supports provided. The limitations can be demonstrated when associations purchase multiple properties and lease to two to three individuals at a time. Often the person's needs are overlooked with the most attention given to reducing waiting lists by filling houses and serving large numbers of people. Supports should be offered which reflect individual need, and are separate from the actual residence.

Individuals should receive allocations to spend as they choose. In so doing, they can lease or buy property, invite people to live and share expenses if desired and take an active role in the planning, implementation, evaluation and revision of their supports. In certain situations individuals will realize their choices may expend more resources, however, determining how they live their lives makes the most sense. Individuals should be afforded the dignity of risk together with the related responsibilities to make these choices, and will require training and support to be proactive. In some situations, individuals will desire additional support to meet potential housemates, to spend time together and to understand life issues surrounding cooperative living. People should be supported to choose housemates outside the "system" and waiting lists. They should also have the opportunity to choose who provides support to them. Individuals should be encouraged to hire support professionals who may be different than those of their housemates.

4. **Increase Clarity about Roles and Responsibilities of Direct Support Professionals**-Individuals' lives change dramatically as they begin to experience more choice and control in their lives. One major area of change is their relationships with service providers which may become more mutual and reciprocal. Roles and responsibilities of direct support professionals will be determined by each individual's unique situation. Comprehensive training should be provided to ensure an ability to implement and realize consumer self-determination. Support professionals should be valued and respected and provided with incentives to develop quality supports with people. Frequently, the significance of their role is underestimated. This is reflected by limited involvement in planning with individuals and their families, low salaries and limited opportunities for education and training. Support professionals by virtue of their roles should assume the responsibility to respond to individual preferences and needs and to enhance positive, respectful and reciprocal relationships among those they support. In return, direct support professionals should be valued and empowered to help individuals actualize their desired futures.

   Opportunities to help individuals develop naturally supportive networks and connections with local communities should be encouraged. They should strive to reduce their reliance on resources from the "system", and become more actively involved in reciprocal relationships in their neighborhoods. Certainly, these are challenges since many support professionals may not be connected to their own communities, nor have the time or resources to develop such connections themselves. To expect that individuals become successful in promoting linkages to their community, and ultimately replacing them with non-paid community supports is a great challenge. Support professionals, however, should be provided with the resources necessary to assist individuals increase their connections, improve their life experiences and begin to assume responsibilities for their choices.

5. **Identify Financial Resources Available**-As funding becomes increasingly scarce, individuals should be offered opportunities to utilize individual budgets. In this way they will be afforded increased flexibility, control and creativity in spending their own allocations. In some cases, individuals who receive federal waiver funds already experience greater flexibility designing supports as they choose, since they are more likely to know what their budgeted allocation is, and to spend it accordingly. Essentially, this gives individuals more opportunity to identify their needs and prioritize spending, rather than relying on professionals to do this for them. Currently, for many individuals who receive monies through other funding streams, individual budgeting is less common. Typically, needs are translated into services with input from individuals, however, little time is given to the actual cost for supports. Unfortunately, this does not give individuals responsibility to account for how dollars are spent or for them to learn to budget money effectively.

   As stated, by empowering individuals to assume more financial responsibility, they will experience increased control and flexibility of their resources. Utilizing budgets, based on unique needs identified by individuals and their support circles is a key step towards self-determination. In addition, individuals will need assistance brokering for necessary supports so they can live successfully in their own homes. As individuals identify their needs they should have access to financial support in the form of start-up money or loans which will facilitate increased independence. Examples for such expenses might include home accommodations or services for job development. As people understand the importance of budgeting, they will realize the significance of using non-paid, informal supports whenever possible. This will safeguard money for other necessary services and more importantly, will enrich peoples lives by creating less reliance on a fee-for-service support system.

   Furthermore, funding sources should not dictate which residential options are available. Individuals should be afforded opportunities to decide where to live and with whom. Individuals will choose whether to lease from a non-profit housing association, an apartment off the open market, or to buy their own house, condominium or apartment, or live with family or friends. Given increased opportunities for creative spending, people will be more likely to think freely about what makes sense to them.

   Overall, "systems" should consider alternative and creative ways to fund and empower individuals to encourage self-determination. In so doing, funding sources can save money which can then be reallocated to other individuals in need. Currently, most individuals experience limited control since their allocations remain part of entire agency budgets. Funds have also been tied up in housing which has limited individual choice. Individual budgets should complement the individual planning process by infusing creative spending with cost-effective measures.

While individuals are supported using budgets, "systems" must create a reserve pool for emergency situations, to help others on the waiting list or those not currently served. Allocations negotiated for individuals will not be consistently available. As individual needs change and abilities develop, budgets may change, leaving resources available for those who need them.

6. **Develop Education and Training Opportunities**-Individuals with the assistance of families, friends and direct support professionals need a clear understanding of what constitutes self-determination, person centered philosophies and how this can translate into personal empowerment. Individuals, together with people who care about them, must develop the skills to think about what is important and ways people can more lead self-directed, autonomous lives. Often, individuals lack an understanding of what they want or how to reach their goals. Education will help individuals develop a clearer sense of self and define their desired life course by building on their identified strengths and abilities.

   Self-determination is about choice and power. Individuals are more likely to realize personal power when others who care are empowered to share their vision and support them to develop their goals. Individuals and their circles of support should be provided with the tools and resources to build the knowledge and consider various life choices on their path towards independence.

   Educational programs should be developed for consumers and presented in ways that make sense to them. Education is successful when individuals learn to see their lives as a process of growth and change in which they have the power to determine its direction. Furthermore, education is meaningful when it is functional and will be used to directly support individuals to improve their lives.

   Individuals will be best supported through the training by people who know them well, who are invested and who are chosen to participate by the participant. Where individuals do not have the skills to participate independently, family, friends and support professionals should be empowered to advocate on their behalf. Overall, with education and training individuals will assume the ability to make informed choices and increase their control in the decision-making process.

   Given these skills, individuals and their circles of support will become less reliant on the "system" for direction and can look to themselves to develop plans of action and to their local communities for the support and opportunities to make valued, reciprocal contributions. As individuals develop their abilities and exhibit their strengths, their life quality will be enhanced.

These basic principles clearly challenge the way we currently support individuals. Families, advocates, direct support professionals and friends must share the vision of each person's desire to realize their own futures. Quite distinct from how things have traditionally been done, key stakeholders must ensure that supports are individualized and reflect a commitment to providing needed, outcome-based supports defined by the individual. By definition, success is quality of life defined by the individual and becomes the standard for evaluation, rather than the number of "programs" completed in a given day, in a particular residence. Success truly becomes a celebration when individuals feel their lives make sense and they are supported to move towards their personal visions.

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With special thanks to: Elizabeth Burkart, Melissa Brundage, Thomas P. Bilodeau, and Larry Macintosh

TOPIC V: EMPLOYMENT

Papers/Presenters:

RESULTS OF THE EMPLOYMENT WORKGROUP: RECOMMENDATIONS FOR REALIZING MEANINGFUL AND REAL WORK WITH PERSONALIZED SUPPORT

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MINUTE MAN ARC FOR HUMAN SERVICES, INC.- OWN ON YOU OWN PROGRAM

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BREAKING OUT OF THE STEREOTYPE: RETHINKING TRADITIONAL JOBS FOR WORKERS WITH MENTAL RETARDATION

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EMPLOYMENT

Recommendations for Realizing Meaningful and Real Work with Personalized Support

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In August 1997, young leaders from around the country gathered in Washington, D.C. at the President's Conunittee on Mental Retardation's Next Generation Leadership Symposium to discuss the achievements and challenges in their field and to provide recommendations about specific policies and practices. The results of the workgroup of young leaders charged with discussing and making recommendations about employment are reported below. This workgroup was comprised of young leaders (people under the age of 35) who are self-advocates, direct support professionals, administrators and researchers from across the nation. The diversity of their professional and personal experiences coupled with their commitment to ensuring meaningful and successful employment of people with mental retardation created a forum for lively debate, insightful analysis and solid recommendations to the President's Committee on Mental Retardation. The results of the young leaders' discussion are organized in three sections: the State of Employment, the Vision of the Future of Employment and Recommendations to Achieve the Vision.

In preparation for their discussion, the workgroup heard presentations from senior presenter, Dr. John Kregel and young leaders, Joy Orzechowski and James McAleer. Dr. Kregel highlighted the growth of supported employment attributed to the enactment of the Rehabilitation Act of 1986 and the Rehabilitation Act Amendments of 1992. In 1986 only 10,000 people participated in supported employment, whereas by Fiscal Year 1995 over 139,000 people participated in supported employment. People with mental retardation are the most frequent participants in supported employment, comprising more than 61% of those participating (Kregel, 1997).

In addition to the promising reports of the growth of supported employment across the nation, Dr. Kregel discussed the benefits of employment experienced by the employee, her co-workers and her employers. Although on an individual by individual basis, the development of jobs and support of individuals may be challenging, the effects are quite positive.

Ms. Orzechowski and Mr. McAleer provided the audience of young leaders with best practice solutions to the challenges of developing jobs and supporting people in those jobs. Ms. Orzechowski's discussion of the application and effectiveness of person centered planning in the job search and job development reiterated the theme of self-determination and individualization of support and services heard throughout the symposium. Mr. McAleer discussed the individual and organizational implications of supporting people in their own businesses. Again, the necessity of using person centered planning techniques becomes apparent. Additionally, Mr. McAleer's discussed the impact on direct support staff and the organization when moving from center-based (e.g. sheltered workshop) to supported employment and business ownership. From all three presenters, the workgroup participants heard the charge that (1) the individual's interests, desires and abilities must drive the planning process, (2) creative conceptualization of jobs and work are key to any individual's success in a job, and (3) organizations must divest themselves of center-based work models in order for people with mental retardation to have the jobs they want and in which they will succeed.

State of Employment of People with Mental Retardation
With those charges in hand, the Employment Workgroup set about outlining the state of employment for the President's Committee on Mental Retardation. Multiple issues and concerns about employment of people with mental retardation emerged from these discussions. The issues and concerns most frequently mentioned and discussed in detail center around the benefits of work; self-determination, choice and best practices in employment; and the impact of policy on employment opportunities for people with mental retardation.

The benefits of work: Young leaders point out that the benefits of work captured by most workers in the US often elude workers with mental retardation. In their experience, workers with mental retardation seldom received adequate compensation for their work (sometimes below the national minimum wage) and efforts to maintain eligibility for entitlements to support services and medical insurance (Medicaid) limit the amount they may earn. Thus, workers with mental retardation are left in positions of economic insecurity despite the fact that they work. Additionally, standard fringe benefits such as paid leave time (sick and vacation) are frequently not available to such workers.

Further the young leaders who gathered in Washington point out that the benefits of work extend far beyond the financial gains for the worker. They note that employers of supported employees experience the benefit of a stable workforce and the deferred costs of training and support for the employee. Additionally, paid work *offers* all workers, regardless of disability, the opportunity to be included in the day *to* day life of their communities, increased and enhanced self-esteem resulting from doing meaningful work, the opportunity to succeed and grow in one's career and the expansion one's social network of friends, colleagues and acquaintances.

Self-determination and the implications for practice: The young leaders find that assisting people with mental retardation to gain and maintain meaningful employment *rests squarely on the* utilization of best practices in career planning, development and support. The individual's desires, abilities and concerns must be the drive the process. They maintain that the practice of person centered planning, the utilization of natural supports, generic conununity services, commitment to the individual's dreams and visions and equal and fair treatment in the workplace are necessary prerequisites to successful employment.

This firm commitment to the self-determination of the person extends beyond the planning process and must be incorporated in all aspects of supporting the worker and his career development. The young leaders maintain that choice about jobs, career development and direction must be informed and that there must be options from which to choose. (That is, a choice of "do you want to work in this job or location?" is not informed or meaningful if no alternatives exist.) Additionally, the young leaders note that while the natural supports, in particular fancily, can be key to a person's success at work, choice making and direction belong with the worker.

These young leaders point out that best practice in employment support relies on specialized and generic resources and opportunities available to the workers with mental retardation and the people who support them. Although they find that low regional unemployment can impede the job development process, knowledge of what is available in the community and good job carving techniques create employment opportunities. A focus on worker abilities, internships and skillful career exploration activities are part and parcel of best practice in job placement and development. Additionally, job and career development requires focused attention across systems. Although it is primarily adults who participate in supported employment, career and job development must begin before people become adults. These young leaders suggest that when skill building for employment for people under age

16 occurs, these people are better prepared to enter the job market. Additionally, they find that the availability and use of assistive technologies (e.g. adaptive devices, communication boards, etc.) can increase and enhance the job opportunities for people needing such technologies. Finally, the young leaders note that choices about job changes and continuing education (such as college and certificate programs) are frequently overlooked in planning ad supporting workers (or future workers) with mental retardation. Such choices are, in fact, typical of many workers and should not be overlooked.

Further, the young leaders find that access to support for employment can be limited by the practices of the professionals. Their experiences indicate that, although many people with mental retardation are participating in supported employment, those with labels of severe and profound mental retardation have limited opportunities to ,work in integrated settings. (In fact, just 10% of the people with mental retardation who participate in supported employment have labels of severe or profound mental retardation [Kregel, 1997]) These young leaders suggest that the field is moving away from "creaming" (providing support to those most likely to succeed, those who may not need support as much as others), and that when such movement occurs, it is the result of individual, family Viand staff attitudes and commitment to removing barriers to employment and support.

The impact of policy: The young leaders identified several policy issues which effect the employment opportunities and experiences of people with mental retardation. In particular, they expressed concern about the :impact of block grants on funding of support and services to people with mental retardation. They find flexible --funding schemes (those where the consumer and family control and direct the purchase of support and services) promising for the continuation of supported employment and the development of better support practices.

The lack of integration of employment initiatives, such as the separate funding streams of School to Work and adult vocational services, was seen is ill-conceived and a barrier to effective career development for people with mental retardation. Additionally, they found that policies which are seemingly unrelated to the field of mental retardation can negatively impact the work opportunities of people with mental retardation. In particular, welfare reform and the focus on work requirements creates competition for those entry-level jobs which people with mental retardation typically seek.

Finally, the young leaders noted that bureaucratic red tape and work disincentives are embedded in some policies. For example, they debated the utility and accessibility of the Social Security Administration's PASS program, ultimately resolving that the program is complicated enough that they, as young leaders, are unable to reach a conclusion about it. Further, they assert that individuals enrolled in Medicaid and/or receiving services funded through Medicaid and Home and Community Based Waiver programs experience work disincentives and limitations to the income they can earn through paid work. The young leaders believe that some people with mental retardation and their supporters find that the risk of becoming ineligible for support and services through Medicaid is too high. Additionally, for those who do work for pay, income and asset ceilings limit the amount of money they can earn and can keep some individuals in a perpetual cycle of economic insecurity.

The Vision of the Future of Employment

The vision of the future of employment for people with mental retardation includes simultaneously a vision of work which is integrated and beneficial regardless of disability and a vision of support which is individualized and consumer, rather than system, driven. The young leaders defined the ideal future of employment as one where all workers (people with mental retardation and others) receive adequate and commensurate pay and benefits for their labor. They see a world of work where people are not penalized for their successes, where working does not make one financially vulnerable. They envision workers having opportunities to advance in their jobs, opportunities to explore careers, and access to resources and training and education. The vision of the future of employment includes real choices among opportunities and the availability of meaningful work, jobs that do not necessarily involve food, filth, flowers and filing. The person making those choices is the worker him/herself.

They envision employment services and support which are no longer balkanized along age or disability lines. They see support available as people need it, when and where they need it whether preparing to enter the workforce or to sustain oneself in a job. The young leaders see an end to funding and subsidies of work programs that segregate people from their communities and real workplaces, and they see an increased financial commitment to supporting people in real jobs. They envision the universal availability of personal assistance/attendant care, transportation and transition services.

Recommendations to Achieve the Vision

The young leaders recognize that to achieve the vision of employment they have set forth will require major changes in public perception and policy effecting people with mental retardation and others. They offer the following four recommendations as first steps to improving and enhancing the employment opportunities and experiences of people with mental retardation:

1. Influence public opinion
2. Create incentives to work and eliminate disincentives
3. Increase flexibility of funding of support and services
4. Create transportation options

- **Influence public opinion**-The young leaders in the field of mental retardation call for a campaign to educate employers about the opportunities and benefits of employing people with mental retardation. They recommend expansion of the efforts of the President's Committee on Employment of Persons with Disabilities and continuing the efforts of the National Disabilities Awareness Month throughout the year. In addition to showcasing in the media the employment success of people with disabilities, concentrated and coordinated efforts should be made to educate employers about the benefits of employing people with disabilities (including workforce stability, workplace integration and tax incentives for employers.)

- **Create incentives to work and eliminate disincentives**-The young leaders recommend revising social security and other regulations which create barriers and disincentives to work. Specifically, they suggest revisions which would allow workers who receive benefits to retain their earnings as they develop their careers and revisions which would raise the assets ceiling to allow workers to save money for retirement, emergencies, and other contingencies. Additionally, they recommend that personal assistance/attendance care be available to workers as long as needed, and that such support not be subject to income limitations.

- **Increase flexibility of funding of support and services**-The young leaders reject the funding schemes of service delivery which have limited choices and control of services for people with mental retardation and their families. They believe that individuals and their families can best determine which services they need, and recommend attaching funds to consumers rather than programs, so that market forces of quality and demand can influence service and so that consumers may design their own service and support packages.

- **Create transportation options**-The young leaders recognize that the lack of adequate and accessible transportation poses a significant barrier to employment

> for many people. They recommend advocacy for enhanced public transportation and the development of alternatives to public transportation, where public transportation is not available or feasible. Creative funding and financing mechanisms (including reimbursement to neighbors, friends and private companies) should be considered in the alternative transportation solutions.

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Minute Man Arc For Human Services, Inc. Own on Your Own Program

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Synopsis

Minute Man Arc for Human Services, Inc. (MMAHS), a 501 (c)(3) non-profit agency dedicated to providing support to persons with labels of disability in Massachusetts, has implemented a business ownership program for persons with significant labels of mental retardation. The MMAHS Own On Your Own Program, recognizing how such individuals are often underemployed, identified eight people who were being served in sheltered workshop settings and developed business plans tailored to their individual desires, talents and resources. The Own On Your Own Program employed a comprehensive planning approach that included: accessing personal support networks and the resources found therein; targeting individual desires, skills and strengths; and forming a community based employment advisory board to support the individuals as they formed businesses over an extended period of time.

The goal of the Own On Your Own Program was to successfully plan and implement individual business initiatives over a period of two years with business plans manifesting over five years. Through this process, individual consumers experience real employment opportunity through the development of their skills, mentored by MMAHS staff, family and community supports.

