

**New Jersey
Developmental
Disabilities Stakeholders'
Forum**

Final Report

August 29, 2003

*Janice Ballou
David Frank
Audrey McDonald
Julie Rothbard*

Submitted to:

University of Medicine & Dentistry of New Jersey
School of Public Health
675 Hoes Ln.
Piscataway, NJ 08854-5635

Project Director:

Lois Grau

Submitted by:

Mathematica Policy Research, Inc.
P.O. Box 2393
Princeton, NJ 08543-2393
Telephone: (609) 799-3535
Facsimile: (609) 799-0005

Project Director:

Janice Ballou

ACKNOWLEDGMENTS

This project would not have been possible without the cooperation and generous contribution of time from the participating stakeholders. Members of the planning group provided invaluable insights and guidance to direct the research team and focus the project. In particular, the extensive efforts and cooperation of Patrick Brannigan, Deputy Chief, Governor's Office of Management and Operations, and Kevin Ryan, Deputy Chief, Governor's Office of Management and Operations; Theresa Wilson, Deputy Commissioner for Disability Services, James Smith, Director, Division of Developmental Disabilities, and Carol Grant, Acting Deputy Director, Division of Developmental Disabilities, from the New Jersey Department of Human Services; and Maureen Babula, Chair, Susan Richmond, Deputy Director, and Ethan Ellis, Executive Director, from the New Jersey Developmental Disabilities Council, ensured an inclusive process.

Dr. Lois Grau, Associate Professor and Head of the Health Systems and Policy Division, Dr. Bernadette West, Assistant Professor, and Dr. Susan Hammerman, Project Director, Developmental Disabilities Family Support and Information Project, from the University of Medicine & Dentistry of New Jersey, worked closely with Mathematica Policy Research, Inc. to provide policy background, develop project materials, and assist in methodological decisions.

At Mathematica Policy Research, Inc., Audrey McDonald, David Frank, and Julie Rothbard professionally and skillfully conducted the stakeholder interviews and assisted with the Stakeholders' Forum. Janice Ballou directed the project, conducted the stakeholder interview coding, and prepared this report. Darlene Hrbek and Monica Capizzi provided exemplary production support, and Laura Berenson carefully edited the report. Craig Thornton provided professional consultation and a thorough review of the report.

These contributions are gratefully acknowledged; the author accepts sole responsibility for any errors or omissions in the report.

CONTENTS

Chapter		Page
	ACKNOWLEDGMENTS	iii
	EXECUTIVE SUMMARY	ix
I	INTRODUCTION.....	1
	A. METHODOLOGY.....	4
	1. Project Development Meeting.....	4
	2. Planning Group Meetings.....	4
	3. Stakeholder Interviews.....	5
	4. Stakeholders' Forum.....	6
	B. ORGANIZATION OF THE REPORT.....	7
II	SYSTEM PLANNING NEEDS.....	9
	A. SYSTEM PLANNING NEEDS: RESOURCES AND FUNDING.....	10
	1. Reduce Inequities.....	10
	2. Optimize the Use of Current Resources and Funding.....	12
	3. Increase Resources and Funding.....	14
	B. SYSTEM PLANNING NEEDS: PROGRAM AND SERVICE PLANNING	16
	1. Choice and a Continuum of Care.....	16
	2. Expertise.....	17
	3. Availability.....	19
	4. Communication.....	20
	C. SYSTEM PLANNING NEEDS: COMMUNITY INTEGRATION.....	22
	1. Promote Community Acceptance of People with Developmental Disabilities.....	22
	2. Use and Enhance Local Services.....	23
	3. Provide Family Support.....	24

CONTENTS *(continued)*

Chapter		Page
II (con't)	D. VISION FOR QUALITY OF LIFE	24
	1. Having Opportunities to Make Choices	25
	2. Establishing Quality Standards.....	26
	E. ROADBLOCKS TO SYSTEM CHANGE.....	27
	1. The Current System	27
	2. Managing Change.....	28
	3. Gaining Trust and Overcoming Fears.....	29
	4. Nature of the Developmental Disabilities Population	29
	F. HOW CAN IT BE DONE?	30
	III	NEW JERSEY DIVISION OF DEVELOPMENTAL DISABILITIES OPTIONS PLAN.....
	A. OVERALL IMPRESSIONS	34
	B. PRIORITIES FOR NEXT STEPS	35
IV	STAKEHOLDERS' FORUM SUMMARY	37
	A. OVERVIEW OF THE STAKEHOLDERS' FORUM AGENDA.....	37
	B. OVERVIEW OF THE BREAKOUT GROUPS	39
	1. Breakout Group Themes.....	41
	2. Recommendations for the Stakeholders' Forum	43
	3. Forum Summary	44
	BIBLIOGRAPHY	45
	APPENDIX A: MEMBERS OF THE STAKEHOLDERS' FORUM PLANNING GROUP.....	A.1
	APPENDIX B: STAKEHOLDER PARTICIPANTS	B.1

CONTENTS *(continued)*

Chapter	Page
APPENDIX C: MEMBERS OF THE NEW JERSEY DEVELOPMENTAL DISABILITIES COUNCIL COMMITTEE ON QUALITY IN LONG TERM CARE	C.1
APPENDIX D: STAKEHOLDER INTERVIEW MATERIALS	D.1
APPENDIX E: STAKEHOLDERS' FORUM MATERIALS	E.1
APPENDIX F: RECRUITMENT SCRIPT AND PACKET	F.1
APPENDIX G: STAKEHOLDERS' FORUM: SUMMARY OF BREAKOUT GROUP DISCUSSIONS	G.1

EXECUTIVE SUMMARY

The State of New Jersey has the challenging task of providing cost-effective, high-quality services to people with developmental disabilities and their families. The inadequacies of the current system have been recognized, as has the necessity of conducting both long-term and short-term planning. New Jersey Governor James McGreevey acknowledged this need by requesting that New Jersey Department of Human Services (DHS) Commissioner Gwendolyn L. Harris “...conduct a thorough assessment of the Division of Developmental Disabilities and provide recommendations for improving the continuum of care offered by the State for persons with developmental disabilities.”¹ In a press release dated September 20, 2002, Commissioner Harris announced “broad changes to the state’s system of services for people with developmental disabilities.” She commented in the press release:

When I took over the job of commissioner seven months ago, it was evident that the state’s service system for people with developmental disabilities was in crisis. The federal government was threatening to decertify our institutions. The waiting list for community services had grown longer and longer every year. It was time to take a look at the entire system.

To inform discussions to plan for system change in the provision of services to people in New Jersey with developmental disabilities and their families, the study sought to inform the public debate on the future of the developmental disabilities system by engaging stakeholders, who are key members of the developmental disabilities community recognized throughout the state as experts in various aspects of developmental disabilities issues. The 33 stakeholders who

¹Governor McGreevey’s support for the stakeholders’ forum is stated in a March 25, 2002, letter to Maureen Babula, Chairperson of the New Jersey Developmental Disabilities Council (DDC).

participated in the project were selected through a nomination and review process. They represent a broad group of interests, including advocacy groups, service providers, union employees, government agencies, families of people with developmental disabilities, and people with developmental disabilities.

DDC commissioned the School of Public Health of the University of Medicine & Dentistry of New Jersey (UMDNJ) and Mathematica Policy Research, Inc. (MPR) to conduct this study. Through interviews and group meetings, the project team obtained information from the stakeholders to outline what is needed for system reform, and to provide a forum in which the stakeholders could discuss their recommendations. This process resulted in a synthesis of the stakeholders' views on the problems with the current system and recommendations to improve its abilities to meet the needs of people with developmental disabilities and their families. In addition, a diverse group of 15 family members representing a range of developmental disabilities and including African American, Hispanic, and Asian ethnic groups, participated in a focus group discussion.