These business initiatives were supported in the first stages through a combination of funding resources including: MMAHS funds generated by contract with the state Department of Mental Retardation (DMR); funds produced by the businesses themselves; funds from federal programs such as the Social Security PASS and IRWE Programs; grant funds; and in-kind contributions of services and supplies generated by the

employment advisory board. The program is continuing to serve the needs and desires of additional consumers through the same primary funding sources. First year grant funds are being replaced through community business support and an increase in MMAHS program offset in the original target group.

Each individual business plan includes short and long term goals wherein funding support is decreased incrementally. The plans allow individuals or a small group of individuals with mental retardation to successfully own and operate their own, self-sustaining businesses, sometimes in concert with non-disabled business partners.

Purpose/Problem Statement

Minute Man Arc for Human Services, Inc. (MMAHS) implements the service principles of rights, dignity and individual control in every aspect of service design and delivery. It is agency policy and practice to treat all individuals receiving services from the agency with the utmost respect and dignity. MMAHS staff value the opinions and choices of individuals with disabilities as the most important component of any program. Every aspect of agency service delivery is offered with consumer choice in staffing, location and all other areas as the baseline. MIVIAHS promotes the development and growth of relationships and natural support networks within the context of community living. Families are encouraged in their efforts to promote the inclusion of family members with a disability in educational and recreational activities as well as in other aspects of community life.

MMAHS provides vocational services to 64 individuals with labels of mental retardation As services have shifted from facility based programming to community based programming, MMAHS has developed a significant number of supported and competitive employment opportunities in eight communities in Massachusetts. Nine individuals have been encouraged to continue their education through the ground breaking Personal Enrichment Program (PEP). Forty-seven individuals have been successful in finding and maintaining competitive or supported employment opportunities through the MMAHS Business Resources Program (MMBR), with an additional eight people in the process of job searching.

MMAHS is committed to providing employment opportunities without regard to perceived level of disability and without prejudice in regard to stated levels of handicapping conditions. The mission of MMAHS is to impact positively on the lives of persons with mental retardation, thereby supporting the concept that each consumer has an equal right to employment and employment services, regardless of the perceived extent, nature or significance of their disability.

According to statistics available as far back as 1985, unemployment figures for persons with severe disabilities were calculated as high as 88%.3 This clearly defines a trend of unemployment for individuals with "severe" mental retardation. It has become increasingly difficult to equalize opportunities for those individuals with significant labels of disability. Therefore, the individuals without immediate access to work opportunities beyond sheltered work due to the level of their disability have been the target population of the Own On Your Own Program. Of all persons served in supported employment, it has been shown that only 1.2% are classified with the now seldom used classification of profoundly mentally retarded. As Kregel noted in his research of 1989, increased severity of handicap can necessitate development of tailored support services.

Significant labels of mental retardation often preclude consideration of an individual for available jobs. The process of "cream skimming," or selecting those individuals who have the most immediately identifiable skill sets for employment, has relegated persons with less obvious talents to sheltered work and day habitation, regardless of their desire to find employment. According to the President's Committee on Employment of People with Disabilities released in 1997, 800,000 more people with "severe disabilities" between the ages of 21 and 64 were employed in 1994 than were employed in 1991.6 While this represents a positive shift, it may be inflated by an increase in the population size.

The Committee's report goes on to note that 73.9% of people with "severe" disabilities were not employed as of 1994. 26.1 % of the 14.2 million people who carry a label of significant disability as defined by this report, or 3.71 million people, are considered to be employed. When juxtaposed against the 82% of the general population considered to be gainfully employed, the obvious need for targeted services is shown.'

Compounding the problem, local government funds are not available in Massachusetts for vocational services to persons with labels of mental retardation. State and Federal funds are increasingly sparse. Existing contract money has been level funded in respect to operations for eight years, forcing more consumers to be served with fewer resources. Any significant innovation funding available in recent years has come from the private sector, as the state and federal governments struggle to provide minimal services to all who are in need.

The State of Massachusetts has defined a residential and vocational services waiting list for persons with mental retardation of 4,000 people! As noted, there has not been a rate increase for over eight years to most contracts, thereby reducing the funds available to existing consumers as a result of inflation. These facts underscore the ongoing and increasing shortfall of state funds. Federal funds, as represented through Social Security Programs, also fail to keep pace with inflation and other cost of living indicators. The obvious decrease in value of dollars provided, coupled with the continual rise in the unserved or underserved populations, evidences the need for innovative and self-sustaining services which allow the consumer some measure of self-sustenance.

MMAHS Response

The purpose of the Own On Your Own Program has been to provide individuals with significant labels of disability with realistic employment opportunities through the development of ownership in businesses tailored specifically to the individuals' skill sets and desires. The initial process of identifying and developing support services involved a group of eight MMAHS consumers, three targeted MMAHS staff members, a community based advisory committee and a variety of community supports.

The Own On Your Own Program selected eight consumers and three staff members to enter the program. Staff members worked with each consumer to identify resources within the consumer's circle of support. For example, a consumer may have a neighbor able to provide transportation, a brother interested in providing support or a friend with contacts in business or banking. All resources, both tangible and motivational, were identified. Each consumer was asked to participate in defining skills and interests in an effort to tailor new business ventures to both ability and desired work.

Wehman, Kregel, & Seyfarth, (1985) Employment Outlook for Adults with Mental Retardation, Rehabilitation Counseling Journal. 29 (2), 90-98.
Shefer, (1989) National Supported Employment Initiative: A Preliminary Analysis, American Journal of Mental Retardation, 1990, Vol. 95 No 3, (316 - 332).
Kregel, Wehman, Revell, & Hill, (1990), Supported Employment in Virginia: 1980 - 1988, Supported Employment for persons with severe disabilities: From Research to Practice, (Vol. 3, pp. 1-30).
'Ability To Bridge The Future, President's Committee on Employment of People with Disabilities, Released July, 1997. Op Cit., July 1997.
People First: What Massachusetts Does for People with Disabilities, Massachusetts Developmental Disabilities Council, Massachusetts Human Services Coalition Publication, February, 1997.

After supports available and supports needed were charted, the potential for new businesses was analyzed. Originally intended to be sole businesses, it was clear in the early stages that a greater chance for success was found in forming partnerships with several consumers who clearly identified similar interests. Consumers were presented with many potential businesses, including options currently found in day service enclaves, such as cleaning crews, packaging crews, etc. New business ideas, including printing and laundry concerns, were also presented. Consumers and staff partners chose the business concept that most appealed to them, and an initial sketch was drawn of that new business.

MMAHS successfully identified a large group of community members, businesses and groups that agreed to assist with this project. Each member of the community advisory committee agreed to assist in the development of individual businesses for one or more consumers as identified in the initial stage of the program plan. The advisory committee meets quarterly as a group to evaluate business plans, to make recommendations and to offer support. Individual members agreed to be available as needed to provide direct services such as loan assistance, in-kind donations, management consulting and other ancillary business assistance. Members have served as business mentors for new business owners. The advisory committee analyzed each potential business for viability. Resources from the committee were added to the resource lists compiled from staff and consumer support circles, and complete business plans were formulated.

Potential business areas were presented to the community advisory committee for review and recommendation. Following the committee's input, a business plan was then outlined for the consumer or for a group of consumers. The business plan incorporated the following elements: the consumer's support networks, the financial resources needed, a fade-out plan for any external subsidy, identification of subsidy and alternative funding plans such as MMAHS loan financing, community financing and individual initiative grants.

The overall project outcomes were the creation of three new businesses to be owned and operated by people with mental retardation and the creation of an ongoing program to continue to support business development. The three new businesses included the following groups: three individuals involved in a marketplace, four individuals involved in a stables maintenance business and four individuals in a cleaning business. One non-disabled business partner is involved in each of the three businesses and is counted in the aforementioned numbers.

Plan Of Work

The MMAHS Own On Your Own Program began in month one with the identification of one staff member within day services and the hire of one additional staff member, both dedicated to providing support to persons with labels of significant disability. The Project Director, with the assistance of the Project Manager and staff, called the initial meeting of the advisory committee to begin the initial evaluations of consumers needed to develop targeted business plans. The target population was defined as those individuals with labels of significant disability currently served by the state Department of Mental Retardation in sheltered work, day habilitation or respite services. Project staff worked through months two and three on identifying what supports existed in each consumer's sphere that could assist in the formation of a business. Family supports, established relationships in the community and any other existing supports were studied and charted. Project staff dedicated 20 hours per individual to identify desires, strengths, and skill sets prior to the selection of a possible business plan.

Months four through seven included the establishment and evaluation of business plans for each consumer that included timelines for implementation, evaluation by the advisory committee, securing of financing, establishment of PASS and IRWE plans as needed and the acquisition of appropriate community services as identified in the plans.

Months six through nine included the implementation of the business plans developed and the identification of at least one new consumer to enter the program for each consumer established in a business. New consumers entered the process as outlined and were recruited from outside the existing population through established DMR contacts.

Months nine through twelve included the implementation of business plans for the initial target consumers, continuation of business plans for consumers previously implemented, and the identification of new individuals to begin the project process.

Finance

As previously stated, the Own On Your Own Program and its initial business initiatives are supported through a variety of funding resources. MMAHS provides funds generated by contracts with the state Department of Mental Retardation (DMR). Additional funding comes through federal programs such as the Social Security PASS and IRWE Programs. Grant funds provided by foundations and in-kind contributions of services also supplement the program's funding. In addition, the businesses contribute from their generated revenues.

The business plans incorporate into their goals the incremental decrease of external funding over the first three years of the business. In this way, the businesses become self-sufficient entities, owned by the consumers and the non-disabled business partners in the third year of operation.

Careful consideration is to be given to the impact of the business implementation and ownership on consumer finance. As consumers gain more independence financially due to increased salary potential and as the ability to be gainfully employed increases, the consumers' eligibility for governmental benefits may be jeopardized. These factors may affect eligibility for Social Security Disability Income (SSDI), Supplemental Security Income (SSI), Medicare, Medicaid, food stamps, Section 8 housing subsidies, low interest housing loans and fuel assistance.

Further issues are raised regarding the consumers' financial status by the shared value of the business itself. Each business plan incorporates an individual analysis of consumer finances, the impact of income and business value, and contingency plans for future problems should benefits be compromised.

Breaking Out of the Stereotype:

Rethinking Traditional Jobs for Workers with Mental Retardation

By Joy Orzechowski
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Let's face it, workers with mental retardation are often classified into stereo typical jobs. When people think of supported employment, they most often think of baggers at the supermarket or table cleaners at McDonalds. Individuals with mental retardation are often boxed into entry level jobs with little room for advancement. Commonly known as the five Fs, these jobs can be broken down into the following categories: Food (cafeteria assistant, dishwasher etc.) Filth (cleaning), Folding (laundry, retail stocker) Filling and Fetching. While not to minimize the value of these jobs, we as human service providers need to look beyond the traditional job roles that people with mental retardation usually fill and come up with a more person centered approached to job development that addresses the skills, interests, and dreams of the individual.

We need to reassess the role of vocational programs and create better opportunities for workers with mental retardation. Although much progress has been made in the field of supported employment, human service providers need to take it to the next level to transition people into the economic mainstream. By looking at jobs that encompass a greater variety than the five Fs, we can expand the possibility of finding jobs that lead to careers, and the potential for advancement.

A Brief History of Supported Employment

In the early 1980's a paradigm shift occurred which changed the way human service providers served consumers with mental retardation. Traditionally, the only work opportunities they were provided were sheltered workshops or enclaves. While these programs did provide valuable training opportunities, they could not replicate an actual job. Individuals with mental retardation who were served by the day program model were not integrated into the economic mainstream. Often work shop jobs provided minimal, if any pay. They also segregated consumers from the general population. The workshop jobs offered no opportunity for advancement and growth.

Supported employment is defined as "real jobs for real pay." Workers are supported on site by a job coach until they have transitioned into the workplace. Since the 1992 amendment to the Rehabilitation Act, approximately $2.3 billion in federal funds have been targeted to employment services for individuals with disabilities. (National Council on Disability, 1996) The Amendment also requires state vocational rehabilitation agencies to provide the individual with a choice of services and providers; to focus on careers, not just entry level jobs; and to presume that most individuals with disabilities can and should work.

Many work incentive programs have also been developed by the Social Security Administration to encourage individuals with disabilities to enter or reenter the workforce. Programs such as the PASS (Plan for Achieving Self Support), the IRWE (Impairment Related Work Expense) and the BWE (Blind Work Expense) have been very useful in allowing individuals with mental retardation to receive and pay for the supports they need to become successful in the workplace. (See charts A & B at the end of this paper)

While all of these programs have had an impact on the lives of people with disabilities and allowing them to achieve their employment goals, much work still needs to be done. Although unemployment rates are dropping nationally, individuals with disabilities continue to have the highest unemployment rate. According to the National Council on Disability, in 1995 only 28% of the 16.8 million working age Americans with disabilities were employed.

- 86% of consumers with mental retardation/developmental disabilities are being served in segregated day or employment programs
- Three times as many people with developmental disabilities are being placed into sheltered employment settings as are entering into supported employment.
- 84% of rehabilitation facilities currently providing supported employment or who are planning to provide supported employment will retain segregated work sites.
- 80% of state funding dollars are used to fund segregated day or employment programs (Keirnan, McGaughey, Lynch, Morganstern & Schalock, 1991)

Vocational rehabilitation agencies have been successful in getting people with disabilities jobs. They currently serve about one million individuals and successfully place about 200,000 per year in employment. (National Council on Disability, 1996) However, the types of jobs that people with mental retardation are consistently placed in often remain within the five F's. While national statistics are not readily available, a recent demonstration grant tracked 44 supported employment placements in Massachusetts over a three year period. Although this is only a cross section, it does give an example of the typical jobs that individuals with mental retardation hold. All of the jobs were part time and provided few if any benefits.

Industry type	Percent	Type of Employment	Percent
Restaurant	30%	Cleaning/Maintenance	34%
Retail Store	30%	Food Service	14%
Supermarket	14%	Assembly Worker	14%

Factory	11%	Inventory/Stock Clerk	11%
Other	13%	Floral Assistant	7%
		Delivery Person	7%
		Bagger	6%

Benefit type	Percent of Jobs providing Benefit
Medical Benefits	0%
Paid Sick and Vacation	0%
Free Products or Services	9%
Discounts on Products or Services	39%

To combat the problem of boxing people into employment types, vocational rehabilitation professionals need to be more creative in their approach. Vocational assessments need to become more positive. Traditionally, assessments had been used to weed out people rather than weed them in. Focus was on the disability. More positive assessment tools focus on the skills, interests and talents of the individual regardless of the disability. Focusing more on what the individual can do rather than what they can't is the first step. Brainstorming for employment options is the next.

Brainstorming

An effective way to brainstorm about possible employment for the individual is to hold a person centered planning meeting. These meetings are completely consumer driven. Focus is on the positive and what the person's strengths, skills, and abilities are. A team is created that consists of people who know the individual well and can provide positive insights as to their talents. The team might consist of staff, such as a vocational rehabilitation counselor, teachers, family members, friends, or past employers; anyone who can be a resource. The facilitator then directs the team to explore all areas of the persons life to see how those skills and interests might translate into a job.

One format based on the self-help book "What Color is Your Parachute? A Practical Manual for Job-Hunters and Career Changers." was implemented by the Massachusetts Rehabilitation Commission via the Massachusetts Supported Employment Statewide Systems Change Grant. The person centered planning meetings proved very useful as a way to get the individual, their family and support group to look at them in a new light. Hidden talents were discovered that were then transferred into job skills. Because all members of the person centered planning team were committed to finding and supporting the individual on a job, the synergy that was created was enormous.

By compiling a group of people that could be used as a resource, the individual increased their networking circle and increased the possibility of finding a job. The following is a breakdown of the person centered planning process, taken from the Supported Employment Systems Change Project Massachusetts Rehabilitation Commission, Office of Employment Services & the Institute for Community Inclusion.

Initial Career Planning Session Focus-Overall Components

- Conducted as a friendly, informal and positive brainstorming session: everybody's contributions but the focal person has the power.
- Held in a comfortable location, for example the persons home
- Include person's significant others, e.g. family, friends and colleagues.
- Modeled after, marketed as and follows a "non-disability, non human service" approach to avoid creating additional "labels"-goes beyond existing traditional service models.
- Written on flipcharts so everyone can see input -transferred after meeting so everyone can have a copy.

Format

1. **Leisure Learning Labor**-This section lists past, present and future strengths, experiences and or interests a person may have had under each of these headings.
2. **People Things Information**-This section lists transferable skills, preferences, interests and assets a person may have and/or may want to cultivate in the future under each of these headings.
3. **Working Conditions**-This section lists both favorable and unfavorable working conditions, e.g., schedule, geographic location, environmental factors, person and/or technology supports, transportation needs, health coverage and work culture.
4. **Work Rewards**-This section lists concrete needs, e.g. salary and insurance but also other motivating factors that make a job positive, e.g. social contact, challenge, respect, creativity.
5. **Outcomes/Potential Jobs**-Following a review of all the information gathered in sections 1- 4, what are patterns of strength, skills, interests, work rewards and working conditions? What does an ideal career, job look like for this person? What kind of supports might be necessary?
6. **People Contacts/Who Do We Know?-**Following the identification of potential jobs, the group brainstorms on contacts each member may have in these areas to contact regarding potential employment in these areas.
7. **Strategies**-The group describes planning tactics that might lead to jobs identified in the Outcomes such as job visits, talking to someone doing the job, researching potential employers needs, taking a course, internships, developing a resume or volunteering. Also identified in this section are plans for job supports, assistive technology, assistance in one's home that is needed for work, and insurance needs.
8. **Action Plan**-This last step specifies tactics identified in Strategies and the group develops specific objectives, responsible person(s), and time lines. Each participant usually shares responsibility in helping the person achieve his/her work goals. Usually, the group schedules a follow-up meeting at this time to review progress toward Action Plans.

Following the meeting, a designated person writes the notes from the planning session and then disseminates them to each participant. Once the skills and interests have been assessed, and a career plan has been developed, the actual job search needs to take place. Based on the career plan, the job search should also be a creative process. If for example, the individual is interested in working with children, a number of possible jobs could be explored. Depending on the person's skill level, a job could be created at a day care center, a school, or an activity center. The person might also want to explore working at a place where children are likely to be such as a museum, a toy store, the children's section of the public library, a zoo or pediatricians office. There are any number of possibilities as long as the individual and vocational rehabilitation staff, allow themselves to think outside the parameters of a traditional job. Ideas should also not be written off before exploring them. Do not eliminate an individual's career goal as unrealistic, instead refine it so it may become obtainable. One consumer in particular stated that she wanted to be a doctor. Rather than explaining that this was an unrealistic goal, the job developer asked her to explore the reasons she wanted to be a doctor. The woman explained that she enjoyed helping people and wanted to work in a medical facility. After further exploration, a job was carved for her in a nursing home. She works in the evenings assisting residents with their dinner. This allows her to help others and to work in a medical facility. If her original goal had not been further developed, she may never have received the opportunity to work in place where her skills were so well suited.

Where The Jobs Are

According to the Department of Labor:

1% of the population has found their job through private employment agencies
2% through public employment agencies
3% through the help wanted advertisements in the newspaper
6% through school placements
24% through having a direct contact with the employer
48% through friends and relatives
13 % through friends and relatives having direct contact through employers.

The Internet is a very good way to search for jobs. More and more companies are posting their openings on the Web. Nationally read newspapers such as the New York Times and the Boston Globe post their help wanted section, and national job banks are continuously creating more diverse sites. The search can be done by job type, location, industry type or any number of variables. To find job postings on the Internet try the following sites.

Job Posting	Site Address
Americas Talent Bank: Job Seekers Section	http://www.atb.org/atb/text/consorts.htm
Americas Job Bank	http://www.ajb.dni.us/
Career Magazine	http://www.careermag.com/careennag/ http:/
Career path- to search in national newspapers /	www.careerpath.com/info.html
Catapult	http://www.jobweb.org/catapult/catapult.htm
Job Bank USA	http://www jobbankusa.com/search.html
Job Hunt	http://www.job-hunt.org/
The World Wide Web Employment Office	http:www.harbomet.com/biz/office/annex.html

Job Carving

Job carving is an excellent way to get individuals with mental retardation into the workforce. With the advent of "down sizing" companies are more willing to look at alternative staffing to meet production needs. Job carving breaks down the components of a job and assesses which pieces can effectively be done by the applicant.

Often times job carving benefits both the employer and other employees in the worksite because it breaks the job down into more effective steps. An effective approach to job carving is to sit down with the hiring manager and discuss what there employment needs are. Find out if there are any needs that currently aren't being met. The following is a job carving questionnaire that has successfully been used to get managers to think of workers with disabilities as an asset, rather than a burden.

Job Carving Questionnaire

- Does your department have any entry level tasks which many employees do or which direct employees from their more critical job?
- Are there tasks which you would like to see done more efficiently or in a more timely fashion?
- Are there busy times of the day or week when you feel you could use some extra help?
- Are you paying higher wages to technical or highly skilled employees to perform entry level tasks?
- Are there any tasks which aren't being done on a regular basis because there isn't enough work to justify hiring a full time employee?
- Are there jobs that you fill with work study students, high school students or temporary workers?
- Would you like someone to fill those needs on a more stable basis?

Examples Of Job Carving

A secretary making $15 an hour found that 30% of her time was spent faxing and photocopying. By having someone come in 2 hours a day to take care of those responsibilities, she became much more productive and her time was used more effectively. A chef spent much of his time measuring out the serving portions before preparing the meal. Several of the items on the menu were very popular and sold consistently. By creating a position called a food portioner, the kitchen ran much smoother. The chef could use his time to create mere extravagant meals while the portioner weighed out each amount. A restaurant manager found that much of her wait staffs time was spent folding napkins. This was a dreaded task because it took away from the time they were working toward tips. The manager hired a worker with a disability to come in when the restaurant was slow to pre fold the napkins. This allowed the wait staff to spend more time with the customers, providing better service.

What Can Vocational Rehabilitation Providers Do?

One of the most difficult obstacles that job developers have to overcome is the individual with mental retardation's lack of self esteem and awareness of their talents. It is as though they have been programmed to believe that they can only do a certain type of job. When several people with mental retardation were asked what their ideal job would be, the number one answer was "To work in McDonald's". Not only do we as human service professionals need to think outside the boundaries of traditional placements, but we also need to encourage the individuals to see themselves in a different light. The biggest problem is lack of exposure. People with mental retardation aren't exposed to a myriad of employment options the way the mainstream population is. A very simple way to get an individual with mental retardation to think about different employment options is to go through the yellow pages. Open it up to any section and read the names of the business. Ask the person to imagine what the company does and what types of jobs they may have. If the person doesn't know anything about the company, call them and ask then what they do. Many companies are willing to talk briefly with an individual if you explain to them that this is only an information gathering phone call.

Another way of exposing people to different job settings is to have them walk around in their own neighborhood and see how many different types of employment settings they can name. Make sure not to overlook the obvious such as the police and fire stations or the local hospital. There are many different types of job descriptions that an individual with mental retardation may not know about such as the dispatcher or support staff:

An informational interview is also helpful to introduce people with mental retardation into different types of employment situations. The applicant can meet with a human resources representative or hiring manager to discuss the job and get an idea about the skills and job descriptions. The informational interview allows the applicant to explore different work opportunities in a low pressure environment. Because the person isn't actually applying for a job, the interviewer may be more inclined to share information and allow the person to find out what a day in the company would be like. This also gives the person the opportunity to practice interviewing so they become more and more comfortable with it.

An even more effective way of exposing people with mental retardation to a variety of work opportunities is the situational assessment. A situational assessment allows the applicant to actually go to the job site and try the job out for a short period of time such as an hour or a day. This is positive for both the employer and the applicant. The applicant gets the opportunity to try out the job and see if it is something they might be interested in doing. The employer benefits by actually seeing the employee perform the task. Many people with mental'retardation have a difficult time during the interview session, but they are more than capable of handling the job. If the hiring manager sees the applicant perform the job, they may base their hiring decision on the person's work skills rather than their interview answers. It allows the employer to try the applicant "risk free". A situational assessment is also helpful for vocational rehabilitation professionals because it allows them the opportunity to assess the applicant's skills in a real job setting. A workshop can't adequately duplicate a work situation. But a situational assessment may show an applicant's hidden talents. To break the stereotype of the five F's, vocational rehabilitation providers must first acknowledge that individuals with mental retardation can do a myriad of different things. If job development is driven by the skills and interests of the consumer, a job can be carved out in almost any industry. Vocational rehabilitation providers can also prepare the consumers for the workplace by exposing them to more opportunities. Rather than providing contract work at a sheltered workshop, day programs should focus more on transferable skills such as interview techniques, job search strategies and appropriate work attitudes.

Three Examples of Non-Traditional Jobs

Joan H. is a thirty six year old woman with mental retardation. Joan had been working in a supported workshop as a cafeteria aide. She enjoys interaction with people and especially enjoyed new people coming in to the cafe. Although she liked her job, she was interested in working outside the workshop and getting a job in the community. Joan applied for a job as a line server in a local high school cafeteria, but she found the fast pace difficult to keep up with. Although Joan had a job coach to support her at the worksite, she still could not maintain the steady pace. After a few weeks, Joan was terminated from her job. An assessment was made to determine all of Joan's strengths, her skills and her interests. A job where there is a lot of customer interaction was important to her, as social interaction is one of the main reasons she enjoyed her job in the workshop cafeteria. She has a very outgoing personality and can be very persuasive. It was decided that Joan should get a job where there is a much customer interaction, but where she could also set her own pace. Several options were explored until the perfect job was found. Joan currently works as a product demonstrator for C.A. Courtesy Demo. Joan's job involves greeting the public and demonstrating new products to them. As new food products go on the market or go on sale for the week, Joan hands out free samples and coupons. Joan's outgoing personality is perfectly suited for this job because she gets to speak to people and convince them to try the product.

Joan gives out free samples of new products such as Nabisco Crisps. She also tracks how well they did in the store that day by counting how many items were on the shelf before she gave out the samples, then counts how many were on the shelf at the end of the day. This allows Nabisco to know how successful the product demo was. Joan also takes comments from people and she asks them how they like the product. Joan loves her job. She has a flexible schedule and can work at her own pace. This job was found through an ad in the Cambridge TAB, a small local newspaper. Because Joan was so perfectly suited for this job, no carving was necessary. Joan is supported by a job coach who helps her with transportation to and from the worksite. As each demonstration is different depending on the product, Joan's job coach also assists her by explaining the minor details and going over the paperwork to ensure that it is accurate.

Jane G. is a 54 year old woman with moderate mental retardation. Jane had been institutionalized for much of her life, and had only one work experience at a flower shop. Jane had expressed an interest in working with plants, but she didn't enjoy the close interaction with the customers. A person centered planning meeting was held to brainstorm about an ideal work situation. During the person centered planning meeting, it was discovered that Jane had a love of crafts. While she was in the institution, her favorite activity was sewing. Several craft stores were contacted to expose Jane to a variety of job types but all of the jobs involved heavy customer contact. Finally a craft store agreed to hire Jane to do the detail work on items that they sold. Her job only entails the actual making of the craft, it does not involve selling to the customer. Jane is now able to do a job she loves and she is provides a valuable service to the craft shop.

Bob A. is a 28 year old man with mild mental retardation. Aside from his mental retardation, Bob has a secondary disability of being wheelchair bound. A person centered planning meeting was held to discover what Bob's interest were. It was determined that Bob particularly enjoyed talking on the phone and helping people. Bob also had light typing skills and was able to operate a computer. Different career opportunities were explored and several local businesses in Bob's area were contacted. The local cable company was willing to meet with Bob to see if he could work in their customer service department. The job entailed setting up new appointments, confirming the appointments and handling customer complaints. After a situational assessment, it was discovered that Bob had difficulty handling the customer complaints. However, a large part of the job was the actual confirmation of appointments. Because it was difficult to reach people at home, this was the most time consuming aspect of the job. The cable company agreed to restructure the position so Bob would only do the confirmation of appointments. Incoming calls for appointment setting and customer complaints were rerouted to other customer service representatives. The company carved a job that utilized Bob's strengths and at the same time made their customer service department run more efficiently.

Summary

People with mental retardation can and should work. They should not be boxed in to stereotypical jobs that do not make use of their particular talents. By expanding the realm of possibilities to include jobs that are nontraditional, workers with mental retardation can increase their possibility for a career and advancement. By looking at a variety of job settings and industries, vocational rehabilitation professionals can increase the number of people with mental retardation who are employed.

Recommendations For PCMR

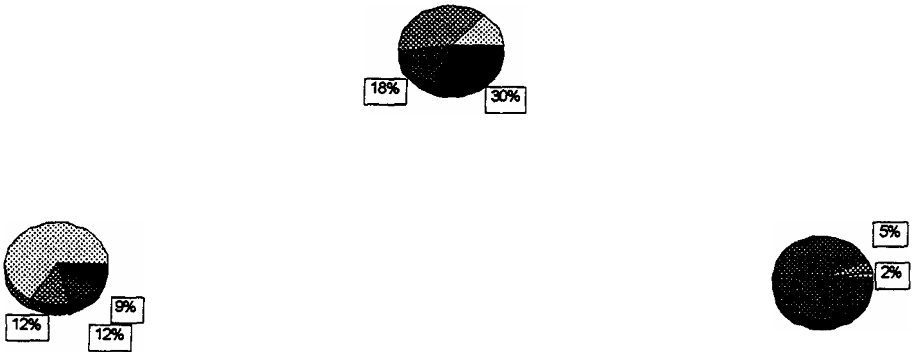
1. Individuals with mental retardation should be empowered and the primary director of their job search. They should be provided with a variety of services and employment providers so they may make an informed decision about the best service for them.
2. Vocational rehabilitation should be made more available to eliminate the wait list and create more opportunities for individuals with mental retardation to enter the workforce.
3. School to work programs should implement several internship opportunities to expose students to a variety of work situations.
4. Vocational rehabilitation agencies should develop a variety of employment options for their consumers.
5. The Department of Labor should be made aware that adults with mental retardation are a viable part of the workforce. Statistics should be kept on individuals with disabilities to track their unemployment rate. Labor market trends for workers with disabilities should also be tracked to determine if people moving out of entry level or part-time jobs into viable careers that can sustain them financially.

6. More initiatives need to be developed to support people with mental retardation in real jobs for real money. The focus should continue to change from sheltered workshops to supported employment.
7. Greater flexibility should be built in to the support system of SSI & SSDI so that people with mental retardation can continue to receive the supports they need while they are transitioning into the workforce.
8. Companies should have more access to information on assistive technology. Human resource managers should become more aware of assistive technology and how it can help a worker with mental retardation. Many large corporations have realized the benefit of hiring a worker with a disability. The Marriott and McDonalds have both been very proactive in hiring workers with mental retardation and were accommodating to supported employment, but other industries such as computer and high tech need to follow suit. If employers become better educated about the benefits of hiring a worker with a disability, more jobs can be created for them in these fields.
9. The expectation should be that people with mental retardation will be employed and integrated into the economic mainstream.

Chart A

Diagnosis of SSI work incentive recipients

June 1997

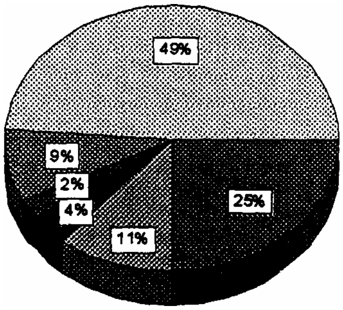


Retardation Pschiatric Nervous System Other Physical

Chart B

Diagnosis of SSI Disabled Workers

June 1997



Retardation Other Physical Encodrine
Musculosketletal Nervous System Psychiatric

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TOPIC VI:
EDUCATION ISSUES

Papers/Presenters

EDUCATION WORK GROUP

Laurel Menthey-Silvio
Gaithersburg, MD

EARLY INTERVENTION AND PARENTING SUPPORT IN PUBLIC SCHOOL INCLUSIVE PROGRAMS

Heidi L. Miller, Ph.D.
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EDUCATION WORKGROUP

By Laurel Manthey-Silvio
Gaithersburg, MD

Background
Education is the foundation of any functional society. It is this foundation that provides individuals with the skills, knowledge, and ability to become contributing members of society. Individuals with mental retardation are legally guaranteed the same education and outcomes. Inclusion in the educational system consists of equitable access to learning and social opportunities and the expected outcome of becoming a functioning member of society.

At the 1997 Next Generation Leadership Symposium, the Education Work Group examined the state of education in our society as it prepares individuals with mental retardation for their role as contributing members of society. The Work Group consisted of self-advocates, parents, educators, administrators, and related service providers. This group of individuals are the shareholders in the education of individuals with mental retardation. This group, these shareholders all need to be involved in the educational process providing direction, support, and ownership for the educational system. Through a combined perspective, the Work Group assessed the state of education for individuals with mental retardation, discussed changes in attitude and policy that would benefit individuals with mental retardation, and developed recommendations to implement positive and necessary changes in the educational system.

The Work Group began with an introduction from the senior presenter, Michael Remus, the Director of Special Education for the state of Kansas, who challenged us to contemplate philosophical questions. How do we empower students with mental retardation and their families in their educational process? What is inclusive education? Are students succeeding? Why do we teach what we do in the way we do? Are the classes and subjects related? Do we believe that all students have value and worth? Does the present educational system lead to an individual who has the skills needed to function in society? He challenged us to develop a vision statement on which to base our actions as future leaders of the educational system.

State of Education for Students with Mental Retardation

Students with mental retardation have the legal right to be educated in the general education classroom. The Individuals with Disabilities Education Act (IDEA, P.L. 94-142 passed as the Education of All Handicapped Children Act in 1975) entitles students with disabilities to the right to educational opportunities with nondisabled peers. This law provides the legal basis for the inclusion of students with mental retardation in the general education classroom. Therefore, inclusion in the educational system is not an education issue, but an issue of civil rights.

Inclusion is the practice of educating students with disabilities, regardless of the severity, in the general education classroom, with an appropriate level of on-going supplemental support. The student with a disability is an active, equal member of the general education class. Both general and special educators are responsible for the instruction and progress of the student with mental retardation in an inclusive setting. The student should begin his or her education in the general education classroom with the support needed to be successful. A student can only be removed from the general education classroom and placed in an alternative, more restrictive setting, such as a special education classroom or segregated center, "when the nature or severity of the handicap is such that education in the general classes with the use of supplementary aides and services cannot be achieved satisfactorily" (20 U.S.C. 1414(a)(1)(C)(iv). Removal from the general class must be decided on an individual basis and not on the type of severity or the disability. In other words, a student being labeled mentally retarded is not reason enough to put the student in a more restrictive environment.

In the present educational system, students with mental retardation are often placed directly into segregated settings and removed completely from any opportunity to be educated in the general education classroom. They are expected to gain the skills needed to be successful in the general education classroom in the more restrictive setting. Students with mental retardation are not considered developmentally ready for the general education classroom. Placement in a segregated setting lowers the expectations of the student. The deficits are seen to be in the individuals skills and abilities and not with the educational system that is legally charged to support and educate individuals with mental retardation with their nondisabled peers.

This practice has led to the development of general and special education into two separate entities, each with its own values, foci, curricula, and outcomes. Over the years, special education has become viewed as a placement instead of as a supplemental support to the general education system. Inclusion in the general education class seen as a privilege to be earned and a student could only leave the segregated special education placement if he/she has reached a certain level of skills and functioning.

This educational system promotes a society of inequality through the segregation of individuals with mental retardation. The educational system is comprised of two distinctly separate components: general education for nondisabled students characterized by outcome based instruction and special education for students with disabilities characterized by fragmented instruction based on developmental readiness. This dual system supports a society in which individuals with disabilities are perceived as inferior and forced to live outside the mainstream of the community . In order for individuals with mental retardation to be valued members of the society, the educational system must change to accept diversity. The educational system must reflect the equality among all individuals and their differences.

Changes in Attitudes and Policy

> *"Decide on the kind of society you want, then organize your school by that. Twelve years later, you will have that society. " John Dewey*

The Education Work Group's vision is a society in which all individuals are valued members with their unique contributions recognized and accepted. Individuals with mental retardation should not be kept behind the walls of segregation, but instead integrated into the community for housing, recreation, employment, and education. An educational system that educates all students, an inclusive and unified educational system, teaches students to value all individuals and expresses equality among all, regardless of their differences. This system would promote a society organized on equality for all individuals including individuals with mental retardation. Schools must be organized in a way that all students are educated together as a community of learners regardless of ability levels. An inclusive educational system is child centered. It offers acceptance and it celebrates diversity.

General and special education should be unified into one effective educational system that holds high expectations for all students. Creating an inclusive, unified school system is an on-going, ever evolving, long-term goal. It requires flexibility, patience, and belief in the basic principle of inclusion: all students, regardless of their abilities, have the right to belong. Belonging means being treated with dignity and valued as a productive member of the classroom, neighborhood school, community, and society in general. Students with and without mental retardation are educated in an atmosphere of acceptance of different levels of abilities as a community of learners.

In a unified educational system, students with mental retardation need to be taught functional skills in the environment in which they will be required to use the skills. If these students are expected to function in a society alongside their nondisabled peers, they must be educated alongside them. General education is the real world on a school level. The curriculum is designed to teach concepts and subjects to general education students, to prepare them for life as adults. Students with mental retardation need this as well. The specific goals for the student with mental retardation can be integrated into the general education curriculum with creativity and ingenuity to the benefit of all students. All students would be better prepared for life as independent adults in society.