Changing the current system is a complex task, and there are many competing agendas. This project facilitated an inclusive dialogue among the stakeholders and the policy makers to inform the process. The stakeholders were generally consistent in their identification of the limitations of the current system and in their goals for reforms. To systematically describe the issues that the stakeholders have recommended be included on the state's agenda for policy formation, the results of the stakeholders' interviews have been organized around the key themes they identified: resources and funding, program and service planning, and community integration.

A. RESOURCES AND FUNDING

The stakeholders' observations about resources and funding to reform services for people with developmental disabilities and their families focused on the following three themes:

1. ***Reduce Inequities.*** The stakeholders were very candid when making observations about the inequities in the provision of services to people with developmental disabilities and their families. Although their comments focused on the negatives in the system that can result in some people receiving excessive services, the stakeholders also described people who do not receive enough services or who have limited access to services. The stakeholders noted that the suggestion to take services from people who already are receiving them or to ask some families who have the resources to pay for services is unpopular, even though the result of those actions would make the system more equitable.
2. ***Optimize the Use of Current Resources and Funding.*** The stakeholders' comments on how to optimize current funding raised the issue of the costs and benefits of spending resources on the developmental centers, which one stakeholder described as "your mother lode, there's your money." No clear consensus for action emerged on this issue. Some stakeholders noted that the funds used to maintain institutional infrastructure could be used to provide services to people with developmental disabilities; however, others felt that the unique expertise and services provided by the developmental centers are required to have a system with a range of service options. The stakeholders also observed that the way that resources are used would change in a more consumer-focused market for services, in which people with developmental disabilities could purchase their own services, rather than be required to take a package of services, some of which they may not need.
3. ***Increase Resources and Funding.*** The methods of obtaining additional funding sources that the stakeholders discussed included increasing New Jersey's Medicaid funding; creatively using such programs as those offered by the U.S. Department of Housing and Urban Development to provide funding for housing and federal funds for senior services for elderly people with developmental disabilities; seeking federal funds intended to help to address issues raised by the Olmstead decision and other actions; obtaining grant money from foundations; and assessing the ability of people with developmental disabilities and their families to increase their contributions for services. However, the stakeholders also voiced concerns about depending on Medicaid for additional funds; their concerns focused on the lack of knowledge at all levels of the system about the Medicaid waiver.

B. PROGRAM AND SERVICE PLANNING

The stakeholders felt that identifying the types of programs and services necessary to reform the system requires long-term planning. The following four themes emerged from the stakeholders' discussion of program and service planning:

1. ***Choice and a Continuum of Care.*** The stakeholders expressed a preference for avoiding a structured process of providing services and instead giving people with developmental disabilities and their families a continuum of program and service options from which to choose. One end of this continuum should provide the option to receive services at a developmental center or at some new type of entity that would offer the same level of support as does a developmental center. The other end of the continuum should offer supported independence for individuals who choose to remain in the community. The stakeholders noted that program planning should support the transition from one type of program or service to another, rather than assume that a person who has been placed in a particular program will remain there.
2. ***Expertise.*** The stakeholders acknowledged that expansion of programs and services and the availability of choices are dependent on having trained, experienced people to provide the range of services needed. They identified three broad categories of expertise that are needed: (1) assistance with basic daily living activities (that is, home care, cooking, cleaning, and personal hygiene); (2) treatment and developmental expertise to maximize the abilities and potential of people with developmental disabilities; and (3) professional health care, such as medical, dental, and psychological treatment. However, the stakeholders also acknowledged that a system that encourages professionalism and expertise in the provision of programs and services will increase the cost of these services.
3. ***Availability.*** The stakeholders cautioned that, even if people with developmental disabilities and their families gain more control over the resources needed to obtain services, a "market" of services that can be purchased may not exist.
4. ***Communication.*** System change is dependent on the information that is available to people with developmental disabilities and their families. The stakeholders described the necessity of having a system in which there is an awareness of existing programs and services. They underscored this need by noting that both the families who are entering the system and those who would be expected to serve as references are not knowledgeable. The stakeholders observed that the reformed communication system must serve as a standardized source of information. Inconsistency results in mixed messages, erodes people's trust, and requires that people expend time and energy unnecessarily to find useful information.

C. COMMUNITY INTEGRATION

The stakeholders identified community integration as having definite benefits for people with developmental disabilities and for the implementation of system change. Their comments about community integration can be organized into the following three recommendations:

1. ***Promote Community Acceptance of People with Developmental Disabilities.*** The stakeholders agreed that one of the goals of system change is to support community living for people with developmental disabilities. According to the stakeholders, to achieve this goal, the community will have to recognize and accept people with developmental disabilities, and it will have to identify the best ways to provide support.
2. ***Use and Enhance Local Services.*** Having people with developmental disabilities live in the community provides for opportunities to use public funding and public resources more effectively. Instead of investing in duplicate or parallel services that segregate people with developmental disabilities from others in the community, and that result in expenditures to build or administer separate systems, the stakeholders suggest seeking opportunities for integration.
3. ***Provide Family Support.*** A clear message from the stakeholders is that finding a way to keep people with developmental disabilities at home will improve the system. Family members underscore this point with the reminder that no one “can care for a loved one better than his or her family.” However, it is also clear that families need support and public policies that sustain the family in order to provide this care.

D. VISION FOR QUALITY OF LIFE

The stakeholders offered many suggestions for system change. To understand what these changes would mean for a person with a developmental disability, the stakeholders described their visions of how such a person would obtain the highest possible quality of life. There was a consensus that the foundation of a quality life consists of giving an individual who has a developmental disability the opportunity to make his or her own choices. The stakeholders recognized that this approach to providing the highest-quality life possible for people with developmental disabilities carries some risk, but they also agreed that the current approach to providing care and services to people with developmental disabilities is too risk averse. The system should “let go” and allow people to make decisions that might be mistakes.

A challenging aspect of any discussion about a vision of quality of life for people with developmental disabilities is the lack of agreement about the definition of “quality.” The stakeholders observed that discussions of quality must shift from the current focus on the quality of services to a focus on the quality of experiences and the outcomes for individuals.

One of the stakeholders, who is a person with a disability, summarized his vision:

We as a society need to start looking at everyone as an individual. And everyone has something to offer, no matter what. You may look at me in this chair and see me in one aspect, when the aspect could be totally different once you get to know me. So if we don't get to know people, then how are we making assumptions that people can and cannot do certain things? How are we to know unless we let somebody try, and give them the option to try?

E. ROADBLOCKS TO SYSTEM CHANGE

The observations from the stakeholders outline optimistic plans for improving the current system of providing care and services to people with developmental disabilities and their families. Although the stakeholders offered many suggestions about what a reformed system should look like, they also were realistic and identified roadblocks that could prevent system change from happening.

The stakeholders identified multiple aspects of the current system that were potential roadblocks, including the previously described inequities in service provision, a lack of integration and cooperation among the different groups and agencies within the system, a continuation of “business as usual” within key state agencies, and the lack of stability in developing and implementing programs. The stakeholders recognized that changes in the system must be managed in order to be successful. They recommended having a transition plan as the state moves from the current system to a reformed approach to providing services to people with developmental disabilities and their families.

The stakeholders also identified another roadblock to system change: the need to bring together all of the participants in the system, including those who have had negative experiences with the current system, and who therefore have concerns about the viability of any future reforms. One stakeholder summarized this concern:

But I think at the heart of a lot of the resistance are fears. Whether it's people's jobs changing or people in the community, I think we need to really be listening to what the underlying fears are and address them.

F. HOW CAN IT BE DONE?

All of the stakeholders have recognized that changing the current system will be complicated. The most difficult question that the stakeholders tried to answer was that of how change can actually be done. The stakeholders also acknowledged that, despite agreement about the necessity of changing the current system and a consensus about the services that a reformed system should provide, the challenge will be to maintain solidarity after specific changes have implemented. According to the stakeholders, one way to maintain cohesion within the developmental disabilities community during the change process is to ensure inclusion. As one stakeholder stated:

I'm not saying that I have all of the answers, but I just wish—again, as long as people are listening and as long as there is dialogue, there is always hope. It's when we stop listening and there is no dialogue that there is not hope.

G. NEW AND EXPANDED OPTIONS FOR NEW JERSEY'S CONSUMERS WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

In September 2002, DHS's Division of Developmental Disabilities (DDD) distributed a plan for reforming the provision of services to people with developmental disabilities and their families, called the "New and Expanded Options for New Jersey's Consumers with Developmental Disabilities and Their Families" (Options). To offer insights on their reactions to

the proposed reforms, the stakeholders commented on what the state had outlined in this document.

Almost unanimously, the stakeholders had positive overall reactions to Options. In giving their initial impressions, they used such phrases as “Breath of fresh air”; “First time I feel listened to in 20 years”; and “I think they’re wonderful. If they could be realized, it would be a very significant improvement in the system.” However, the optimism was almost universally tempered with the concern that “the devil is in the details.” Thus, although the stakeholders agreed that the Options document both captured the key weaknesses in the current system and outlined useful concepts for consideration, they also expressed concern that the state would not be able to move from concepts to action. The stakeholders stressed that the process for implementing the actions outlined in Options should be inclusive.

H. THE STAKEHOLDERS’ FORUM

The Stakeholders’ Forum was held on March 1, 2003, to review the results of the stakeholder interviews, and to give the stakeholders an opportunity to discuss the results in breakout groups. The presentations that summarized the breakout group discussions underscored the general consensus among the participants about issues that also had been identified in the stakeholder interviews. Topics that were the focus of the presentations included:

- Maximizing the efficiency of the use of current resources
- Ensuring that communication within the developmental disabilities community is clear, consistent, and easily accessible
- Achieving equity in a variety of ways, such as by providing financial resources and improving and integrating systems of care
- Creating a system that gives people with developmental disabilities and their families more choice about all aspects of their lives
- Having a system reform process that is inclusive, that forges partnerships, and that develops a shared understanding of what actions must be taken

In conclusion, the stakeholders recognized that “change happens in small increments.” The Forum’s discussions underscored the consensus that there is a need for change and for the principles that should guide that change. The stakeholders share a sense of what would have to be accomplished to change the system. Although these issues are complex, the stakeholders are committed to a process that will improve the quality of services and the quality of life for people with developmental disabilities and their families.

I. INTRODUCTION

The State of New Jersey has the challenging task of providing cost-effective, high-quality services to people with developmental disabilities and their families. The inadequacies of the current system have been recognized, as has the necessity of conducting both long-term and short-term planning. New Jersey Governor James McGreevey acknowledged this need by requesting that New Jersey Department of Human Services (DHS) Commissioner Gwendolyn L. Harris "...conduct a thorough assessment of the Division of Developmental Disabilities and provide recommendations for improving the continuum of care offered by the State for persons with developmental disabilities."¹ In a press release dated September 20, 2002, Commissioner Harris announced "broad changes to the state's system of services for people with developmental disabilities." She commented in the press release:

When I took over the job of commissioner seven months ago, it was evident that the state's service system for people with developmental disabilities was in crisis. The federal government was threatening to decertify our institutions. The waiting list for community services had grown longer and longer every year. It was time to take a look at the entire system.

She summarized by saying, "In short, we need a whole new way of doing business."

To inform discussions to plan for system change in the provision of services to people in New Jersey with developmental disabilities and their families, DDC commissioned the School of Public Health of the University of Medicine & Dentistry of New Jersey and Mathematica Policy Research, Inc. (MPR) to conduct a project on the issue. A unique feature of this project was the

¹Governor McGreevey's support for the Stakeholders' Forum is stated in a March 25, 2002, letter to Maureen Babula, Chairperson of the New Jersey Developmental Disabilities Council (DDC).

creation of a planning group that facilitated collaboration and consultation with representatives from the major state entities involved in developing policies and programs for people with developmental disabilities and their families. This planning group included representatives from the New Jersey Governor's office, DHS, DHS's Division of Developmental Disabilities (DDD), and DDC (see Appendix A). The group met periodically to plan the interviews and meetings conducted with the stakeholders, to share information about ongoing state policy actions related to reforms, and to discuss the issues that were emerging from the stakeholders' interviews. To underscore the importance of holding a systematic, inclusive discussion about possible ways to implement system change, Governor McGreevey endorsed the project and, in his letter to the stakeholders, encouraged their participation.

The project sought to inform the public debate on the future of the developmental disabilities system by engaging key members of the developmental disabilities community, referred to throughout this report as "stakeholders." The stakeholders represent a broad group of interests, including advocacy groups, service providers, union employees, government agencies, families of people with developmental disabilities, and people with developmental disabilities (see Appendix B). They were selected through a nomination process that included members of the DDC's Quality in Long Term Care Committee and the planning group (Appendix C). This process identified 37 individuals who are recognized throughout the state as experts in various aspects of developmental disabilities issues. Through interviews and group meetings, the project team obtained information from these stakeholders to outline what is needed for system reform, and to provide a forum in which the stakeholders could discuss their recommendations. This report is a synthesis of their views on the problems with the current system and their recommendations to improve the system's abilities to meet the needs of people with developmental disabilities and their families.

Because state policy makers are planning to change the current system but still are in the process of formulating policy, the project team felt that it would be useful to have the stakeholders' opinions about key issues that should be included in any new state policies. The team felt that the stakeholders' assessments would serve to both identify the critical issues that should be on the agenda and provide guidance on the preferred course of action to address the issues. In addition, because the stakeholders are knowledgeable about the current status of policy and programs, and because each represents expertise in a particular aspect of the system, the team decided that the most effective approach to developing an agenda for system change was to interview the stakeholders.

In September 2002, DDD released *New and Expanded Options for New Jersey's Consumers with Developmental Disabilities and Their Families (Options)*. This document provided an overview of the current system and outlined the state's future plans. Given the relevance of the document, the project team and the planning group decided to include a discussion of Options in the stakeholder interviews. That discussion was intended to provide the state with a systematic qualitative assessment of the document.

Changing the current system is a complex task, and there are many competing agendas. This project facilitated an inclusive dialogue among the stakeholders and the policy makers to inform the process. To systematically describe the issues that the stakeholders have recommended be included on the state's agenda for policy formation, the results of the stakeholders' interviews have been organized around the key themes discussed later in this report. The objective of this project is to document the stakeholders' recommendations. It is not the objective of this project to analyze either these recommendations or New Jersey's current system for providing services to people with developmental disabilities and their families.

A. METHODOLOGY

The guiding principals for the project were to be inclusive, to listen to the stakeholders as they described the issues relating to system change, to record and organize this information, and to facilitate a discussion using this information. The multi-phased, qualitative approach included an initial project development meeting, ongoing planning group meetings, stakeholder interviews, focus group discussions, and a day-long forum.

1. Project Development Meeting

The project began with a meeting of the members of DDC's Quality in Long Term Care Committee and the planning group. The purposes of this meeting were to develop a list of the types of stakeholders to be included in the project; obtain nominations on specific individual stakeholders to be interviewed; identify resources, such as policy status reports and planning documents, to use to develop the stakeholder interviews; develop a list of topics to be included in the interviews; and coordinate the stakeholder project with other efforts to address issues related to people with developmental disabilities and their families, such as the Olmstead Taskforce and DHS's and DDD's ongoing policy activities. After the meeting, the project team developed a draft list of stakeholders to be interviewed and a preliminary topic guide for the one-on-one discussions.