Factors in Place That Should Facilitate Change

There are three factors in place that should facilitate change in the current educational system: the law, advocacy of individuals and families, and current thoughts of educators on best practices in educating students with mental retardation. As previously stated, the Individuals with Disabilities Education Act (IDEA) mandates that individuals with disabilities be educated with nondisabled peers with supports needed to be successful. Again, inclusion is not an educational decision, it is a civil right. Many individuals with mental retardation and their families are advocating for an education in the general education classroom. Families have decided that it is in their best interest to have their children educated with siblings and peers in their own communities. These are the children who in the future will be living in the communities as adults together. Therefore, they should be educated together.

Educators, supported by research findings, are turning to inclusion as a best practice to educate students with mental retardation. The problems of a dual educational system are becoming evident to more educators, families and advocates. Students with mental retardation need to be taught specific skills in the environment in which they will be using them. If we expect them to function as adults in the community, then we must educate them in the community schools with their peers.

Barriers to Change

There are three barriers that stand in the way of the changes for which we are calling: attitudes of educators, fears of families, and structure of the educational system. Many special and general educators do not believe in educating students together in the general education class. Special educators are set in their developmental instruction and feel that general educators lack the ability to teach students with disabilities. General educators believe that the general education classroom is for the type of child who learns in the traditional ways. Students who learn in different ways should be removed and placed in special education.

Another barrier is the fear of families who, like the educators, do not understand how inclusion would work in a unified education system. They are afraid that their child might receive fewer services and decreased attention from the special educators. Many families are unable to see that, with support of both general and special educators, their children will be exposed to more curricula and effective instruction. Their children would also have the opportunity to learn from their nondisabled peers in a normalized, age-appropriate classroom.

The third barrier is the established structure within the educational system. The educational system has spent years separating general and special education, general and special educators, and students with and without disabilities. People find comfort in established structures and the idea of completely restructuring the educational system is produces fear and anxiety.

Recommendations from the Work Group

1. **Create a unified, child centered educational system for all students that respects differences and celebrates diversity**. One unified educational system that is characterized by outcome based instruction would benefit all students in the preparation to become a contributing member of society. The best components of general and special education should be combined. From general education would come outcome based instruction, curriculum based assessment, and effective teaching strategies. From special education would come the interdisciplinary team approach, problem solving strategies, and individualized instruction. By joining the best aspects of both educational systems and creating

one system, an educational system that teaches all students a functional and effective curriculum would develop. Special education would no longer be a separate entity but a support to general education.

2. **Recognize best practices and model programs.** There are states, counties, and individual school systems that have embraced inclusion and a unified educational system. As the saying asks, "Why reinvent the wheel?" Infonnation and knowledge of effective educational strategies and the task of creating an unified educational system should be shared. Highlighting programs that are including students with mental retardation in general education would educate by example. The most effective argument is proof that a concept works.

3. **Implement changes in teacher training and preservice that focus on a unified educational system that includes all students**. Teacher training and preservice needs to facilitate the unified educational system by preparing teachers in best practices and curricula. that benefits all students, regardless of ability. General and special education teachers who are presently in the classroom need to be trained in the principles of inclusion and how to educate children together in the general education classroom with support from special educators. Preservice training for individuals who want to become teachers needs to focus on outcome based instruction and assessment for all students. No longer should colleges and universities educate general and special teacher candidates separately. Teachers need to be taught the effective strategies that have developed from both general and special education. They should be prepared to deal with all students in an individualize manner and develop a classroom that focuses on the child's abilities.

4. **Educators and families must collaborate**. Students and families need to feel that they are the center of the educational system. Their ideas, issues, and concerns need to be heard and understood. Educators and families are a team and need to work as any effective team with respect, dignity, and honesty. Open communication is the foundation for planning and creating an individualized educational program for students with mental retardation. We are each experts in our own field, be that educational practices, our own children, or ourselves. Without each other, as a team, we are limited in our own abilities.

5. **Develop a curriculum to promote functional living in society**. Students with mental retardation need to learn skills that will enable them to function as independently as possible as adults. Curriculum can no longer focus on developmental readiness and skills. We need to examine the skills needed as adults and specifically teach them in an original or modified form.

6. **Teach self-advocacy skills to students with mental retardation**. Students need to be taught to be their own advocates. The students need to be empowered and involved in their education and lives. We need to teach and encourage them to make decisions, choose options, and voice their opinions. Beyond that, once they are self-advocates, their decisions and choices need to be honored. They need

the skills and ability to choose how to live their lives as much as any other individual.

7. **Develop a system of advocacy and case management that is independent of the educational system**. Students with mental retardation and their families need access to a professional who would represent their best interest. As a safeguard, an advocate who could also play the role of case manager, should be available to families as a part of their guaranteed educational rights. This advocate would help student and family through the technicalities and paper work of the educational system while ensuring that the priorities and needs of the student and family are addressed. This person would not be employed by the school system but by a separate service agency to avoid conflicts of interest. Another aspect of the advocate's role would be to help the student and family through transitions into and out of school. The person would be able to connect students and families with resources and services available through the government and community.

8. **Implement a campaign of public awareness and education regarding disabilities.** Society needs to be aware of the abilities and contributions that individuals with mental retardation and disabilities in general make to their communities. By accepting individuals with mental retardation in the communities, we are sending the message that all people belong. We must live what we believe and teach all individuals, regardless of abilities, have a place of dignity and value in our society. This public awareness campaign would highlight the abilities of individuals through events such as Disability Awareness Day, national conferences, and media coverage. By accepting individuals with mental retardation in society and giving them exposure, their abilities will speak for themselves.

Conclusion

It was an honor to be involved in such an undertaking as the 1997 Next Generation Leadership Symposium. Together, as the education work group and shareholders in the educational system, we examined the state of education for individuals with mental retardation, discussed the needed changes, and developed recommendations. We, as future leaders of education, agreed that we must lead by example and action. Our beliefs in inclusion, equality, and dignity for all individuals must guide our words and actions in order to create the society that we envision. Through us, let there be an inclusive educational system that is child-centered and offers acceptance and celebration of abilities and diversity.

Early Intervention and Parenting Support

in Public School Inclusive Programs

By Heidi L. Miller, Ph.D.
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This paper presents portions from a larger study (Miller, 1994) on providing inclusionary early intervention programs. Included is a proposal for a legislative mandate which would provide early intervention and parenting support programming in the public school system. The intent of this proposal is to spark legislative action to provide the option for early intervention in inclusive settings with services available to all children and their parents who choose to participate regardless of at-risk or disability status. Current legislation, Part C of the Individuals with Disabilities Act, provides a multi-disciplinary system of early intervention services for children with disabilities and those considered at-risk. However, services for the remaining portion of infants and toddlers in this country are not similarly addressed. The benefits early intervention provides are not limited to at-risk populations. Indeed the benefits that early intervention holds for children at varying ability levels in inclusive settings has been documented to benefit both the children with and without disabilities (Ross, 1992). In recognition of the needs of young children and their families many states have implemented forms of inclusive intervention services. However, no program thus far has reached the multitude of American families in need.

Methodology

This study was an analysis of early intervention programs across the country between 1975 and 1994. The purpose of this study was to document findings from early intervention and family support programs to discover key elements of success. Secondly, this study was intended to provided a vehicle for facilitating early intervention and parenting support in the public school system.

Research Questions

- Why begin formal education so early?
- Can variables of success be isolated within viable programs?
- How do we bring these programs to our schools?

1. **Populations and Programs Studied**-An exhaustive literature search was conducted on a variety of programs nationwide. Model programs were selected and reviewed. Eight states were selected as sites of model programs including Arkansas, Connecticut, Kentucky, Maryland, Minnesota, Missouri, Oregon and Vermont.

2. **Scope and limitations of this Study**-This study was limited to research on the educational impetus and components of working programs. As programs in these states have likely undergone some changes in the three years since the original study, details of specific programs are not outlined below. However, a synthesis of successful program components is included in the following legislative proposal. An analysis of legislative processes in program implementation was included in the larger study.

3. **Presentation and Analysis of the Data**-Why begin formal education so early? The learning opportunities of a child during the earliest years of life make a permanent difference in his/her lifelong intelligence and functioning. Scientific research shows that the brain can actually develop more neurons and interconnections so it will become more intelligent and more capable of learning and thinking for the rest of life (Beck, 1993). Additionally, parental attitudes and child-rearing practices, during the child's crucial early years will help or hinder the child's chance for success later in school and into adulthood. Without education parents are likely to perpetuate intergenerational patterns of behavior which may adversely the child's growth and development. Can variables of success be isolated within viable programs? Yes, the findings of this study draw several conclusions about the structure of successful intervention/parenting programs. The goal of these programs is to empower parents to give their children the best possible start in life. This mission must be executed through a highly developed support structure and well-organized system of service delivery. This system of service delivery is outlined in the following section.

How do we bring these programs to our schools? The following program components were synthesized from the literature by the researcher into a model program proposal, hopefully to be adapted into a legislative mandate.

Parent And Child Together (PACT) Goals

To assist children nationwide in maximizing their potential and readiness for school through a curriculum which:

- Realizes the importance of the child within the family and the interdependence of family/school education. Thereby, the program will provide the parents with the necessary education and skills to function more effectively as parent educators.
- Acknowledges the role of the community in the education of children; viewing the child and family as interconnected or as a vital link in the community.
- Promotes the development of a healthy generation with a strong and positive sense of self-worth, and with the knowledge that each individual can contribute and own a special place in society.
- Minimizes the need for expensive remediation, and special education services.
- Reduces the intergenerational dependence of the family on the current welfare system through parent education and skill training.

1. **Services**-The researcher suggests a Federal legislation to mandate the availability of early intervention and family support programming through the public school system. Each state shall be responsible to coordinate programs with local schools systems. Although programs will have universal acceptance (available to all children and their parents or guardians), they will be tailored to the populations and individuals served.

2. **Assessments and Evaluations-**Children should be periodically assessed (or screened) for general development along with language, hearing, vision and motor skills. Evaluation of children's progress in these areas should be noted on an on going basic. Furthermore, any child who is found to be in need of additional services under IDEA should receive them. Additionally, family needs as they pertain to the child's development should be assessed.

3. **Home Visits and Group Sessions**-It is important to see the child interact in the home environment in order to facilitate appropriate suggestions and intervention. Group sessions often provide inspiration and build a support network.

4. **Interagency coordination services**-Interagency coordination with human services and health care agencies in addition to referrals to other community resources for childcare and other necessary services.

5. **Transportation and accessibility**-Transportation should be provided. Successful programs also provide a variety of times for working parents to meet.

6. **Parent literacy and skill training**-Courses that will bring parents up to a high school equivalency should either be provided or a referral should be made to an appropriate resource.

7. **Participants**-Universal eligibility for all children 0-5 (or formal school age) and their parents (primary caretakers or legal guardians) It is suggested that

grandparents, other caretakers, and siblings be included in some sessions. Prenatal education and counseling is suggested as well.

8. **Funding**-The researcher suggests funding through the public school system. Federal funds, foundation grants, bond issues, tax levies, community and corporate contributions (of services as well as money) may also be utilized.

9. **Staff**-Unity and consistency are crucial elements of an appropriate program which outline the need for interagency coordination at the state, local community and program levels(Harbin & McNulty; and Lowenthal; as cited in Chen, 1993) and for trans disiplinary teaming at the program level. Staff should therefor work to coordinate services with any necessary agencies. Regularly scheduled comprehensive in-services should be provided to train all staff about inclusionary methods and special needs of children in their programs as well as to keep staff up to date on current research and practices. It is recommended that all teachers have a certification in special education. Consults and direct care by specialists should be provided as needed. Selection criteria for staff should be set by the state board of education. Due to the particular needs of families and infants, special requirements for qualification and training in the area of early intervention and family support should be established.

10. **Parents Role**-Parents are their children's first teachers as such they share a leading role in the development of the young child. It is a parent's responsibility to ask questions when appropriate, follow-through with interventions at home and view themselves as informed consumers.

11. **Evaluation**-Thorough evaluations are required to meet the program guidelines suggested above. The researcher suggests each state be given the liberty to determine how evaluations are to be conducted in accordance with meeting federal program requirements.

12. **Miscellaneous**-A high degree of creativity is suggested for implementation of this program. Programs are successful when they are frequent and occur over an extended period of time. Services must be provided which are appropriate to the developmental level and needs of the individual child. Note: Although this paper focuses on early childhood programming, studies indicate parental involvement throughout the child's schooling is important. Classes in middle and high school on basic parenting and prenatal care are advisable as well.

13. **Future Research-**Research shows that educating children from birth, when done appropriately over an extended period of time, and with consistent parent involvement, will produce dramatically positive effects. Yet, the full scope of social repercussions from a nationwide program is unknown. An area for further study is the impact of early education and parent involvement on the productivity of our children as adults in the global market. We have already seen evidence that

> by producing happy, healthy, well educated children we are creating a future workforce of adults who will have more productive living and work skills.

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TOPIC VII: RESEARCH ISSUES

Papers/ Presenters:

RESEARCH ISSUES

Yona Lunsky
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REDUCING THE INDICENCE OF DEVELOPMENTAL DISABILITIES: BUILDING BRIDGES BETWEEN RESEARCHERS, POLICY MAKERS AND SERVICE PROVIDERS

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University of California, Davis
Research Associate
President's Committee on Mental Retardation

RESEARCH ISSUES

By Yona Lunsky
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Background

The topic of research is one which relates to every issue discussed at the Next Generation Leadership Conference. Whether one is seeking answers about best educational practices, how to implement a job coach project in a rural town, or the percentage of prisoners with mental retardation in a maximum security setting, some type of research is done or could be done. Thus, research issues apply to the broader field of mental retardation, or at least they should, and not just to those individuals that traditionally refer to themselves as researchers.

At the 1996 conference, the research issues workgroup discussed recent advances in the areas of genetic mechanisms associated with mental retardation, poverty, mental retardation and policy implications, and the increasing need for supports in the community. This discussion led to a series of recommendations about topics for future research, along with some suggestions of how research could be done. This year, the research group chose to focus on the broader importance of research, rather than on specific research topics, with the goal of improving the research process and expanding the utility of research findings. In keeping with this theme, the research issues workgroup was made up of a diverse collection of individuals: administrators, family members, students, direct support workers, and teachers. This diverse group shared a common "drive to discover" and a vested interest in the future of the field of mental retardation and other developmental disabilities.

The combined perspectives of a senior researcher in the field of mental retardation, Laraine Master Glidden, and a junior researcher, Laura Jeliffe, gave the work group several issues to consider in terms of how research is conducted at present and the direction in which it is going. Research was examined in terms of its value, its participants, existing hierarchies, and research training.

1. **Value of mental retardation research**: According to Master Glidden, researchers in the field face the constant challenge of having to prove the value of their research to researchers and non-researchers alike. The non-researchers in the field are not as interested in research as they could be. Their disinterest may be due in part to prior negative experiences with research. For example, some families and consumers participated in past research that they did not fully understand and for which they felt coerced to give their consent. Even in a recent study (Heller, Pederson, & Miller, 1996), 22% of leading self advocates reported that they did not understand the purpose of a study that they completed.

Not only must researchers prove the value of their research to the non-researchers in the mental retardation field, they must convince researchers in other areas that mental retardation research is valuable. Researchers in the general population rarely consider findings from the literature on mental retardation. Reasons for this neglect may be based on imperfect experimental designs, small sample sizes and non-standardized instruments frequently found in mental retardation research. Other researchers may not refer to the mental retardation literature simply because of the misconception that findings are not relevant to their population. A side effect of the self-containment of research is that mental retardation researchers may be forced to "reinvent the wheel," because of limited communication with outside researchers.

There is a third group to whom researchers in the field of mental retardation must prove the value of their research, and that is the researchers themselves. Increasing specialization within the field of has led some researchers of the same topic to feel as if they are speaking different languages. Greenspan discusses an example of this when he compares the quantitative to qualitative approaches to mental retardation, which are generally considered as separate and incompatible. He suggests that few researchers if any, qualitative or quantitative, show any interest in using a combined approach (1997).

2. **Changing role of research participants**: An important shift is taking place in terms of how individuals with mental retardation, family members, and other advocates are viewed by researchers. The leading journals in the field are now requiring that "people first language" be used, emphasizing the humanity of people with mental retardation. Those involved in studies should now be described as participants as opposed to subjects.

   The 1992 definition of mental retardation (Luckasson et al., 1992), emphasizing levels of support in 8 areas of functioning, should further alter how researchers view their participants with mental retardation. According to this definition, a given participant cannot be classified by IQ score alone, or as falling under a broad level of functioning category. Individuals are no longer categorized as having mild, moderate, severe or profound mental retardation. Acceptance of the new definition, viewing individuals in terms of the level of support they require to complete different tasks, requires a major shift in conceptualization and corresponding changes in research design. Such modifications have yet to occur in the research literature. Thus far, many researchers are continuing to use the 1983 definition when they recruit participants and describe them in their studies.

   Individuals with mental retardation are no longer the captive audience they once were when they lived in large state facilities. It is therefore more challenging to recruit participants for a given study. Community research necessitates less control, and brings with it complications. For example, more children are attending their home schools in integrated classes which would require the researcher to go to several schools rather than one school for participant recruitment. Many individuals previously recruited from sheltered work settings may now work in the community with unpredictable hours, making their recruitment difficult. On the other hand, if individuals with mental retardation are more involved in their communities, then it follows that more research should be conducted in those natural settings. The self-advocacy movement deserves mention as another influence on the changing role of participants. Self advocates are voicing their concern about the importance of consent in research, and also an interest in being more involved in the research process. Thus, they are striving to move from being subjects to participants to co-investigators, as are parents and others in advocate roles.

3. **Existing hierarchies in the research community**: As discussed above, traditionally there exists a hierarchy between experimenter and subject. This hierarchy is lessening as subjects become participants and will evolve further if participants become more actively involved in the research process.

   A second hierarchy exists within organizations that support or reject research proposals. When an organization is approached to be involved in research, particular high status individuals make the decision for that organization. With more consumer representation on boards, this process may be changing. However, without the consumers understanding the proposals and feeling safe enough to express their opinions, the inclusion of community members in the decision making process is merely a form a tokenism.

   Young researchers are also confronted with hierarchies. It is difficult for them to obtain grants and recruit participants because of their limited experience. It is challenging to gain experience unless they are somehow attached to a researcher or an administrator in a powerful position. It is also difficult for young researchers to present their ideas, unless they are supported by well known researchers in their field. Those at the bottom of the research hierarchy have limited funds to attend conferences and to present their ideas in conference organized symposiums. Existing efforts to lessen these barriers faced by new researchers include anonymously reviewed journal submissions and young researcher awards and paper competitions. Unfortunately, many young researchers are unaware of the opportunities that do exist.
4. Lack of research training programs: There are few graduate level programs that allow an individual to pursue studies in mental retardation, and such programs are not well publicized. Thus, finding a program that meets ones research interests is challenging, and students often have to settle for peripheral study of mental retardation issues. Few students are drawn to the field of mental retardation research at all because it is so under-represented in the undergraduate curriculum. A common theme articulated by several young researchers at the conference was that they were relieved to meet other individuals in their field, as they felt rather "alone."