2. Planning Group Meetings

As described previously, an ongoing, collaborative planning group was established to provide guidance to the project team. The group met periodically and worked together to identify the final list of stakeholders, and to develop the final materials for the stakeholder interviews and the stakeholder forum.

3. Stakeholder Interviews

The foundation of the project is the interviews conducted with a diverse mix of 33 stakeholders. Initially, MPR sent the 37 stakeholders who had been nominated by DDC's Quality in Long Term Care Committee and confirmed by the planning group a packet containing a letter from Governor McGreevey endorsing the project, a letter that described the project team, a list of frequently asked questions and answers, and a copy of the Options document. MPR then called each stakeholder to schedule the in-person interview. Interviews were conducted with 33 stakeholders and ranged from 45 minutes to almost 3 hours. Although the interviews were confidential, with the permission of the stakeholders, they were tape recorded to assist in reporting the results of the discussions. The interviews covered the following major topics: identification of changes in the current system of services for people with developmental disabilities and their families that must be made; a vision of how a person with a developmental disability would go about obtaining the highest quality of life; and a review of the stakeholders' impressions of Options. The complete topic guide used for the interviews is presented in Appendix D.

The following list summarizes the general classifications represented by the stakeholders who participated in the interviews. The number of stakeholders affiliated with each type of entity is in parenthesis next to each classification.

- Advocacy organizations (11)
- Nongovernment service providers (5)
- Families members and people with developmental disabilities (10)
- New Jersey government agencies (3)
- Education center (1)

- Unions (2)
- New Jersey elected official (1)

This qualitative approach resulted in more than 40 hours of taped interviews. The project director methodically coded each interview to identify the key themes discussed by the stakeholders. The results of the coding are reported in Chapters II and III.

In addition to interviews with stakeholders, MPR held a focus group discussion with families of people with developmental disabilities. A diverse group of 15 participants included African American, Hispanic, and Asian family members representing a range of different types of developmental disabilities.

4. Stakeholders' Forum

The project included a meeting to encourage an inclusive discussion on the system change agenda items identified in the interviews. This meeting, which we call a Stakeholders' Forum, was held on March 1, 2003; the agenda consisted of a report on the stakeholder interviews, an update by DHS and DDD staff on system change activities, and a statement from the New Jersey Governor's office underscoring the administration's support for the system change effort and encouraging the stakeholders to work together to motivate reform.

The Stakeholders' Forum included three breakout groups to enable participants to discuss the results of the interviews, and to make suggestions on next steps for specific reform efforts. The three breakout groups were (1) Shifting Resources, Shifting Decision Making About Resources; (2) Focus on Quality of Lives, not Quality of Services; and (3) Ending the Search, Achieving Information Equity. The agenda for the Stakeholders' Forum and detailed information about the breakout groups are included in Appendix E.

B. ORGANIZATION OF THE REPORT

The results of the interviews are discussed in Chapter II and Chapter III. Chapter II describes the key themes that the stakeholders identified in their discussion of system planning needs and in their vision of the future for people with developmental disabilities. Chapter III summarizes the stakeholders' observations about DHS's Options. The final chapter presents an overview of the Stakeholders' Forum meeting and of the themes discussed in the breakout groups.

II. SYSTEM PLANNING NEEDS

The main focus of the stakeholder interviews was to understand the changes that must be made in the overall system of services for people with developmental disabilities and their families. Because systemic change is a broad topic, and issues related to services to people with disabilities and their families are complex and interconnected, we wanted to design an inclusive process that would enable stakeholders to comprehensively review the current system, and to recommend alternatives to reform the system.

Because we wanted to be able to compare the comments of all the stakeholders, we provided a framework to guide the system planning discussion. The stakeholders were instructed to respond to questions in the context of the overall statewide system, rather than only from the perspective of their particular group or organization. In particular, they were asked to respond to the suggestion to shift the decisions about the use of resources, the parties who deliver services, and the way in which services are delivered to people with disabilities and their families. They also were prompted to provide suggestions on ways to expand services to more people with developmental disabilities and their families while using the same resources. To provide another perspective on system improvements, the stakeholders were asked about their vision of how people with developmental disabilities and their families could have the highest possible quality of life, and they also were asked to discuss the major road blocks that could prevent people with developmental disabilities and their families from achieving that goal.

Although the stakeholders were encouraged to discuss the trade-offs that would have to be made to make change happen, they were reluctant to do so, nor were they willing to speculate about winners and losers in the event that the state were to adopt the changes they recommended.

The key point on which the stakeholders focused was creating a system that was equitable, rather than one producing winners and losers.

Three themes emerged from the discussions about systemic change: (1) resources and funding, (2) program and service planning, and (3) community integration. These topics are complex, and each has several subthemes.

A. SYSTEM PLANNING NEEDS: RESOURCES AND FUNDING

The stakeholders' observations about resources and funding to reform services for people with developmental disabilities and their families fell into three categories: (1) reduce inequities, (2) optimize the use of current resources and funding, and (3) increase resources and funding.

1. Reduce Inequities

The stakeholders were very candid when making observations about the inequities in the provision of services to people with developmental disabilities and their families. They described these inequities from both an individual and a systemwide perspective and recommended that the state examine ways to reduce them. From the individual perspective, people who have learned how to use the system are not only getting what they need, but, in some cases, are getting more than they need. Some stakeholders noted that, because some programs typically provide a prescribed level of service, families can receive more services or a higher standard of services than they need. Furthermore, many families who are able to gain access to the system take every service they are able to obtain, even if they do not need some of them, because they fear the alternative—not being able to get anything. The stakeholders generally felt that resources used for this elevated level of services could be distributed to people who have greater needs or who currently are excluded from the system. The stakeholders also discussed the issue of people with developmental disabilities and their families who could afford to

contribute more to the overall care than they have been asked to. Although the stakeholders generally focused on describing people who may be receiving excessive resources, they also described those who do not get enough services or who have limited access to services.

The stakeholders noted that the suggestion to take services from people who already are receiving them is unpopular, even if the result of such an action would be more equitable. A possible consequence of a more equitable distribution of resources was described by one of the stakeholders:

There are a whole lot of families out there that could do with a little less, but they are afraid to take less because their experience is that what they get is what they get for the rest of their child's life. They've been taught by the lawyers and everybody else in the community—get as much as you can the first time around.... The only potential losers, possibly might be, there are people who are invested in the Cadillac mentality. They want the Caddy or the BMW or the Mercedes. They want it all.

The stakeholders also recognized that, although some families are able and willing to pay for services, the current system does not provide a process to enable these families to do so. One stakeholder summarized the way that additional funding from the families could affect the resources available for people who might not be able to afford services:

There are families who can't get into the system. They're blocked because caseloads are filled and programs have waiting lists. They come and say, we will pay you, and the state says they can't accept it. So there are people even within the service system who are in a position to pay. Some people could be taken out of the system simply by creating a sliding fee scale. In the past, when we've been successful in competing for federal demonstration projects that have then been accepted by the Division of Disabilities for funding, fee for service on a sliding scale has been mandatory. When it's made the conversion and the state has picked it up, of course it's been prohibited. So we've had to call these families who have been in this system and indicated a willingness to pay for these services and say, you're no longer allowed to pay into the system. I think that needs to be looked at.

2. Optimize the Use of Current Resources and Funding

The stakeholders discussed a second approach to increasing resources and funding—using available resources more effectively. The discussion of how to optimize current funding raised the issue of the costs and benefits of spending resources on the developmental centers. Some stakeholders noted that the funds used to maintain and restore the physical plant of a decaying institutional infrastructure could be used to provide services to people with developmental disabilities; however, others felt that the unique expertise and services that the developmental centers provide are necessary if the system is to offer a range of service options.