The training that exists can be so specialized that cross domain work is limited. The young researcher is trained on a specific topic and not given the skills to communicate that topic to others unfamiliar with it, and is not exposed to other important models, or content. It is difficult for young researchers to meet with other young researchers to gain alternative perspectives to their own.

Finally, research is not emphasized in other sorts of training programs in the field, so that research students, unless already studying in an interdisciplinary setting, get minimal exposure to collaboration with others. Conversely, students in non-research oriented training programs gain limited exposure to the importance of research in their area. This dichotomy in training models reinforces the current split between research and practice.

Vision

Our vision of future research centers around three themes: responsibility, accessibility, and utility.

- *Responsibility*: The state of being answerable, accountable, important
- *Accessibility*: The quality of being easy to approach, open to the influence, attainable
- *Utility*: The state of being useful, beneficial, advantageous

These three themes need to be addressed in terms of the research process (how research is done), and in terms of the research outcome (what is done with research). As noted previously, there are several factors in place that hould facilitate the change: new definition of mental retardation (AAMR, 1992); young researcher grants and awards; conferences like PCMR's Next Generation Leadership Symposium; self-advocacy movement; and community collaboration, membership on boards. There are also several existing barriers:

- resistance to change
- lack of training under new model
- lack of funding for training
- low number of young researchers being recruited into the field
- the continued existence of more "invisible hierarchies".

Recommendations-Research process

Researchers must strive for quality research. We define quality research as research that is objective; based upon roper methodology, training and ethics; data driven and is responsible to stakeholders needs. These stakeholders iclude the broader research community, service providers, funding entities, and people with disabilities and their families.

1. **In order to ensure quality research, research should include a strong evaluation component (such as an Institutional Review Board (IRB) or peer review system) which involves all stakeholders**. University IRBs, for example, do not necessarily involve experts in the field of mental retardation research, and certainly no persons with disabilities or their families. IRBS might therefore have

a limited understanding of consent and confidentiality issues as they apply to this population, which are of utmost importance. Involving all stakeholders means that all stakeholders have an equal voice. If a family member, self-advocate, or direct support worker is unfamiliar with the research review process, or any aspects of the study, it is the researchers' responsibility to explain the study in a way that it is understood.

2. **Researchers should maintain a clear focus upon producing research that supports the interests of persons with disabilities and contributes to knowledge of the field.** One way to determine what would be of value to stakeholders would be to take a participatory action-research approach. This would necessitate more qualitative examination of issues in the preliminary stages of research with participants playing an active role. To best contribute to knowledge in the field, this qualitative exploratory work could then be followed by more detailed, perhaps empirical examination. This combined sequential approach has been implemented successfully in some areas, such as research on social intelligence (Greenspan, 1997).

3. **In order to maintain quality research in the future, we need to provide quality training**. Efforts should be made to recruit, support and mentor young researchers, keeping in mind that young researchers come in all shapes and sizes. Training should be more accessible to A) traditional mental retardation student researchers; B) students studying other research areas, so that they can gain an appreciation for mental retardation issues, and C) students in the mental retardation field who would not ordinarily consider themselves to be researchers. A guide listing all avenues of mental retardation research should be made available in every undergraduate studies office, as well as high school counseling office, and reference library.

The programs themselves should offer several perspectives, and teach different research methods, outlining the pros and cons of each. Appreciation for the history of mental retardation research is important, both to celebrate the great steps taken, and to learn from important mistakes in the field. Practice writing grants and reviewing journal submissions should be available to students as part of their training. The leading journals could have a student editorial board, as has been done in other journals (e.g. American Journal of Community Psychology). Young researchers should be taught how to collaborate with other researchers and to work within the community. Existing professional and advocacy organizations (e.g. The Arc, AAMR) could better publicize research grants and opportunities for young researchers. More formal mentorship and internship programs could be implemented. Finally, "non-research" students should study the importance of research in their area of study, and gain an understanding of their potential role as research collaborator.

Putting Research To Use: Everyone Plays A Role

What happens with research is not inherent in the research process itself, but is just as important. To ensure that future research in mental retardation is useful, efforts can be made by all stakeholders, and on several levels. Our recommendations are categorized in terms of responsibilities on a national level, by professional organizations, and by the researchers themselves.

1. **On a national level, a greater and more accurate public awareness of mental retardation research needs to occur**. We propose the information centers or clearing houses be created that disseminate information about research related to mental retardation and other developmental disabilities. In addition to written information, they could establish Internet sites with abstracts and simplified information, as well as information in audio-visual format for non-readers . The clearinghouse would need to be easy to access and those involved would have to be trained to work with researchers and direct care staff, families and consumers. The clearinghouse could also be responsible for dissemination of research literature to public libraries and community newsletters.

2. **We encourage service providers and community organizations to invite researchers into the service delivery system to share their research findings and to learn from the organization**. Meetings with researchers could help community members recognize their own potential to be researchers. Providers could delegate and encourage staff and community members to gather information on topics of interest to present to colleagues, organizations, parents and self advocates. Workers and advocates in the field could generate ideas, observe outcomes, do pilot studies and collaborate with researchers.

3. **Researchers must accept responsibility to do more than publish their product for a select audience**. As Jeliffe describes in her paper, it is vital that researchers publish and present their work in different arenas for different audiences. Researchers could present and prepare simple descriptions of their studies to disseminate, as standard practice. Such descriptions could become a mandatory part of any journal submission. Finally, researchers need to actively explore avenues for sharing information and learning from service providers, parents, policy makers and self-advocates. Community collaboration efforts should not be left entirely to the community members.

Summary of Recommendations-Future Research: Emphasis on Responsibility, Accessibility and Utility

Research process:

- evaluation component that involves all stakeholders in equal manner
- research that supports interests of persons with disabilities
- quality training for young researchers and non-researchers alike (guide listing programs; training under collaborative model; student editorial board; more grants available and better publicized to young researchers)

Research outcome:

- national effort for greater more accurate awareness of research, national clearinghouse

- service providers encourage partnerships, reward staff for using research, foster role as collaborator
- researchers publish findings for several audiences, prepare simple summaries, active role in community

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REDUCING THE INCIDENCE OF DEVELOPMENTAL DISABILITIES:

BUILDING BRIDGES BETWEEN RESEARCHERS, POLICY MAKERS AND SERVICE PROVIDERS

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Overview

The goal of this presentation is twofold; first, the importance of collaboration between researchers, policy makers, service providers, family members and persons with developmental disabilities is discussed with special emphasis on working together without hierarchy towards a common goal of bettering the lives of individuals with developmental disabilities and/or reducing the incidence of developmental disabilities. Secondly, research from The Kauai Longitudinal Study is presented which reflects the efforts of collaborative work that has significantly influenced both policy and service delivery in the past and continues to yield results which suggest avenues for reducing the incidence of developmental disabilities.

Researchers and policy makers alike have noted a shift during the past thirty years in how the concept of early intervention and prevention of disabilities is viewed. In the not so distant past infants and children with developmental disabilities were segregated from their families and institutionalized- often for the entirety of their lifetimes (a practice, which sadly, still persists in some developed and developing countries worldwide). These are trends in the past that young researchers, policy makers and service providers must take note of for they provide the inspiration and grounding for charting a course that reflects a willingness to work together and invest in the futures of ALL children.

During the past twenty years there has been a clear shift towards the recognition of the rights of individuals with developmental disabilities and an adoption of a service approach based on care and understanding. This has, thankfully, led to a great deal of progress in how and where people with developmental disabilities live and has led to the recognition that, people with developmental disabilities may be allowed and encouraged to play an active part in decision making that impacts their lives and those of their peers. In many ways, continuing this trend and carrying this torch is what the Next Generation Leadership Symposium is about. The challenge however, comes in the form of a question: Where do we go from here? This question is especially salient in the area of prevention and early intervention where progress has been made but not nearly at the needed pace given the incidence of developmental disabilities in the United States.

Where DO we go from here?

Making progress in the area of prevention and early intervention (and thus, reducing the incidence of developmental disabilities) will require that researchers, policy makers, service providers and families WORK TOGETHER! What this statement really means is more than has been traditionally accomplished when interested parties have "worked together" and is more than is typically being done in today's venues. For progress to be real progress in prevention and early intervention (as well as in other areas) participants in the process must be invited to the table as equal partners, without hierarchy and without prejudice- only then can those involved in the process truly work together. All too often research projects, policy recommendations, and service delivery plans are drafted and carried out without consideration for the interests and expertise of their fellow professionals, concerned family members, and individuals who themselves have developmental disabilities. An alternative to this scenario (which is becoming more and more common- but is perhaps just as ineffective) takes place when researchers, policy makers, service professionals, family members and individuals with disabilities are invited to participate in decision making activities and are 'Talked-at', 'Talked-over' and/or 'Talked-around'.

'Talked-at','Talked-over' and/or 'Talked-around'

Most concerned professionals, family members, and individuals with a developmental disability have probably had the experience of being invited to participate in a decision making activity and been 'Talked-at', 'Talked-over' and/or 'Talked-around'. This tendency often creates the impression that an approach, decision and/or policy was arrived at collaboratively when in fact, in may be the case that all parties were present but did not participate as partners, or perhaps, did not participate at all but were merely present. This tendency has been all too present in service delivery for the past decade where individuals with developmental disabilities and their families have increasingly been invited to the discussion table but have often been treated merely as observers to a process they are unfamiliar with and unaccustomed to. More recently this tendency is being observed in the realm of policy making and research design where individuals with developmental disabilities, their families, and community members are being invited to decision making forums but are treated as observers to an unfamiliar activity where people speak at them, around them, or over them in 'alphabet soup'. For example, at a recent meeting with parents, policy makers and individuals with mental retardation a physician (who I had done some research with before) turned to me and asked, "do infants with SGA or IUGR qualify under ADA or just IDEA."

Partners in Research, Policy Making and Service Provision

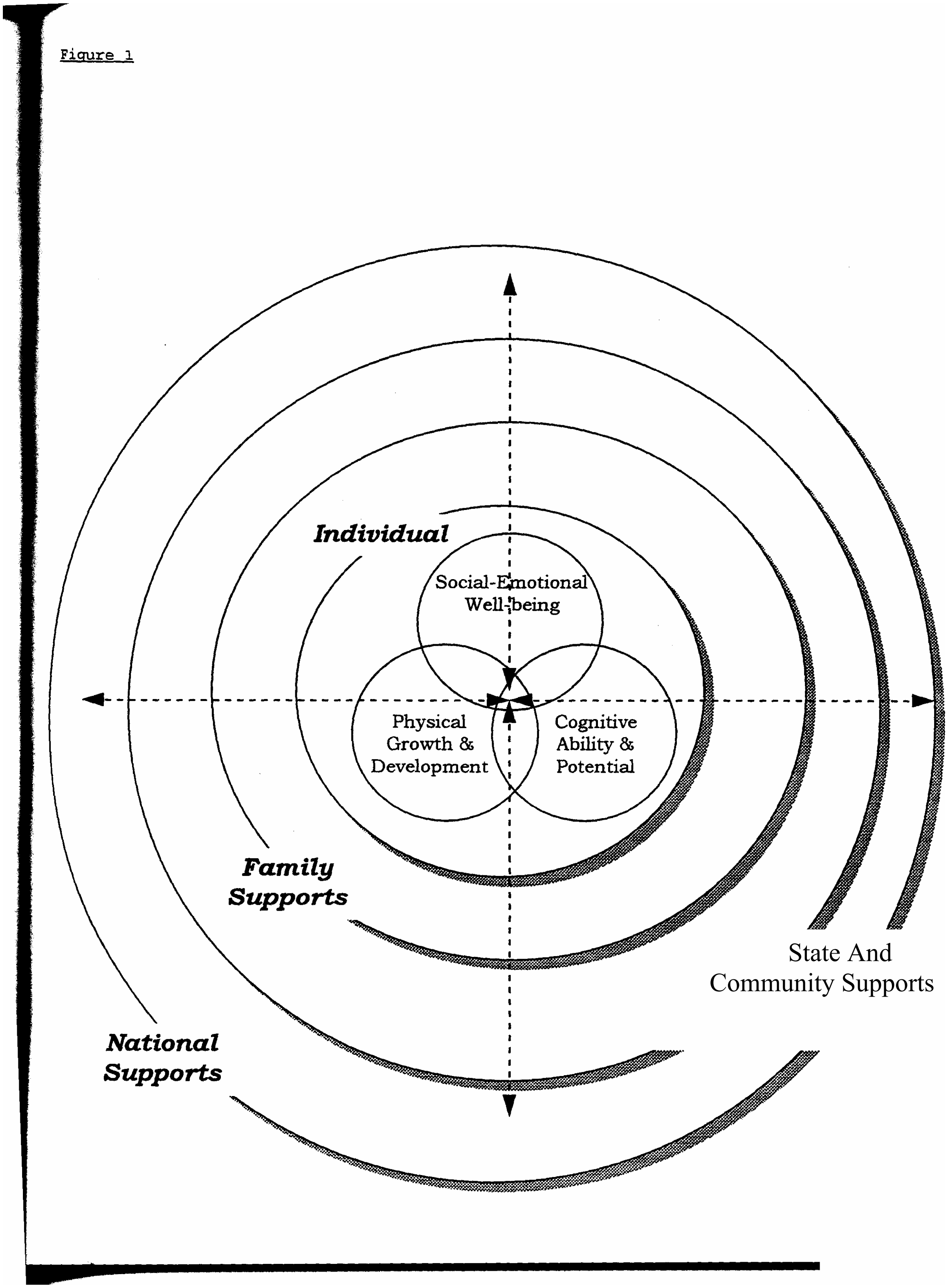
The concept of bringing people together as partners begins with addressing the issue of how avenues of communication can be built, opened, and traversed. Obviously ideas about how this can be done are numerous, perhaps key however, is the importance of encouraging full participation of individuals not familiar with a given decision making process and encouraging researchers, policy makers and service providers to explain concepts, diagnoses, programs, laws etc ... rather than to just refer to them using acronyms or 'code-words'. This is, in many ways, the most difficult aspect of bringing different professionals to the table.

Clearly there is still progress to made in conducting research, creating policies and developing service programs that focus on creating equity for individuals with developmental disabilities. Along with this focus however, is the need for treating individuals with developmental disabilities, their families and colleagues from different fields as experts in their own right. It must be realized that these experts have contributions to make that are essential and without which, research design, data interpretation, policy recommendations and service delivery systems are intrinsically flawed.

Figure 1

Building Supportive Communities:

Levels of Support and Influence



Getting Connected

Working together as colleagues and experts requires that professionals working with or on behalf of individuals with developmental disabilities increase their awareness of how the different disciplines and components of research, policy making and service delivery are connected. An understanding of how disciplines and components are connected can then allow for subsequent evaluation of where and if essential components are located within the communities in which they live and/or study and thus, help professionals, families and individuals with developmental disabilities develop and/or make use of their community resources.

Figure 1 depicts a system of service delivery, policy making and research design that is 'person centered'. What this model suggests is that there are different levels of functioning and support that all concerned members of the system should be aware of-especially researchers, policy makers and service providers. For example, if researchers, policy makers, and service providers are interested in increasing the cognitive functioning of developmentally delayed children, all of these professionals should be aware that there are avenues of potential support and intervention located within and between different levels. At the individual level an infant or toddler may in fact display noticeable cognitive delays but in fact appear physically healthy and happy-thus this individual's physical abilities and social-emotional functioning may serve as a potential support for increasing cognitive functioning. The functioning and level of support and/or intervention most beneficial for this individual may then differ dramatically from that of an individual with cognitive delays and significant health problems. A similar contrast can be made at the familial level where the degree of intervention and/or support needed to prevent long-term cognitive delays may differ dramatically as a function of socio-economic status, the presence or absence of siblings, the presence or absence of extended family members and/or a myriad of other factors. At the community level the availability and accessibility of services and intervention efforts may differ dramatically based on whether or not individuals live in urban or rural settings, and at state and national levels services and intervention efforts may differ dramatically as a function of state interpretation of national mandates and/or as a function of fiscal management.

The degree of understanding by a researcher, policy maker and/or service provider of the different dynamics inherent in each of these levels will likely mediate the effectiveness of a program and/or the accuracy of a given research project, therefore, increasing understanding requires that researchers, policy makers, service providers, families, and individuals with developmental disabilities work together. Without the contributions of all these members who provide essential information regarding potential levels of support and influence in the lives of people with or at-risk for developmental difficulties, building supportive communities for those with developmental disabilities will continue to prove difficult and early intervention programs aimed at preventing developmental disabilities will likely fall short.

Recognizing Interconnectedness: Reducing the Incidence of Developmental Disabilities

In many ways it can be argued that professionals whose aim is prevention of developmental disabilities and/or early intervention with individuals at risk for or diagnosed with a developmental disability are particularly obligated to work with colleagues from other disciplines in order to reduce the incidence of developmental disabilities. Clearly, researchers in this area should aspire to influence policy and service provision. Similarly, policy and systems of service provision should reflect current research and should be open and flexible enough to allow for changes that would serve to buffer individuals against long-term developmental difficulty.

With regard to levels of influence, professionals whose aim is to prevent long-term developmental difficulty should recognize that individual, family, community, state, and national factors may mediate long-term developmental functioning and should therefore be evaluated and addressed in the design and implementation of research studies, public policy and service delivery systems.

Recognizing the interconnectedness of research, policy, and service delivery systems that share the common aim of preventing long-term developmental disability should stimulate professionals into collaborative work with each other. Similarly, the realization of this interconnectedness should serve to encourage individual researchers, policy makers and/or service providers to enter into unfamiliar territory- thus becoming researchers and policy makers, policy makers and service providers, etc...

Case in Point: Research on Intrauterine Growth Retardation

Conducting research that is multidimensional, cuts across different domains of study, and attempts to influence both policy and service provision is a difficult, arduous task- nevertheless, this appears to be what research in the area of prevention of developmental disabilities requires today.

The research presented here reflects an attempt by investigators to conduct research that cuts across individual developmental dimensions, involves subjects from an array of ethnic and socioeconomic backgrounds, involves researchers, practitioners and policy makers in research design and implementation, and reflects an attempt by investigators to create bridges of communication and collaboration between researchers, practitioners, policy makers and service providers.

Study Design

Forty years ago, a team of public health workers, pediatricians and psychologists began following a cohort of about 660 individuals born on the Hawaiian Island of Kauai in 1955. This study population consisted of Hawaiian, Filipino, Japanese, Portuguese, Puerto-Rican, Chinese, Korean, Part-Hawaiian and Caucasian children from a range of socio-economic backgrounds. Beginning in about the fourth week of gestation (through intensive community efforts aimed at identifying all pregnant women early in pregnancy) the reproductive histories, physical characteristics and emotional status' of the mothers began to be collected. Follow-up efforts with these children included extensive data collection regarding perinatal stress, extensive data collection regarding physical, intellectual and socio-emotional development in infancy, childhood, adolescence and adulthood (involving standardized and non-standardized measures), and extensive data collection regarding quality life and of family environment from infancy through age-40. The results from this study- known as the Kauai Longitudinal Study, have been reported in numerous publications including four books most recently of which is "Overcoming the Odds: High Risk Children from Birth to Adulthood" (Werner & Smith, 1992). The 40-year follow-up study with this cohort was completed at the end of 1996.

In light of the growing body of research from around the world indicating that infants suffering from significant Intrauterine Growth Retardation are at increased risk for experiencing long-term developmental difficulty, in 1996 (while the 40-year follow-up with the Kauai cohort was being completed) efforts were undertaken to reevaluate data collected as part of the Kauai Longitudinal Study to ascertain if the patterns observed by researchers in the U.S. and abroad were evident in the Kauai sample. The ultimate goal of this research was to determine if intrauterine-growth-retardation was a significant indicator of long-term developmental difficulty in this sample and as such, could suggest the need to target similar groups of infants for early intervention/preventative services.

Background: What is Intrauterine Growth Retardation

Generally speaking, significant intrauterine-growth-retardation is considered to be indicated when an infant is born 'Small-for-Gestational Age' (SGA). The most commonly used definition of SGA (and the definition endorsed by the World Health Organization) is birth weight which falls below the tenth percentile on published birth norms. SGA birth status is generally thought to be a marker of intrauterine-growth-retardation and a likely indicator that an infant experienced a deficient or otherwise deleterious uterine environment during gestation. In the United States the rate of SGA appears to vary greatly as a function of socioeconomic status and may include from 10% to 30% of all live births in some poor communities (Parker, Schoendorf & Kiely, 1994). It is important to note that infants born SGA often weigh more than 2500 grams, meaning these infants are not categorized as 'Low Birth-Weight' and thus do not qualify for early intervention/prevention services in most communities around the United States.

The Developmental Consequences of Intrauterine-Growth-Retardation: An Introduction

Investigators in the US and abroad have found that individuals born preterm-SGA (< 37 weeks gestation) and term-SGA (3 37 weeks gestation) are more likely to experience developmental difficulty as neonates, infants and children than their preterm and term peers with birth weights above the 10th percentile on published birth norms. Preterm-SGA and term-SGA neonates have been shown to experience more physical problems (Tyson, Kennedy, Broyles, & Rosenfeld, 1995; Pena, Teberg, & Finello, 1988) and have been found to score significantly lower on than their preterm and term peers with normal birthweights on standardized measures of development (the Apgar) at one-minute and 5-minutes after birth (Hack, Breslau, & Fanaroff, 1989; Ott, 1995). Term-SGA neonates have also been found to exhibit more abnormal reflex behavior (Als, Tronick, Adamson, & Brazelton, 1976) and more feeding difficulty (Mullen, Garcia-Coll, Vohr, Muriel, & Oh, 1988) than their normally grown peers of similar gestational age.

Infants, toddlers and young children (age 1-month to 5-years) born preterm-SGA and term-SGA have been shown to present more symptoms indicative minor brain dysfunction including convulsions, seizures and/or other signs associated with cerebral palsy (McCarton, Wallace, Divon, & Vaughan, 1996; Pena et al., 1988; Rubin, Rosenblatt, & Balow, 1973) and have been shown to score lower than their peers with normal birth weights on standardized measures of development and intelligence (Goldenberg et al., 1996; Hill et al., 1984; McCarton et al., 1996; Vohr, Oh, Rosenfeild, Cowett, & Berstein, 1979; Zeskind & Ramey, 1978). Researchers have also shown that infants, toddlers and young children born preterm-SGA are more likely to be growth retarded than their preterm peers with normal birthweights (Hack & Fanaroff, 1984; Pena et al., 1988).

Longitudinal studies conducted both in the US and abroad have found the developmental consequences of preterm-SGA and term-SGA birth to extend throughout childhood and adolescence. Studies with preterm-SGA and term-SGA children (age 6-years to 8-years) have found that those born SGA tend to be smaller than their peers of normal bu thweights with regard to height, weight and head circumference (Hadders-Algra & Touwen, 1990; Robertson, Etches, & Kyle, 1990) and are more likely to exhibit symptoms indicative of neurological dysfunction (including severe psychomotor retardation, severe visual impairment, and symptoms associated with cerebral palsy) (Hadders-Algra, Huisjes, & Touwen, 1988; Hadders-Algra et al., 1990). Research also suggests that children born preterm-SGA and term-SGA are likely to score lower than their normally grown peers on standardized measures of intelligence and are likely to exhibit more learning deficits and/or other difficulties in school between 9 and 11 years of age (e.g. school failure, participation in special education, being held back one or more grades) (Hill et al., 1984; Neligan et al., 1976). Also of special interest with regard term-SGA children is evidence which suggests that those born SGA are more likely than their full-term peers with normal birthweights exhibit behavioral problems. This trend has been confirmed in several different samples (Hadders-Algra et al., 1988; Neligan et al., 1976).

Whereas there is an abundance of studies that have followed SGA samples into childhood, relatively few studies have looked at the impact of SGA birth using adolescent samples. To date, five studies have reported findings with SGA samples followed into adolescence (Hill et al., 1984 (United States); Jelliffe, 1997 (United States); Pryor, Silva, & Brooke, 1995 (New Zealand); Rantakallio, 1985 (Finland); Westwood, Kramer, Munz, Lovett, & Watters, 1983 (Canada)) and two studies have reported findings with samples of SGA individuals identified retrospectively (Heinrichsen, Skinhoj, & Andersen, 1986 (Denmark); Paz et al., 1993; 1995 (Israel)).

In general, studies with adolescents born SGA suggest that the impact of SGA birth continues into the teenage years. This tendency appears to be especially evident with regard to physical growth and intellectual functioning. Studies conducted in Europe, Canada and New Zealand have all shown that adolescents born term-SGA tend to be lighter, shorter and have smaller heads than their peers born with normal weights for their gestational ages. This tendency has been found to remain significant even when the contributions of parental height, timing of puberty, sex, race, maternal disease during pregnancy and/or ethnicity have been controlled for (Heinrichsen et al., 1986; Paz et al., 1993; Pryor et al., 1995; Westwood et al., 1983). With respect to intellectual functioning, all of the studies noted, both longitudinal and retrospective, have found that preterm-SGA and/or term-SGA adolescents score lower than their preterm and term peers with normal birthweights on standardized measures of intellectual functioning during adolescence. Evidence also suggests that adolescents born preterm-SGA and termSGA are more likely than their peers with normal birthweights to experience difficulty in school (Paz et al., 1995; Rantakallio, 1985) and/or be rated by their parents as inattentive (Pryor et al., 1995) (see subsequent discussion for results from Jelliffe, (1997a)). While the vast majority of studies with infants, children and adolescents born SGA have been longitudinal in nature, until Jelliffe (1997a), no published study had reported findings with an SGA population followed beyond age 19. Studies with adults who were born SGA have tended to be retrospective and have focused on the impact of intrauterine-growth-retardation on physical adaptation in later life. Most prominently, continuing research by Barker and his colleagues in the United Kingdom which has found those experiencing intrauterine growth retardation to be at increased risk for heart disease and diabetes in later life (Barker, 1996; Osmond, Barker, Winter, Fall, & Simmonds, 1993; Phillips, Barker, Hales, Hirst, & Osmond, 1994).

Procedure: In Short

The study by Jelliffe (1997a) compared the development of 48 term-SGA infants (born weighing less than the 10% cut-off on Lubchenco charts (1963) for birth weight by gestational age, and gestational age 337 weeks gestation) with that of 459 full-term, normal weight for gestational age infants (birth weight for gestational age between 25% and 90% on Lubchenco (1963) charts and 337 weeks gestation; generally this group is referred to as 'appropriately-grown-for-gestational-age (AGA)). Subjects were divided into a "poor" group and a "non-poor" group based on the economic status of his/her parents at the time of birth. Subjects were compared at the ages of 1, 2, 10, 18, 32 and 40 on several cognitive, psycho-social and physical measures of development. See Werner, Bierman & French (1971) for a complete description of methodology and findings from the prenatal period to age ten for the entire 1955 cohort. Werner and Smith (1977; 1989; 1992) report developmental findings for the cohort through age 32.

Results

The data from this review suggested that infants bom term-SGA/poor were significantly more likely than those born term-AGA/poor to be given a below average or retarded mental rating (33.3% compared to 8.2%, p <.001) and/or a below average or retarded physical rating (46.7% compared to 12.8%, p< .001) by a pediatrician at twoyears. It should also be noted that term-SGA/poor infants were more likely than all other groups (term-AGA/poor, term-SGA/not-poor, term-AGA/not-poor) to be rated by their mothers as nervous, jumpy, placid, fretful and/or not cuddly at age one, and were more likely than all other groups to be given a below average or retarded rating of intellectual status (by a psychologist), a below average or retarded rating of mental status (by a pediatrician), and/or a below average or retarded rating of physical status (by a pediatrician) at age 2. Table 1 is an overview of sample characteristics and findings to age 2. Figure 2 is an illustration of these categorical indicators of developmental difficulty at age 1-year and 2-years of age.

Table I

Overview of sample characteristics and findings Term-SGA infants and toddlers compared to their term-AGA peers born into similar economic circumstances

	Term-SGA Poor n= 18	*Tam AGA Poor n- 211*	*Tam-SGA Not-poor* n- 30	*Tam AGA Not-ow* n= *248*
Sample Characteristics				
Japanese	5.6	22.3	33.3	44.0
Filipino	38.9	24.2	40.0***	10.9
Caucasian	-	.5	6.7	5.2
Chinese	-	-	-	1.2
Puerto Rican	-	1.9	-	1.2
Portuguese	5.6	5.7	3.3	8.1
Korean	-	-	-	.4
Part Hawaiian	33.3	30.3	6.7	17.3
Other/ unknown ethnicity	16.7	15.1	10.0	11.7
Male	33.3	49.8	30.0*	51.6
Female	66.7	50.2	70.0	48.4
Categorical variables: Age 1				
Baby rated by mother as:				
Nervous/ jumpy	7.1	5.6	-	2.6
Placid	21.4	10.2	13.8	10.9
Hard to manage	7.1	4.4	6.7	3.8
Not cuddley	40.0	20.1	13.8	20.4
Distressing habits	28.6	34.2	24.1	24.6
Categorical variables: Age 2				
Psychologist's rating:				
Below average/retarded intelligence	33.3	31.4	25.0	17.3
Below average retarded psychological status	25.0	17.3	32.2*	15.0
Pediatrician's rating:				
Below average/retarded mental status	33.3***	8.2	10.7*	1.8
Below average/ retarded				

physical status	46.7***	12.8	14.3	6.1
Continuious variables: Age 2	n = 12	n = 186	n - 25	*n = 219*
CattellIQ	93.92	95.25	98.44	101.93
Vineland SQ	112.33	115.14	113.30*	117.38

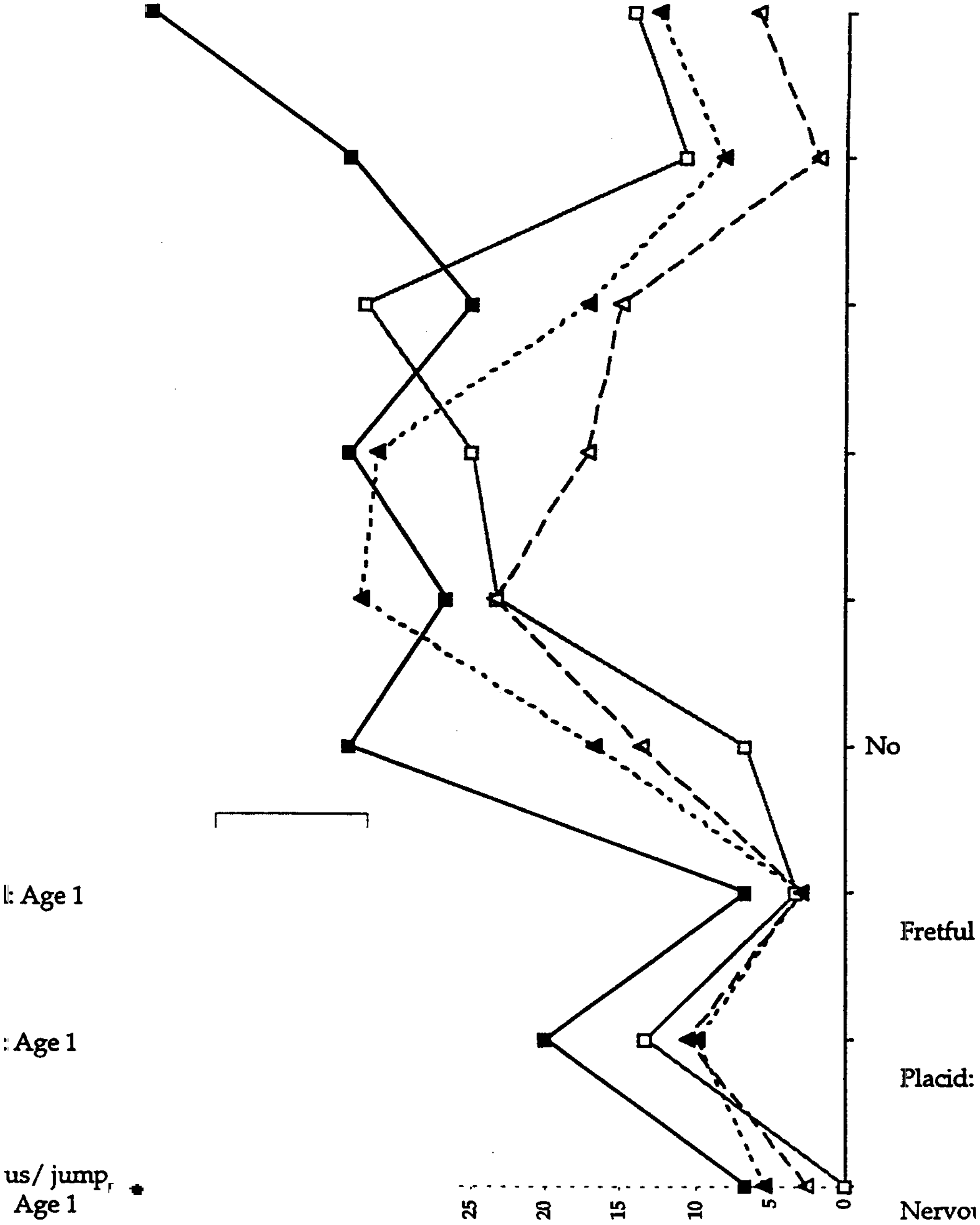
' p<05, term-SGA vs. tern-AGA of same economic background.

'** p<.001, term-SGA vs. trem-AGA of same economic background.

Figure 2

<u>Indicators of Developmental Difficulty at 1-year and 2-years</u>

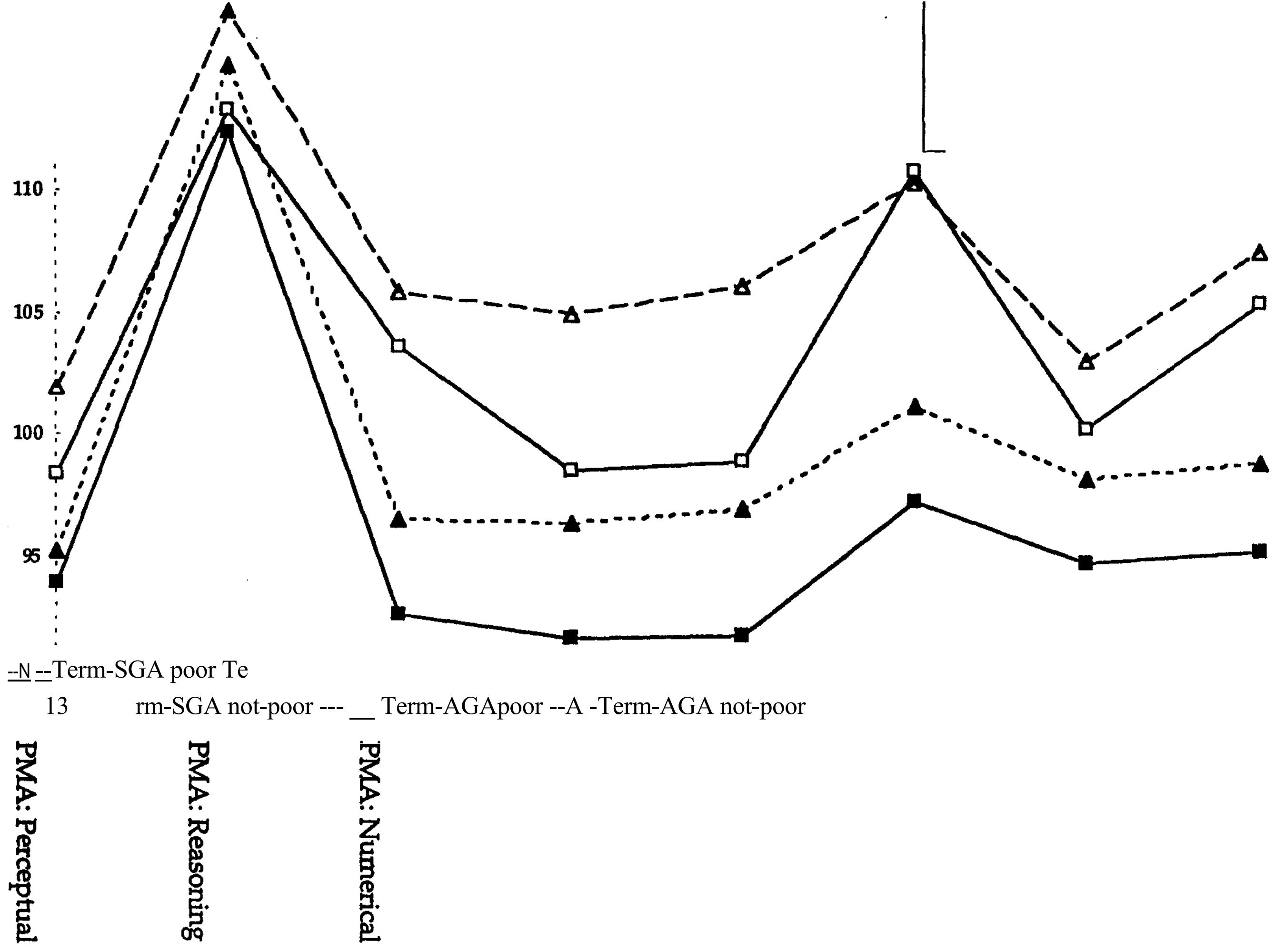
Term-SGA as compared to term-AGA at birth: categorical variable


l: Age 1
: Age 1
us/ jump,
Age 1
25
20
15
10
5
0
Nervoı
Placid:
Fretful
No

Standardized scores on measures of intellectual functioning reviewed for this study suggest that term-SGA/poor infants are more likely to experience cognitive difficulties at age 2 which may hinder their long-term intellectual functioning. Term-SGA/poor infants were found to have the lowest score of all groups on the Cattell Infant Intelligence Scale at age 2 (Cattell, 1940), on the Vineland Social Maturity Scale at age 2 (Doll, 1953), and the lowest score of all groups on the full-scale and sub-scales of the Primary Mental Abilities Test (PMA) at age 10 (Thurstone & Thurstone, 1954). Although the differences between those born term-SGA/poor and term-AGA/poor were not significant at age 2, by age 10 a significant main effect for those born term-SGA compared to those born term-AGA was observed for spatial and perceptual scales of the PMA (F= 4.997, p<.05 (spatial); F= 5.457, p<.05 (perceptual)). Figure 3 is an illustration of these relationships which suggest that with time, the cognitive differences between those born term-SGA/poor and term-AGA/poor widens. This trend towards the widening of the gap in developmental functioning between term-SGA and term-AGA infants and young children (age 1-month to 5-years) has been noted by several other investigators (e.g. Bhargava et al., 1982; Low et al., 1978; Ounsted, Moar, & Scott, 1988; Silva, McGee, & Williams, 1984; Watt & Strongman, 1985) and elucidates the need to intervene with term-SGA/poor infants before cognitive deficits are acquired and/or accumulated.