Some of the stakeholders referred to the percentage of the FY 2003 budget earmarked for services to people with developmental disabilities to underscore the inequities they perceive are inherent in the way that available resources are used. Although only 12 percent of people with developmental disabilities receive services in developmental centers, 35 percent of the budget is used to provide these services. In comparison, 57 percent of the budget is for community residential services for 23 percent of the population, and 7 percent is used to support the 65 percent who are at home with their families.¹ However, as we discuss in greater detail later, stakeholders would like to see a continuum of care for people with developmental disabilities and their families, with the institutions anchoring one end of that continuum. A stakeholder who felt strongly that reallocating the budget dollars spent for institutions would be a major benefit to the system described his rationale:

Well, I thought it was interesting in the report is that they talk about how much money is spent in group homes for how many people and how much money is spent for people not receiving services, the greatest part of the population. But actually, I didn't see the money that is spent on people in the developmental centers, because I know from my

¹These budget statistics are from the DHS's New and Expanded Options for New Jersey's Consumers with Developmental Disabilities and Their Families (Options).

experience that that money is far more than the rest. And that's where your money is—that's where your money is stuck. There are still a lot of people in developmental centers that do not need that level of care. I am not necessarily talking about closing all developmental centers; I know what the outcry of that is in New Jersey, and the difficulty of pulling that off in New Jersey. But, that's your mother lode, there's your money; your money is tied up in systems that don't work anymore in places that are going to be decertified anyway, and you're going to throw good money after bad at these places because you can't keep them up.... But that's your money. It's all sitting there in administrators' salaries, and doctors' salaries, nurses' salaries, and sewage systems, and all of the things that make these communities work that are extremely expensive.

The stakeholders talked about developing a more consumer-focused market for services. If consumers are able to select the services they need, rather than having to take a package of services—some of which they may not need—there would be a change in the way that current resources are used. One stakeholder provided an example of how choice resulted in a reduction of costs in the self-determination program:

One of the things that we discovered through the experiments in self-determination is that, when you give people real choices and when you rely on the natural resources in the community, then the costs go down. In the experiments with self-determination, they reduced costs by 15 percent. The guy who invented the idea said he could have reduced by 25 percent. People who get to choose usually choose only what they need. People who are providing services tend to sell what they want to sell, so the costs go up when you put the guy who's collecting the money in charge of what services to provide.

Another stakeholder described choice from the perspective of the impact it would have on provider organizations:

If the money were following the individual, if I were funded by Medicaid dollars x amount of dollars per year so that I could increase my services to whatever my family needs, let's say I needed more like, instead of 5 hours a week, I said in order to function I need 10 hours a week. If the money followed me, then I would just go to whatever agency; I think that you would get a lot more competition amongst the agencies to provide a better service. And you'd see a lot more flexibility happening. I think flexibility and competition would be a good thing for the provider agencies perhaps if it was funded in that way. The way it is now, the provider agencies, they get a contract for x amount of dollars and offer the services, and we have to come and fit into that service. It's not always exactly what you might want.

Both of these stakeholders illustrate the recommendations of others that current funding can be used more effectively, and that a competitive market is created by permitting people with developmental disabilities to purchase their own services. These approaches to optimizing the use of resources are on the stakeholders' agenda of items that should be included in the discussions of system change.

3. Increase Resources and Funding

Another way to obtain resources for people with developmental disabilities and their families is to identify other funding sources. One of the other methods of obtaining additional sources discussed by the stakeholders was that of increasing New Jersey's Medicaid funding.² During that discussion, however, the stakeholders also raised several concerns about depending on Medicaid for additional funds. They noted that the state currently lacks the expertise to optimize the Medicaid waiver benefits that it potentially could receive. In particular, the stakeholders noted that expertise is required to craft the waiver request to ensure it meets the needs of New Jersey's developmental disabilities community. They also commented that the Medicaid waiver is not a panacea, and so should not be considered a "silver bullet" that will "fix" the funding needed to provide services to people with developmental disabilities and their families. The stakeholders brought up the issue of the lack of knowledge at all levels of the

²The stakeholders who referred to Medicaid or to the Medicaid waiver generally did not go into detail about the specifics of these alternative funding sources. However, their comments focused on the Home and Community Based Services (HCBS) Waiver, which is the section of the Social Security Act that gives states the flexibility to develop and implement alternatives to placing Medicaid-eligible individuals in institutional care. Another source of stakeholder information was Options, which describes DDD's Community Care Waiver authorizing Medicaid reimbursement for individuals. However, Options notes that "New Jersey currently fails to require all persons served by the Division to become Medicaid eligible." Options also states that "the existing Community Care Waiver does not encompass services to families living at home."

system about the Medicaid waiver. For example, if eligible people with developmental disabilities and their families do not apply for Medicaid, the amount of additional resources that the state will receive will be limited. The stakeholders reported that, because there is little easily understandable information about the Medicaid waiver, the developmental disabilities community has many concerns about what the Medicaid waiver will mean to families. The stakeholders also cautioned that it is important to assess potential unintended consequences of the Medicaid waiver that could prevent people who need services from receiving them.

One stakeholder summarized the stakeholders' discussion on the various costs and benefits of using the Medicaid waiver as a source of additional funding for programs and services for people with developmental disabilities and their families:

So the waiver is not an end in itself but that it's one way of maximizing funding. I think that everyone benefits if there are more resources in the system. I think that we need more information, and I don't think that anybody in New Jersey has it yet, specifically about New Jersey, in terms of whether moving to increased reliance on Medicaid, whether that will disadvantage individuals that are presently in the system. So I think that's potentially a concern, but I think there is no alternative but to move ahead with changes in Medicaid. It may be that we need to look closely at the specific strategies around Medicaid, whether it's one mega-waiver or it may be that we need smaller, targeted waivers around a particular type of need, but I think that definitely makes sense in terms of the direction to go....

The stakeholders also suggested being creative in the search for other sources of funding. For example, the U.S. Department of Housing and Urban Development could provide funding for housing. The stakeholders commented that other federal actions, such as the Olmstead decision, will increase funding for people with developmental disabilities, and that grant money from foundations is another possible source of resources. In particular, as people with developmental disabilities age, funding for senior services could be applied to services for people in that population. Finally, as discussed in Section A.1 of this chapter, the stakeholders suggested that another way to increase resources and funding would be to assess the ability of

people with developmental disabilities and their families to increase their contributions for services.

B. SYSTEM PLANNING NEEDS: PROGRAM AND SERVICE PLANNING

The stakeholders felt that identifying the types of programs and services that are needed to reform the system requires long-term planning. They explained that it is important to clearly identify program and service needs prior to seeking funding or Medicaid waivers. Their rationale was that, without first knowing what services those funds must support, it is not possible to know what to ask for. Four themes emerged from the stakeholders' discussion of program and service planning: (1) choice, (2) availability, (3) expertise, and (4) communication.

1. Choice and a Continuum of Care

The current system was described by the stakeholders as a “cookie cutter” system—certain programs and services are available, and people with developmental disabilities are slotted into one of those options. In addition to needing services other than the ones available, however, the needs of people with developmental disabilities and their families change over time. Thus, program planning should support the transition from one type of program or service to another, rather than assume that, once a person has been placed in a particular program, he or she will remain there.

An alternative to a structured process of providing services is to give people with developmental disabilities and their families a system consisting of programs and services from which they can choose. The stakeholders further explained that, to give people choice, the system should support a continuum of care. One end of this continuum should provide the option to receive services at a developmental center or at some new type of entity that offers the same type of services as does a developmental center. Some people with developmental

disabilities and their families may choose or already have chosen institution care, or they may want to have institutional services as a step in the transition to other types of care. The other end of the continuum should offer supported independence for individuals who choose to remain in the community.

The stakeholders suggested that the money used to provide programs and services in a system that supports choice should go to the people with developmental disabilities and their families, rather than to the service providers. This shift in funding would result in people having the funds to shop for services and programs; by contrast, in the current system, the service providers and programs receive the funding, and people have only those agencies and organizations as choices. The stakeholders' suggested approach to program planning reinforces the person-centered system that they envision, and that is described in more detail later in this chapter.

2. Expertise

The stakeholders acknowledged that expansion of programs and services and the availability of choices are dependent on having trained, experienced people to provide the range of services needed. In addition, they recommended that the people who currently are providing services receive training designed to enhance their abilities and skills. The stakeholders identified three broad categories of expertise that are needed: (1) assistance with basic daily living activities (that is, home care, cooking, cleaning, and personal hygiene); (2) treatment and developmental expertise to maximize the abilities and potential of people with developmental disabilities; and (3) professional health care, such as medical, dental, and psychological treatment. The stakeholders also noted that people with developmental disabilities need programs and services that provide appropriate care and professional assistance to enhance their development and to maximize their potential.

A system whose professionals have the expertise necessary to focus on people's individual needs and that operates with the approach that people can improve their talents and abilities would differ greatly from a system that fosters the attitude that people with developmental disabilities cannot improve. In particular, among the stakeholders, parents and family members of people with developmental disabilities expressed their concern that the current system has given up. They believe that it does not encourage professionalism among providers of services. In the current system, the care provided to people with disabilities focuses on maintaining basic services for living, but it does not extend to developing a person's potential. However, the stakeholders also acknowledged that a system that encourages professionalism and expertise in the provision of programs and services will increase the cost of these services. Although many types of staff would be needed to provide services on this level, one stakeholder discussed the importance of providing formal training of direct care workers:

The one element that hasn't come up, and if it's going to come up later on stop me and I'll address it later, but it has to do with what we have to do by way of staffing. And that's the one issue that I've minimized. We need to get more people involved, more people with formal education. I think a lot of times the direct care positions are being filled with people with good hearts and good intentions largely, but we need to continue to professionalize staff and give them more education to make them better decision makers and improved care providers, and those kinds of things. I think at some level we need to make sure that we are investing in the support services and the people who are providing those direct care supports.... I guess what I'm saying is that, if we do all the culture shifting and we get people to really look at people with disabilities as more normalized, that they are just people, that they have the same wants needs and desires as the rest of us, then essentially what I'm saying is that we need to value the care that people are providing and pay commensurate with that value.

The stakeholders also discussed case managers as another type of professional who provides services to people with developmental disabilities. They noted that an assessment of this position must be conducted to clarify how—or whether—it benefits the system.

3. Availability

The stakeholders raised the concern that, even if people with developmental disabilities and their families gain more control over the resources needed to obtain services, there may not be a “market” of services that can be purchased. Currently, both the professionals and staff to provide services and programs are limited. As one approach to encourage an increase in services, the stakeholders suggested that the pricing structure be changed. If an attractive cost structure develops, more services will become available. In other words, increases in services are related to the way that the services are priced, and to the value that the system places on these services. One stakeholder summarized the dilemma of instituting changes to the system that give people with developmental disabilities more choices and more resources, but that do not support market incentives that will result in having services available: “If the pricing is right, it will open up opportunities for new businesses. You can make a change to the system, but if you don’t price it right, you won’t have any providers.”

The stakeholders described two direct consequences of failing to have services available. Specifically, they noted that the lack of availability imposes a burden on the family of the person with the developmental disability, and that it also results in a missed opportunity to tap the undeveloped potential of the person with the developmental disability.

One area of particular concern was the availability and amount of support for respite care. Currently, the system supports 20 hours per month of respite care. According to the stakeholders, however, that amount represents only about five percent of the hours of care that a person with a developmental disability actually requires. The failure to provide the remaining 95 percent can be detrimental to the well-being of other members of the household. One family member who cares for a person with a developmental disability described the inadequacy of the current respite program and the consequences on the family:

Currently, in New Jersey, if you go through DDD, there is 20 hours per month of so-called respite services, which is what I'm eligible for. That's not adequate; especially as the children age, problems come about if you're attempting to go to work or you have other younger children. When your child becomes an adult, it gets very difficult with the current system to maintain a normal functioning life. I had to quit work when my son left the school system.

4. Communication

System change is dependent on the information that is available to people with developmental disabilities and their families. The stakeholders' comments about communication can be organized around three themes: (1) awareness of existing programs and services, (2) standardization and consistency, and (3) program acceptance and participation.

a. Awareness of Existing Programs and Services

Services will not be accessed if people with developmental disabilities and their families do not know that they are available. As the stakeholders pointed out, people need to know what is available before they can use it. Furthermore, it is not only the families who are entering the system who are not knowledgeable, but those who would be expected to serve as references. A stakeholder discussed the way that this lack of information throughout the system has a direct impact on the families of people with developmental disabilities:

When you come into the system, you don't even know what to ask of your case manager.... They [the family] spend an inordinate amount of time figuring it out because sometimes the people who are there to help them also don't know enough. Usually it's a case manager or a pediatrician. Some pediatricians are great; some don't even refer to DDD.

b. Standardization and Consistency of Information

The stakeholders recommended establishing a communication system that serves as a standardized source of information. In the current system, the amount and the quality of information available are inconsistent across the state. For example, the amount and quality of

information are better in some regions of the state than in others. This lack of consistency results in mixed messages, erodes people's trust, and requires that people expend time and energy unnecessarily to find useful information. A resource center that people would know about, use, and trust could improve the system. The variety of messages and messengers in the current system at the state level were summarized by one of the stakeholders:

There's no coherent state message on a lot of things, whether you're talking about caregivers or families with disabilities. You get a lot of different messages: The DD Council gives you one, DDD gives you another, DMH will give you another. They need to work on their communication.

Statewide communication is not the only issue that the stakeholders believe is a problem. As described by one stakeholder, improvements are needed in different geographic regions of the state:

There seems to be a communication issue about what's available in each area. If the communication about availability of resources were standardized, so that every region had some kind of standardized manual of resources, that would eliminate a lot of this scrambling around and multiple phone calls.

c. Program Acceptance and Participation

Communication is critical to convey information about new programs, but the current system has not been effective in educating people with developmental disabilities and their families. For example, the state must communicate about programs, such as changes in the Medicaid waiver, to gain support and encourage participation; the result of not informing the target population may be resistance to the new program or program component. In speculating about the introduction of a new approach to funding programs through participation in a revised Medicaid waiver, a stakeholder cautioned about the consequences of failing to communicate effectively:

Communication is going to be key. You talk about a waiver-based program and people's eyes begin to glaze over, except those who think they're going to have to pay more for the care of the individual. There's going to be a healthy education component here.

Some stakeholders described communication inefficiencies from the perspective of the costs to the system when communication is not done effectively. People have to expend time and energy to find useful information. Without information about the existence of programs and services, people with developmental disabilities do not obtain the care that they need.

The stakeholders also expressed concern about the difficulty of correcting misinformation after it has been disseminated. According to some stakeholders, there has been an erosion of trust and confidence in the current system, and a focus on improving communication is needed if there is to be effective system change.

C. SYSTEM PLANNING NEEDS: COMMUNITY INTEGRATION

The stakeholders identified community integration as having definite benefits for people with developmental disabilities and for the implementation of system change. The stakeholders' comments about community integration can be organized into three themes: (1) promote community acceptance of people with developmental disabilities, (2) use and enhance the availability of local services, and (3) provide family support.