Figure 3

Scores on Cognitive Measures at age 2 and 10 Term-SGA as compared to term-AGA at birth



Conclusions

Results from this comparison suggest that being born term-SGA may place a child at increased risk for developmental difficulty in infancy, childhood, adolescence and adulthood. This conclusion is particularly true for those born term-SGA and born into poverty. Trends evidenced in this comparison elucidate the need for more study of the effects of term-SGA birth using larger samples; however, in concert with other studies, this research elucidates the need to target infants born term-SGA-especially those born into poverty, for early intervention services that may serve to ameliorate some of the effects of intrauterine-growth-retardation (as indicated by preterm-SGA or term-SGA birth status).

Avenues for Intervention Across Domains and Levels

Much of the research on the effect of intervention with SGA infants has focused on the prevention of secondary medical conditions often associated with SGA birth status and on intervention strategies aimed at improving the nutritional status of the SGA infant. Examples of intervention strategies that appear to be help reduce the occurrence of secondary medical conditions in SGA infants include Glucagon and/or corticosteroid administration to treat the often found condition of hypoglycemia (Carter, Lloyd, & Duffty, 1988) and growth hormone therapy aimed at maximizing catch-up growth (Chaussain, Colle, & Landier, 1994; de Zegher et al., 1996). Researchers and physicians have also found that nutritional status and associated patterns of growth may be improved if SGA infants are given zinc supplements (Castillo-Duran, Rodriguez, Guillermo, Alvarez, & Icaza, 1995) and/or iron supplements (Olivares et al., 1992).

Evidence also exists which suggests that SGA infants and young children may benefit from non-medically based intervention strategies and/or participation in daycare. For example, in response to findings which suggested that SGA infants are less responsive to stimulation, less likely to initiate interaction from caregivers, and less likely to receive positive stimulation from caregivers (Watt & Strongman, 1985), Watt (1990) initiated an intervention program aimed at improving interaction patterns between mothers and SGA infants. In this study Watt found that simple intervention techniques aimed at encouraging tactile stimulation of the SGA infant by his/her mother had a significant impact on the cognitive functioning of SGA infants at 6-months.

Research on the benefits of daycare for the SGA infant and toddler includes an often cited study by Zeskind and Ramey (1978) in which researchers divided two groups of term-SGA infants and their mothers (from low SES groups) into an intervention plus daycare group and into an intervention only group. In the intervention only group, mothers and term-SGA infants received social, nutritional and medical assistance but did not receive daycare services. In the intervention plus daycare group, term-SGA infants and mothers received similar social, nutritional and medical assistance but the infant also participated in a daycare program for 8 hours per day, 5 days per week (from age 3 -months to at least 2-years). These researchers found that SGA infants who attended daycare showed significantly fewer cognitive deficits at 18-months and 24-months than SGA infants who did not attend daycare.

The benefit of daycare services for the SGA infant is also evidenced in a more recent work by Dowling and Bendell-Estroff (1991) who, in a sample of mostly poor children attending daycare, found no significant differences on cognitive or behavioral measures of development for preterm-SGA children as compared to their pretenm-AGA peers.

Building The Bridges

It is at this point that many researchers in this field stop. The literature has been reviewed, the results presented and published, intervention studies have been cited and recommendations for intervention have been given- thus begging the question, "Then what?"

The results of this study were first presented at the American Psychological Society Conference in May. These individuals are in many ways, my colleagues who speak my language and were trained at similar institutions. The report to this group included a review of the data in this area-which actually came mostly from medical research which perhaps helped build some bridges between disciplines; however, researchers cannot stop with giving presentations to their peers and colleagues, even if the work presented crosses a few domains. Truly working to build bridges of communication and collaboration between researchers, policy makers, support workers, families and individuals with developmental disabilities requires, to a certain extent, that researchers take responsibility for the dissemination of the results from their studies-especially in areas that can have a significant impact on policy and service provision. Achieving this goal also requires that researchers get involved in policy making and service delivery systems.

In attempt to bridge these barriers and create new avenues for collaboration, the results from this study and a review of the other studies in this area have been presented not only at academic conferences but were also presented at the National Head Start Conference in May. My presence here today, and in fact my presence at the President's Committee on Mental Retardation for the past three months, reflects my belief that researchers must get involved in all arenas where their research may be applied and where the direction of future work may be influenced.

NOTE: A FULL SET OF APPENDICES AND CHARTS/FIGURES ARE AVAILABLE FOR THIS PAPER UPON REQUEST. PLEASE CALL 202-619-0634 FOR MORE INFORMATION.

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TOPIC VIII: DIVERSITY

Papers/Presenters:

DIVERSITY, REDEFINING, REFOCUSING, AND RESTRUCTURING OUR EFFORTS

Marisha Tapera
Cabin John Middle School
Rockville, Maryland

IMPROVING THE QUALITY OF LIFE FOR PEOPLE WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES: THE CHURCH AND COMMUNITY RESPOND

Angela Mccants
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INCLUSION IN CHURCH COMMUNITIES

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DIVERSITY:

REDEFINING, REFOCUSING, AND RESTRUCTURING OUR EFFORTS

By Marisha Tapera
Cabin John Middle School
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Any discussion of cultural diversity would benefit from establishing clear definitions of the word "cultural" and "diversity". From an etymological standpoint, the word "cultural" represents a set of beliefs, customs, arts and institutions that are shared by a group of people. "Diversity" emphasizes the ways in which entities separate, or are distinct from one another. Although such a definition is almost entirely positive from a biological standpoint (e.g., the need for biological diversity in the food chain, or on a genetic level in reproduction in higher level organisms), it has long been a source of fear for human beings. As a society, the fear of differences has been one of our greatest weakness, Ignorance has been another.

As the President dedicates himself to examining and ameliorating of level of communication between Americans of diverse cultural backgrounds, it is imperative that he take note of the exacerbation of issues of discrimination for persons with disabilities who are also of diverse backgrounds. Since the enactment of Public Law 94-142, encouraging societal inclusion of. persons with disabilities has presented, and continues to present, a rather persistent challenge. For those people who are also of diverse backgrounds, the challenge has been exponentially greater. Laws such as 94-142 have, in many cases, provided an excuse for the removal of culturally diverse persons from the mainstream of society. In spite of the numerous safeguards for civil and human rights in existence In the US., a lack of cooridnation between them has meant large gaps in available supports for diverse persons with disabilities.

The President has often spoken about the idea that the health and well-being of American society rests on our appreciation and embrace of the gifts of all our people. Sociologists have argued that American's dominance in the world order is owed in significant part to the unique range of diversity in our citizenry. If our leadership truly holds that particular vision of the future, persons with disabilities must be counted-all persons in the full spectrum of their cultural needs, languages and unique life perspectives. Those persons include:

- Persons of diverse racial/ethnic backgrounds
- Persons of diverse cultural/linguistic backgrounds
- Persons of diverse religious/spiritual orientations
- Persons of diverse socioeconomic strata
- Persons with diverse sexual orientations

Each of these groups includes people with disabilities, but does not necessarily include them in the scope of their individual fights for social justice. Persons with disabilities often find themselves disenfranchised from their cultural groups and defined solely as persons with disabilities. Instead of gaining the dual support of the cultural and disabilities movements, they may be "shut out" on the cultural side by internal discrimination, and also left without protection against the culturally-based social unbalance President Clinton is working to combat. As an example, a number of families are experiencing discrimination and exclusion from resources they may need most. They have been denied the community and spiritual support of their churches because they have family members with disabilities (See the paper "Inclusion in Church Communities" by Mel Dugosh.)

Current issues in the area of recognizing and addressing the impact of diverse backgrounds on the provision of services and quality of life for people with disabilities include the need for:

- Inclusion of persons of color in the disability movement
- Identification, education, and support of disabled offenders
- An increase in the number of service providers, agencies, and direct care staff with diverse cultural and racial backgrounds
- Better coordination between MR/DD programs and public policy efforts in other disability areas
- Outreach to less populated or rural areas
- Greater availability of resources and education in the area of MRJDD
- Culturally appropriate job training and on job support for employers/employees
- Attention to issues affected by socio-economic strata, such as inaccessibility of government-funded services for mid-income persons with severe/profound disabilities
- Culturally-appropriate advocacy and support for family systems in all service arenas
- Appropriate, practical, and empowering choices in educational opportunities
- Ethnically-diverse representation in policymaking and legislative bodies, including self-advocates, families, service-providers, and professionals
- Respect for both the right of persons with disabilities to speak their native languages, and for the complex and dynamic process involved in the acquisition of English as a second language

Recommendations

1. Clearer, national guidelines and standards should be established for the definition and identification of various disabling conditions.
2. State Developmental Disabilities (DD) council should serve as clearinghouses of information and training for legislators, families, service providers, and self-advocates throughout the State.
3. Advocates/liaisons should be placed in correction facilities to support individuals of all ages with DD though the court and corrections process.

4. State Attorney offices should provide information that will improve political awareness and activity by people affected by Mental Retardation (MR/Developmental Disability issues, such as how to access free or low-cost legal assistance, public information meetings, etc.
State-funded or supervised training should be provided for:
   - self-advocates of diverse cultural backgrounds
   - improved community education about DD (e.g., the differences between DD and mental health issues)
   - cultural and disability sensitivity for grassroots organizations and groups
   - legislators, educators and health care providers
   - jobs that provide opportunities for each individual with disabilities to utilize his/her inherent skills, talents and creativity.

This training could be provided, with improved governmental funding and support, by the State Education agencies and their advocacy divisions.

- Federally-and State-funded grants and scholarships should be offered through Universities and other educational agencies to increase the numbers of qualified MR/DD professionals with diverse backgrounds.
- Annually mandated training in the area of MRJDD for State and Federal legislators and/or their staff. This training should include annual town meetings with persons with DD, families, and community-based programs.
- Emphasis on "people first" language, across areas if diversity.
- Federal guidelines and supports that would encourage the use of natural supports in the lives of persons with developmental disabilities.
- Improved budgeting, coordination and configuration of currently available resource

There is a perception that oversight agencies created by the Federal government have become increasingly less effective and more entrenched in bureaucracy. Clearly, broad-based, decisive action needs to be taken on behalf of those people less able to protect their own rights. We, as a society, know what needs to be done-do we have the courage to do it?

IMPROVING THE QUALITY OF LIFE FOR PEOPLE WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES:

THE CHURCH AND COMMUNITY RESPOND

By Angela McCants
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In order to improve the quality of life for people with mental retardation and developmental disabilities, the church and community must have a vision to empower all families regardless of race, socioeconomics or demographics. This vision must assist families in recognizing their strengths as well as their weaknesses.

Families often need support when dealing with both formal and informal support systems outside their immediate family. Surveys reveal that families prefer to receive services and support in the familiar surroundings of their homes and communities. In order to empower families, we must view them as competent and capable of helping themselves rather than viewing them from a deficit model that focuses on inadequacies.

Six years ago my husband and I were fortunate to be able to take over the care of my 15-year old nephew. I remember when he was born on March 4, 1977. We counted 10 little fingers and 10 little toes and thought he was perfect! Emotions were running high that day as he represented the start of a new generation. No one knew at the time of his birth the difficulties and challenges that lay ahead of him regarding disabilities.

During the next few years we celebrated Daytric's first steps, his first birthday, and his first words. The first day of kindergarten was a day for celebration. We realized this as the beginning of the formal education that would help him succeeds as an adult. The skills did not come easily for Daytric. By mid year we knew something was wrong. The teacher's reports were not encouraging and a formal evaluation placed the label "mild mental retardation" on this "perfect" child. The next ten years for Daytric were years of transferring from one grade to another, Individualized Educational Plans that were unaccomplished, and years being ignored because he was not a behavior problem. This brings up a classic point, if a child is not a behavior problem in the classroom, he/she is often passed over when assistance is needed.

We began our search for community organizations to help us create successful school situations as well as community resources that supported diversity. We also wanted emotional and informational support from families who were living with some of the issues that confronted our family. To our dismay, resources were few in the African American community in Raleigh, North Carolina. We knew that if we felt the need for this support, there were others who needed it as well.

The Church and Community Respond

Families are often frustrated and confused by the number of professionals, agencies, and service providers they deal with on any given day. Appendix I pictures a family in their support environment as they try to move toward stability and self-sufficiency. In this eco-map many services are offered to this family. However, when we view these services from a family's perspective, we see just how difficult a task it can be to cope with the process of receiving services (Project Uplift, 1997). The hardships that families face are ever changing and life long. In order for the church and community to impact the quality of life for people with mental retardation and developmental disabilities, the church and community must be able to recognize the issues affecting the community and respond to the needs of families.

In the African American community, the church has been the primary cornerstone that builds families. The leadership of the minister(s) should embrace families through independent and interdependent means by enhancing and supporting family strengths. Communities are strengthened around providing resources within reach for all families in need.

Many churches understand that improving the quality of life for people extends not only to members but also to the entire community. Failure to undertake such a task would place communities at-risk for extinction because of the value the African American community places on the church.

The Black Church Family Project examined churches in the northern United States regarding the existence of a youth program. They found that 176 churches out of 635 actually targeted non member adolescents. Many of these youth were from low income homes.

Another example of a church and community response to identify family needs is the Help Empower Local People (HELP) program. This organization is made up of 20 black and white churches that are working together in Mecklenburg County (Charlotte, North Carolina) to address issues of youth and education, housing, crime and safety, jobs and wages. These issues have a tremendous affect on families and congregations.

In Raleigh, North Carolina, Rochester Heights Church of Christ and the Learning Disabilities/Attention Deficit Support Group have developed a working model for empowering families. The church uses member resources in implementing a workable and cost effective program to address the prevention of mental retardation, related disabilities, substance abuse, and other issues of concern affecting the community. The LD/ADD Support Group draws upon the resources from the church. There is a substance abuse program director, substance abuse counselor, social worker, family advocate, women's health advocate, health care technician, fitness instructor/professor, general manager of a TV/radio station, English professor, and two computer specialists-all members of the Rochester Heights Church of Christ body-responding to the needs of families.

Several community agencies also collaborate with the LD/ADD Support Group. The Southeast Raleigh Health and Community Development Center addresses the need to improve access to health care for children and families at the community level. The lack of accessible and affordable health care for families is a life-long obstacle that places them at risk for many significant difficulties. These problems include deficit immunization status, and progression of chronic diseases, as well as inappropriate utilization of emergency room for non-emergency health cares. The Southeast Raleigh Health and Development Center and the LD/ADD Support Group work together to provide comprehensive clinical care to families with children diagnosed with Attention Deficit Disorder, Attention Deficit Hyperactivity Disorder, Impulsivity, and other disabilities.

Church and Community Model

In January 1995, the first meeting of the Southeast Raleigh Learning Disability/Attention Deficit Support Group was held at Rochester Heights Church of Christ. The Church sponsors this support group as an outreach ministry program. The goal of this ministry is to build stronger and healthier families with children with disabilities by providing emotional, information, and financial support. This allows families to gain control and keep control over their situations when dealing with the community, schools, or service agencies. The LD/ADD support group uses a positive approach to encourage parents to become involved in their child's education. Parents have the opportunity to develop advocacy skills and acquire knowledge regarding employment and post-secondary educational resources available to their families.

Rochester Heights Church of Christ support includes financial resources and in-kind services. An annual budget of $800.00 provides scholarships to parents to attend local learning disabilities conferences, educational material for parents and children, speakers, mailing distribution, and food. Services include van transportation, office space, administrative support, and a telephone number to inquire about the Support Group.

The stated mission of this support group is to assure that children and young adults with special needs will not have to endure a life filled with society-imposed limitations and rejections. We have listened and have provided an avenue for families to voice their concerns related to disciplinary measures by the school system. This includes excessive "suspensions" for misunderstood behaviors, and over-representation of African American males in Behaviorally Emotional Handicapped (BEH) classes. We are continuing to address the lack of appropriate resources for the development of vocational, problem solving, and communication skills for individuals with special needs in the Raleigh community. The Rochester Heights Church of Christ model includes several components; monthly meetings, a youth program, a rites of passage program, and a transition to workforce program.

Monthly Meetings

The adult program has scheduled monthly meetings year-round to discuss topics such as Helping Your Child Be Successful, Developing a Strong Individualized Educational Plan (IEP) and Individualized Transitional Plan (ITP), Understanding I.D.E.A. and 504 plans, planning for college, and acquiring financial aid for vocational schools and colleges. We are adhering to a well-recognized fact that parent involvement is most effective when it is comprehensive, long lasting, and well planned.

The LD/ADD Support Group also drew upon the resources of the Center for Development and learning at the University of North Carolina at Chapel Hill. The developmental evaluation center employs personnel from special education, audiology, nursing, pediatrics, neuropsychology, psychology, social work, occupational therapy, physical therapy, and speech/language. Many of them have helped with the development of monthly programs, as well as being available for consultation and development of appropriate interventions and support for families.

Youth Programs

A vital component of the Support Group is the Youth Program. This program was initially designed to enable parents to attend the meetings without the worry of finding a baby-sitter. During the first year of the support group we provided basic childcare needs. We soon realized that the hour the children were in childcare was a perfect opportunity to help them understand about their strengths and weaknesses associated with their disabilities. Although our children range from ages 5-10 years old, all children are welcome despite their disability or level of care needed.