1. Promote Community Acceptance of People with Developmental Disabilities

There is consensus among the stakeholders that one of the goals of system change is to support community living for people with developmental disabilities. According to the stakeholders, to achieve this goal, the community will have to recognize and accept the best ways to provide the support. The stakeholders described positive improvements that they have experienced, but they also noted that those types of improvements must be expanded. For

example, one stakeholder described a time in the past when taking a group of people with developmental disabilities to a fast food restaurant would result in other patrons leaving. He then commented that he has seen that type of behavior decline. However, a parent of a child with a developmental disability described a recent trip to a mall, during which people moved to the other side of a walkway to avoid his daughter. Thus, despite some improvements, community acceptance still has to be nurtured and improved. Realistically, one stakeholder described community acceptance as a long-term objective:

The first one [roadblock] is trying to change the public's perceptions of people with disabilities. That's a huge task, and I don't know if that's going to be accomplished in any short amount of time.

For another stakeholder, community integration is at the top of the system change agenda:

The top improvement I would like to see is for the individual to feel included in their community in some way, whether socially, through recreation, through someone's interest by coming to the home to help the family with any unique situation.

2. Use and Enhance Local Services

Having people with developmental disabilities live in the community provides for opportunities to use public funding and public resources more effectively. Instead of investing in duplicate or parallel services that segregate people with developmental disabilities from others in the community, and that result in expenditures to build or administer separate systems, the stakeholders suggest seeking opportunities for integration. For example, a community or institutions within the community, such as religious organizations or local libraries, that already have programs for recreational activities, cultural events, or transportation assistance can incorporate services for people with developmental disabilities. As one stakeholder commented,

in the past, the system focused on creating separate services for people with developmental disabilities, whereas in the future, the system should promote integration:

We created these barriers as providers and as the general public, thinking that it wasn't a match or a fit. We need to get communities more attuned to who is living there and find ways to serve them with other people that are there using existing services.

3. Provide Family Support

A clear message from the stakeholders is that finding a way to keep people with developmental disabilities at home will improve the system. Family members underscore this need when they remind us that no one “can care for a loved one better than his or her family.” However, it is also clear that families need support and public policies that sustain the family in order to provide this care. The stakeholders suggested providing the following types of support: (1) time off from caring for the person with the developmental disability; (2) education for the caregivers, so that they will know what services are available in the system and can gain the expertise to care for people with developmental disabilities; (3) assistance with programs and actions that are preventative, rather than having the family members wait for a crisis to develop; and (4) access to the resources that are needed to support a person living in the community.

Even though providing families with staff to assist them could appear to be a solution, one stakeholder reported that, by itself, such a step might not be sufficient:

One thing I've been hearing a lot is that managing staff—hiring and firing people—that's a very hard thing for many families to deal with. I'm hearing there's a recognition that families need to be trained and supported in that role because it doesn't necessarily come naturally.

D. VISION FOR QUALITY OF LIFE

As described in the previous sections of this chapter, the stakeholders offered many suggestions for system changes. To understand what these changes would mean for a person

with a developmental disability, the stakeholders were asked the following question: “What’s your vision of how a person with a developmental disability would go about getting the highest possible quality of life?” The responses to this question centered around two themes: (1) having opportunities to make choices, and (2) establishing quality standards.

1. Having Opportunities to Make Choices

There was a consensus among the stakeholders that the foundation of a quality life consists of giving an individual the opportunity to make his or her own choices. The stakeholders recognized that this approach to providing the highest-quality life possible for people with developmental disabilities carries some risk. In particular, there is the risk that people with developmental disabilities might make bad choices. Even so, according to the stakeholders, the current approach to providing care and services to people with developmental disabilities is too risk adverse; the system should “let go” and allow people to make decisions that might be mistakes. A system that overly protects people is one with additional costs. Thus, keeping a person with a developmental disability in a “bubble,” as one stakeholder described the actions of the current system, can have adverse consequences for people and the resources available in the system. Changing this attitude and giving people with disabilities choice was described by one stakeholder as a major shift in the current approach to care:

The other thing is the system—the government, the funding, the DDD—there needs to be a cultural shifting in the way we look at how paternal we are. Sometimes we try to protect people from every sort of risk imaginable, so it becomes very costly to try to provide community services. It requires more staffing, such as protective staffing. We can’t try to fix everyone. People need the right to risk, the right to dignity, the right to make their own decisions for better or for worse.

2. Establishing Quality Standards

A challenging aspect of any discussion about a vision of quality of life for people with developmental disabilities is the lack of agreement about the definition of “quality.” The stakeholders observed that, in discussions of quality, they focus on the quality of services, rather than on people’s experiences and the outcomes for individuals. One stakeholder described the difficult task of redefining quality from the perspective of the person who has a developmental disability:

The field of developmental disabilities has only begun to think about quality. They talk about quality, but in essence, they’re not really talking about quality, they’re talking about monitoring, about licensing, about regs. They’ve really not looked beyond what’s a quality program.... I just don’t think we’ve got enough experience under our belts as a whole system to talk about the issues of quality. Systems have been regulatory in nature, they’ve been monitoring in nature, they’ve been essentially trying to enforce regulations rather than looking at quality-of-life issues.

One of the stakeholders, who is a person with a disability, summarized his vision:

We as a society need to start looking at everyone as an individual. And everyone has something to offer, no matter what. You may look at me in this chair and see me in one aspect, when the aspect could be totally different once you get to know me. So if we don’t get to know people, then how are we making assumptions that people can and cannot do certain things? How are we to know unless we let somebody try, and give them the option to try? In a perfect world, in this world even as it is, I would say, yes, people have a right to live where they want to live, whether it be minimal supports or whatever it takes. Because I think in the long run, and this is what everybody wants, we’re saving money. But on the other hand, I don’t want to save money and jeopardize somebody’s well-being. But I think that people should have the freedom to do as they choose. If they do not have the freedom to choose, I think they should be in the least restricted environment they could possibly be in to enjoy whatever freedoms they can enjoy. If that makes me a “rose-colored glass” type, so be it, maybe I’ll be the only one standing there, but at least that’s my opinion. And because I’m in the United States I can express it. Maybe someday somebody’s going to take a piece of that and say “You know what, [he] wasn’t so far off base.” We could tweak it and if we fine-tune it, and we take this piece from over here. I’m not saying that I have all of the answers, but I just wish—again, as long as people are listening and as long as there is dialogue, there is always hope. It’s when we stop listening and there is no dialogue that there is no hope.

E. ROADBLOCKS TO SYSTEM CHANGE

The observations from the stakeholders outline optimistic plans for improving the current system of providing care and services to people with developmental disabilities and their families. The stakeholders also described their vision for their type of life that would be most desirable for people with developmental disabilities. However, although they offered many suggestions about what a reformed system should look like, they also were realistic and identified four roadblocks that could prevent system change: (1) the current system, (2) managing change, (3) trust and fear of change, and (4) the diversity of the developmental disabilities population. These are examples of the types of roadblocks that the stakeholders identified. It is also important to note that, because of potential differences in the decision makers' and stakeholders' approaches to implementing change, additional barriers may be created as change actually begins to happen.

1. The Current System

During their discussions about aspects of the current system that must be changed, the stakeholders also spoke about roadblocks to any type of reform. These roadblocks can be summarized as follows:

- ***Inequities in the Current System.*** As previously described, the current system favors people with developmental disabilities and their families who are in the system, who may be getting more resources than they require, and who therefore will have a vested interest in keeping the system as it is.
- ***Lack of Integration and Cooperation.*** Within the current system, different groups and agencies have forged their own paths. To effectively change the system, collaboration among these groups and agencies is essential.
- ***Change Service Delivery by DDD.*** Conducting “business as usual” within the key state agency that provides services to people with developmental disabilities and their families will be a barrier to changing both the idea of how service is defined and the way that service is delivered.