In December of 1996 the TAPS (Teen Advisors Providing Services) program was initiated to provide peer support. This program is taught by teens from the congregation and the community who have an interest in helping others, and teens who have experienced their own difficulties with the school system related to suspensions, and learning differences. For them the program helps develop leadership skills by mentoring younger children. Issues addressed in this program include coping with learning differences, understanding Attention Deficit Disorder and Attention Deficit Hyperactivity Disorder, asking for help, self-advocacy, problem solving, communication, self-respect, and respect for others.

The LD/ADD youth transition from TAPS into Rites of Passage. The Rites of Passage program is a proactive process, designed to positively transition young boys and girls into adulthood. This program is taught by members from the congregation and enhanced by community resources. Modules include Family History, History of our People, Spirituality/Community Spirit, Sex Education, Assertiveness/Leadership, Time Management, Taking Care of Self/Etiquette, and Housekeeping/Finances.

Workforce

The current system devalues many young adults with mental retardation and developmental disabilities. Therefore, we challenge our youth to meet their fullest potential. In one example of the Support Group's success in creating one situation that eliminated a barrier for developmentally different individuals, I will once again use Daytric's experience. Saint Augustine's College is a private co-educational liberal arts college in Raleigh, North Carolina that has historically served African American students. Daytric is known to be mechanically talented and to have an interest in video production. A collaborative effort between Athens Drive High School, Saint Augustine's television station WAUG TV 68, and Rochester Heights Church of Christ was begun to give Daytric the opportunity to be employed in the community.

As an intern at WAUG TV 68, Daytric acquired knowledge of television and radio master controls, and audio and video equipment including camera, lights, microphones, and editing equipment. He successfully mastered the skills required to be hired as a Production Assistant in television operations. Due to the success of this initial effort, WAUG, TV 68 has agreed to continue to be a community-based training site for young adults with special needs. Daytric has also been responsible for taping community and congregational programs for Rochester Heights Church of Christ Tape Ministry. It is now evident that the church's investment was a worthy one.

There is evidence that persons with mental retardation and related disabilities are employable but many are unemployed or working low-wage jobs. Although African Americans comprise only 12% of the population, the prevalence of disabilities for them is (15%). The prevalence for whites with disabilities is (8%). After graduation a person with disabilities has approximately a (50%) chance of being hired. According to the 1990 Census Survey, 60% of all working age Americans with disabilities are not participating in the workforce either full or part-time. Almost 40% of employed people with disabilities earn 35% less than those without disabilities.

Daytric's success as a production assistant demonstrates what an "opportunity" can yield. While some special considerations were made, the station manager noted that it did not significantly impact the day-to-day operations of the station. Other institutions and community businesses must be willing to open their doors to people with disabilities because they are valuable productive members of the workforce and the community.

The Absence of Church and Community Model

The lack of these opportunities have created life-long obstacles that further hinder the progress of children with special needs. One example is the increasing number of youth who are in detention centers or incarcerated. Once incarcerated, inmates with mental retardation seem noncompliant, but often do not understood the order or request given by staff Offenders often want to be accepted , and in their attempt to do so they unknowingly involve themselves in criminal behavior.

Many offenders with mental retardation can not earn gain time because of the difficulty of having to navigate through the prison system. Because of this difficulty they often acquire a number of rule infractions. These infractions make early parole unlikely.

There are 93 prison facilities and 5 youth detention centers in North Carolina. The state of North Carolina has 100 counties; this represents almost one prison facility per county. In most studies, offenders with mental retardation are members of minority groups. In many cases the offender will not be identified as having mental retardation until he is convicted and sentenced to prison. Although the Division of Prisons offers special education services, almost 75% of all inmates refuse services because of their poor relationship with the school system (Young, 1997).

Educating the community about the realities of individuals with developmental differences, rather than endorse many of the common misperceptions, is an ongoing challenge. As an example, there is the misinformation that students with moderate and severe learning differences cannot learn and will eventually drop out of school prior to graduation. According to the National Longitudinal Transition Study, 1993,.most students with disabilities remain in school until the age of 18. Fewer than one fourth of students with disabilities who drop out of high school do so before the age of 17, indicating those students with disabilities are motivated to remain in school as long as their non-disabled peers.

Conclusion

Almost every family of a child with a disability has at least one horror story. Families must begin to tell a different story that promotes accomplishments and acceptance of those with mental retardation and developmental disabilities. Many front-line workers are often overworked and underpaid. They have devoted time, energy, and resources to the endless tasks of improving the quality of life for families.

I applaud Rochester Heights Church of Christ and other congregations for leading the way in providing services for children and families with special needs. However, there is much more work to be completed, not just in the Southeast Raleigh community, but across the country. We must address all issues affecting the entire community. Taking on such a task takes a long-term commitment to helping families who sometimes do not want to be helped. We must journey towards community empowerment by going beyond ourselves by shaping our community and homes. I encourage all workers in the church, community and public service providers to make a difference in someone's life.

It is evident that it takes an entire community to educate our children. I hope that the Rochester Heights Church of Christ Learning Disability/Attention Deficit Support Group Model will motivate you to continue the fight and initiate a church community program in your area.

Dedication

I would like to dedicate this paper to my husband Robert, who supports me through my many endeavors, which often keep me away from home. To my nephew Daytric, who has entrusted his life to my husband and me. To Rochester Heights Church of Christ for its commitment to building stronger and healthier families. To my colleagues at The University of North Carolina, Chapel Hill for providing a wealth of knowledge and experience to be fully utilized by the Southeast Raleigh Community. To WAUG Channel 68, television station for opening the window of opportunity for Daytric rather than closing it with excuses. Last, but certainly not least, to the families of Southeast Raleigh: You have graced us with your presence, without you there would be no support group.

NOTE: A FULL SET OF APPENDICES ARE AVAILABLE FOR THIS PAPER UPON REQUEST. PLEASE CALL 202-619-0634 FOR MORE INFORMATION.

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INCLUSION IN CHURCH COMMUNITIES

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Introduction
In 1995, I attended a conference sponsored by C.A.M.P., which stands for Children's Association for Maximum Potential, and moderated by the editor of Exceptional Parents Magazine. The conference objective was to improve relationships between parents of children with significant disabilities and medical and education professionals. After ten years of parenting one such child, I admit that I had become very cynical that those relationships could do anything but worsen. The workshop was dry and predictable with the professionals extolling their expertise and the parents participating little. Suddenly a male parent stood and said " Hey, lets talk about what's really bothering me ... we can't even go to church as a family anymore ... our child isn't welcome there. When we find a church that wants all of us... that is where we are going to go."

The meeting went haywire, with the parents all speaking at once ... out loud and amongst themselves, each of them sharing a story of exclusion at the hands of a church. I said nothing; this hardened parent had dissolved in tears, silently grieving the church I had lost. The church that had asked us to stand in the lobby during a song because our son was disruptive. The church that was not able to provide care in the nursery because of his special needs. The church I took my son to for healing, and they "cast the devil out of him." This huge famous church that showcased its deaf ministry and occasionally proudly handed over its pulpit to an evangelist with cerebral palsy, had no room for our tiny lovable son Chris, who was born with blindness and deafness but sees and feels what most of us cannot. Our son Chris, who without his hands somehow manages to touch us with warmth each day.

It had been the ultimate rejection. The rejection that I had not allowed myself to even think about and it suddenly seem that it was not that uncommon. For months after the meeting I wondered about other parents and their church experiences. Eventually with the help of C.A.M.P., their agencies commitment to the many aspects of the physical and psychological needs of both the child with disabilities and their entire family unit, I launched a very unscientific qualitative survey to discover if in fact other families with children like mine were finding a policy of exclusion in their community churches.

First Responses

The research indicates that when a child with significant disabilities is born into a family their first initial contacts for assistance are within their immediate family, the medical community, and their church community. These crucial "first responses" to what the family may perceive as a crisis situation, seem to set the tone for their interactions with government and community resources that will follow. The historical legacy of placing persons with significant physical and mental disabilities in institutions or segregated in their homes may be a contributing factor to the hostile atmosphere that some of the survey responding families found, that initially sought comfort and guidance in their local church community and were met with blame, accusation and rejection.

Pressure for Compliance

In several denominations, instances were reported where new families having a child with physical disabilities and/or mental disabilities with no previous advocacy training or experience with community inclusion heard doctrines of "retribution" and felt pressure to "repent" and "seek a healing" for their child. A parent responded,
"I somehow felt that I must apologize to the congregation because my child with mental disabilities and an ongoing chronic illness did not have a complete recovery, (or even close), as if my faith wasn't strong enough to receive a healing from God for my child."
Results reported from these types of incidence yielded: emotional distress, anger at God, withdrawal from church and community, and reluctance to discuss these happenings.

Denial

It is not uncommon for parents dealing with the difficult circumstances to keep their thought and emotional pain to themselves. Not saying anything or saying very little protects them against vulnerability. A parent remembers, "My sons Down Syndrome was not obvious in his appearance for the first few months after his birth. Our church was so large that many people did not know that my husband and I were dealing with the initial pain and shock of the news ourselves. The problem was that I wanted to continue keeping his Down Syndrome a secret. I wanted everyone to think of me as a happy and fulfilled new Mom and not feel sorry for me. While I continued this 'happy face,' inside I felt as though I was surrounded by a huge dark cloud of despair and it was many months before I was even ready to face the reality, or even admit to anyone that there was a problem."

Parents that are not openly expressive and are not exhibiting sadness in more obvious situations can also be perceived by those in the church community as having already successfully dealt with their circumstances. A parent expressed his thoughts in this way:
"I was alone those first few days after our child with disabilities was born. Friends and relatives came to visit my wife in the hospital, they hugged, talked to her and cried with her. Our pastor and his wife came and spoke to my wife; but he did not speak with me."

Grief Process

People may have difficulty getting through the stages of grief because they are not aware of the nature of those stages. These natural stages may contribute to the church communities inability to assess the situation and provide assistance. "After caring for my child with disabilities alone for many years I know that I need God's strength to continue. I also know that I need the help of our entire congregation. How do I tell them now, that I alone, am not equipped."

Anger

Vague and undefined anger is common . Parents may become easily upset and frustrated and have no focus for their anger. These feeling of isolation and anger can be devastating. One parent described her feelings as, "...intense humiliation, guilt, condemnation, hopelessness, confusion, fear, lack of purpose for living, deep depression and despair, distrust for those in the medical profession, abandonment, and betrayal by God"

Many people were not aware of how their beliefs about God, could relate to the birth of their child with mental and physical disabilities. Struggling with an unshakable image of God from their own past while coping with an overwhelming situation can be especially difficult. Parents dealing with these intense emotional issues need a safe and secure environment within their church community to explore their anger and other emotions, especially the anger directed specifically at God.

Acceptance

When a family reaches the point in the grieving process, in which they are able to accept their circumstances, they begin a tentative move in a positive direction. When the family no longer sees their child's physical or mental limitations as a source of shame or as something they must overcome. When they can accept that it is okay to be a person with disabilities, this is the beginning of advocacy efforts on behalf of their child and other children with disabilities for inclusion in all aspects of community life. A parent explains, "Our family is currently looking around, again for a church. It is so difficult for us to find one where we feel the we belong. Sometimes I go scope them out by myself on Sunday, just to see if the church has others with disabilities and how they treat them. I am no longer willing to allow my child to be hurt by an uneducated church."

Advocacy Efforts

Once a parent of a child with a physical or mental disability becomes empowered to advocate for their child within their church community, humanity cries out for a new vision. Inclusion spreads throughout the community as a whole as shown in this example from a parent, "At one time we wondered how our new baby daughter would suffer from having a brother who, because of his disability, would restrict her life and embarrass her in front of her friends. Those nightmares of the past will never come true! I now speak to other parents, professionals, Chambers of Commerce, school boards, churches, organizations and public officials. I'm no longer ashamed, I have knowledge and confidence and I plan to continue my work in advocacy for my son and other with disabilities."

Accessibility

If barriers of attitude, communication or architecture exist for anyone, the foundation of the House of God is weakened for all. Inclusion in the church community will become a reality when parents of children with disabilities and adults with disabilities determine that they will deserve the opportunities to achieve whatever is possible despite the difficulties. "The church needs to provide the parishioners guidance on how to 'include' children with disabilities with their dignity intact, in the church as well as the community."

American with disabilities have the right to attend the church, synagogue, meetinghouse, mosque, or temple of their choice. However, this may mean negotiating stairs or narrow doorways, print media that is to small to read, inadequate sound systems, and bathrooms that are not accessible. The Americans with Disabilities Act, (ADA) was signed into law on July 26, 1990. This sweeping civil rights law provided a national mandate for the elimination of discrimination against individuals with disabilities in employment, state and local government services, public transportation, public accommodations, and telecommunications. A religious entity however, is defined under the ADA as a "religious corporation, association, educational institution, or society." Using this interpretation, church congregations, camps, church offices, and other church facilities fall within the ADA definition.

Religious organizations or entities, including places of worship are exempt for any Title III public accommodation requirements of the ADA. Even when a religious entity carries out activities that would otherwise make it a public accommodation (for example, a restaurant, a place of lodging, a theater, a library) the religious entity is entitled with the exemption from the ADA coverage.

If a church entity operates a public nursing home, day school, child care facility, and summer camp, those operations again, are not subject to the ADA's public accommodation requirements. This also applies to religious institutions led by lay boards. The test is whether the religious entity controls the public accommodation, not who receives the services. However, a church facility operating as a profit-making, non-charitable institution does not qualify for the religious exemption. A church can provide a daycare and avoid these issues by choosing to lease the space to a non-religious organization that will operate the public accommodation. The tenant then becomes responsible for compliance with the ADA not the church leasing the facility. If a church service organization operates with assistance of federal money, the shelter will be required to be accessible to people with disabilities under section 504 of the Rehabilitation Act of 1973. Section 504 prohibits discrimination against persons with disabilities by entities receiving federal financial assistance.

Conflicts?

The First Amendment provides, "Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof...." The Supreme Court has interpreted these words to mean that government entities-federal, state and local; must avoid activities which advance or inhibit religion. Under the Supreme Court's Lemon test, named for the case in which it was adopted [Lemon v. Kurtzman, 403 U.S. 602 (1971)], the federal government may fund a religiously-affiliated program that 1) has a secular or civic purpose; 2) has a principal or primary effect that neither advances nor inhibits religion; and 3) avoids fostering an excessive government entanglement with religion.

The broad latitude afforded by the Lemon test for federal funding of churches' nonsectarian social programs can allow for federal support for religiously affiliated programs in the areas of housing, child care, nutrition, health, inclusion, drug intervention and assistance for the poor.

Adults with Disabilities

An adult with mental disabilities expresses herself in this way, "Not only do people with physical disabilities get shunned, but people with disabilities do as well. Many 'Mega Churches' define your personal success by the job you hold or the social circles you fit into. Churches make a glaring and condescending spectacle of people who think differently than they. Many times it is assumed that we are stupid and are seldom called upon to fulfill meaningful roles in church life. In Austin, Texas; my former 'mega church', was called upon to bake cookies for a Christmas party at the Austin State Hospital. They flatly refused, this church is approximately two blocks from the hospital and has had no known ministry to a 'community' that were truly its 'neighbors.' The good news is that the church recently issued an apology. They have become interested in the folks over at the hospital and have begun to minister to them and welcome them into the congregation."

Many parents of children with disabilities report that they converted to different denominations or left churches with policies of exclusion to join churches with visible adult congregates with disabilities that had already begun paving the way to inclusion in that church community.

Diversity

A parents with a child with mental disabilities describes his new church in this way, "Our church is represented by extremely diverse personalities and backgrounds. Yet we are united into a close knit group because of God's gifts of helps and hospitalities. God has blessed our congregation with many that need special accommodations and He has given us the tenderness to understand and provide these needs." Looking past impairment to discover the unique gifts and potential of those who live with mental and physical disabilities is a celebration of life. This celebration, rather than the segregation of diversities allows for the threads of interaction to become reinforced into the fabric that holds the church community together. Repeating and patterning these actions can serve as an example to the surrounding communities increased awareness and acceptance of community inclusion.

The Full Circle

In many communities the church is among the few viable indigenous social organizations committed to fostering the development of individuals, families and the community as a whole. There are in fact church leaders with or without disabilities, who are creating new inclusive church communities across America. Some have taken forthright measures and thoughtfully improved their buildings and programs. In so doing, many people have come to recognize the gifts which persons with mental and physical disabilities bring into the church community. A parent describes the programs in her church community, "Our church now has a Ministry for Special Needs with a council of fourteen people. We have a director of programs which coordinates the Sunday School programs. There are two special classes for children and one for adults. As well as mainstreaming for those higher functioning individuals. There is an interpreter for individuals who are deaf at worship and in Sunday School. We have plans for programming during family night activities on Wednesday evenings during the school year, and our future goals include respite services. We also have an outreach for residents of several group homes and institutions in the area. We have coordinated transportation with congregates that live nearby. We recently contracted with a non-profit agency to provide after school care for children with special needs of elementary school age, and are hoping that some of these children will bring their families and become a part of our growing ministry."

As social injustices, ignorance and apathy are replaced with increased sensitivity and warm acceptance; the church community will begin to fully appreciate the contributions that persons with mental and physical disabilities present. In addition to virtues like courage, patience, perseverance, compassion that can serve as an inspiration to all those in the community.

Assessments

- For our goals for inclusion and accessibility to succeed in communities and schools, churches must take the lead and set the example for others to follow.
- The leaders and the general membership of the Church must educate themselves to fully appreciate the contributions persons with disabilities can make to the church community.

Church Community Inclusion Education Resources
National Organization on Disability
Religion and Disability Program
910 16th Street, N.W.
Washington, DC 20006
(202)293-5960, (202)293-5968 (TTY)
(202)293-7999 (Fax)

Union of American Hebrew Congregations
Liheyot Advisory Committee
838 5th Ave.
New York, NY 10021-7064
(212)650-4075 (212)650-4229 (Fax)

National Catholic Office for Person with Disabilities
P.O. Box 29113
Washington, DC 20017
(202)529-2933 (Voice/TTY) (202)529-4678 (Fax)

- The use of assistive technology. Such as large-print media, amplification of sound, assistive listening devices, adequate lighting, printed and audio taped sermons.
- Elimination of architectural barriers. Review parking, paths, ramps, stairs, space and seating, bathrooms, water fountains, elevators and lifts. doors, doorways, worship audio loop and other

Conclusion
On Saturday July 26, 1997, President Bill Clinton made this statement honoring the seventh anniversary of one of our nation's most significant civil right laws, the Americans with Disabilities Act (ADA). "Across America, barriers in communication, architecture and attitude are tumbling. To continue this progress, communities and businesses must do more to ensure that all Americans, regardless of their disability, can live and leam, work and play along side their fellow Americans."

APPENDIX A

Next Generation Leadership Symposium

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