- **Committees.** Although establishing different committees to address the needs for system change can be useful, these committees also can be a barrier to change. If committees are established to recommend actions, rather than to develop a meaningful process for actual changes, they can be more detrimental than useful.
- **Continual Changes.** The types of system change suggested by the stakeholders will not take place within the term of one elected governor's administration. The stakeholders suggested that, as an optimistic projection, some changes would occur within a five-year time frame. For meaningful change to occur, the stakeholders recommended that stability in developing and implementing programs be ensured. In addition, programs will have to be evaluated while they are being implemented. The stakeholders have envisioned a process that provides a timely assessment of what does and what does not work. They recommended this process so that program revisions would be evidence based, rather than political choices made by newly elected administrations.
- **Bureaucracy.** The current system is supported by an established bureaucracy. If the existing bureaucracy is not changed or dissolved, it will be a barrier to system changes.

2. Managing Change

The stakeholders recognized that changes in the system must be managed in order to be successful. They recommended having a transition plan as the state moves from the current system to a reformed approach to providing services to people with developmental disabilities and their families. A key role of managers of the transition will be to act as communicators. As the example of possible changes in the Medicaid waiver to gain additional resources showed, participants in the system would have to understand why the waiver is important. Managing change also will involve convincing all the members of the developmental disabilities community to work together. Historically, this community has focused on individual needs, rather than on system needs. One stakeholder described why it is important to convince this community to collaborate:

Well, what you're really doing is opening a can of worms, as such, you have a divided community; each aspect of it has a vested interest in its own needs and not a sense of what's integrated or constitutes great services that would most effectively benefit the entire population.

3. Gaining Trust and Overcoming Fears

The stakeholders identified another roadblock to system change: the need to bring together people who have had negative experiences with the current system, and who therefore have concerns about the viability of any future reforms. Promises of reform have been made in the past but have not materialized, so there is a climate of distrust among members of this community. Given these failed promises and past instances of misinformation, convincing people with developmental disabilities and their families to buy in to any type of change will involve addressing their concerns. In addition, these consumers currently are facing real-time needs. They wonder whether they will be able to wait for changes to happen. The stakeholders commented that people with developmental disabilities and their families who are anxious for a “quick fix” to their immediate needs may not be willing to wait for longer-term solutions. One of the stakeholders did not have high expectations that he would benefit from any reforms. He noted that he is participating on committees and other efforts for system change to help people in the future, not because he believes that his effort will help his own daughter now.

The stakeholders noted that people with developmental disabilities are not the only ones who mistrust the system, and who have concerns about the future. As one stakeholder summarized, the concerns of all of the participants in the system must be considered to ensure a successful reform effort:

But I think at the heart of a lot of the resistance are fears. Whether it's people's jobs changing or people in the community, I think we need to really be listening to what the underlying fears are and address them.

4. Nature of the Developmental Disabilities Population

The stakeholders have recognized that one of the roadblocks to system change is the nature of the developmental disabilities population. There is a great deal of diversity within this

population, and that diversity must be considered in any change effort. The population's diversity extends beyond the various types and levels of disabilities to the economic and social conditions of people with developmental disabilities and their families. In addition, this population is fragmented, decentralized, and sometimes isolated, so that activities, such as communicating information and providing services, can be complicated efforts.

F. HOW CAN IT BE DONE?

All of the stakeholders have recognized that changing the current system will be complicated. The most difficult question that the stakeholders tried to answer was that of how change can actually be done. The following points highlight the key changes suggested by the stakeholders and discussed in this chapter:

- Change the perceptions of who people with developmental disabilities are, and change the perceptions of their capabilities.
- Change the kind of support that is given to people with developmental disabilities and their families, particularly within the communities in which they live.
- Change the way that the current system is structured to promote a broader continuum of services, and to increase the choices for service options.
- Change the contracts that are given to provide services in order to increase flexibility. In this way, funding that is not used for one service can be allocated easily for another service that is needed.
- Change communications to maximize the information available to the developmental disabilities community.
- Change the service and care priorities based on what members of the community identify as their needs, and give people with developmental disabilities and their families the resources to purchase what they need.
- Change the leadership and program development so that it is stable and permanent. Policies and programs that are not given time and continuity to develop cannot be established.

The following profile summarizes the stakeholders' view of the challenges inherent in the current system and the steps that must be taken if the system of providing services to people with developmental disabilities and their families is to be changed:

The most important piece for me is that the projected changes really are profound improvements to the system. It means being able to better serve more people or to serve more people. I also think that this plan has the public interest at heart, where the current system is essentially designed to meet the needs of the people who have the squeakiest wheel. Right now, we—through resources—my impression is that the people who get the most services or the most expensive services right now are folks who sue, who get politicians involved, who yell, rant, and rave, and they get attention. In order for people to keep quiet, resources are thrown at individuals and families to make nice again, to keep them quiet, to keep the politicians off your back. I really think that by having a more fair and equitable system, a system that goes after as many of the resources as possible—I think whatever system comes out, you need to balance the needs of the individuals and the families against the public interest and that public dollars are being spent wisely, fairly, and equitably.... It depends, it's probably not all 30,000, but there's probably individuals in that 30,000—I can't tell you if it's 5 or 5,000—but there are certain people who get Cadillac services. We change their lives, we change their value systems. They come from being poor, inner-city families, and we put them in large, upscale affluent communities in super group homes, and we change people's lives. There are certain individuals who get a lot more of the resources than many others, and it's got to do with who can manipulate the system, who can call more politicians, who can yell more, who cry more, who can get a lawyer. I don't necessarily know it's done in the public interest. I think it's done to ameliorate a situation.

III. NEW JERSEY DIVISION OF DEVELOPMENTAL DISABILITIES OPTIONS PLAN

In September 2002, the New Jersey Department of Human Services, Division of Developmental Disabilities (DDD), distributed a plan for reforming the provision of services to people with developmental disabilities and their families, called the New and Expanded Options for New Jersey's Consumers with Developmental Disabilities and Their Families (Options). Many of the stakeholders had been included in the process that produced the topics in this plan, and they also participated in the initial Options informational meetings. A copy of Options was included in the pre-interview packet sent to each stakeholder. The topic guide for the stakeholder interviews included questions about the plan so that the stakeholders could comment on what the state had outlined in this document. The interviews focused on obtaining an overall impression from the stakeholders of Options, as well as a priority ranking of the six actions listed as next steps for FY 2002. They were an opportunity for Mathematica Policy Research, Inc. to obtain insights for DDD on the stakeholders' reactions to the reforms proposed in the Options document.

Options is a 14-page document that begins with a profile of the current system, including statistics on expenditures, a description of institutional care and community services, and an outline of current resources and revenues. (See Appendix F for the complete Options document.) Options includes a vision of the direction in which the state would like the system to evolve, and the expected changes that would be made if this vision were to be realized. Options describes an approach to maximize revenues, reinvest in expanded services, design family-friendly service options, build on investments in institutions, work in partnership with members of the developmental disabilities community, and explore interdepartmental and interagency

agreements to expand resources. Specifically, it lists six short-term actions for FY 2002 and concludes with a summary of the dynamics of change that support the actions outlined in the document and a commitment to the process.

A. OVERALL IMPRESSIONS

Two key themes emerged in the stakeholders' observations about Options. Almost unanimously, the stakeholders had positive overall reactions. In giving their initial impressions, they used such phrases as "Breath of fresh air"; "First time I feel listened to in 20 years"; and "I think they're wonderful. If they could be realized, it would be a very significant improvement in the system." However, the optimism was almost universally tempered with the concern that "the devil is in the details." Thus, although the stakeholders observed that the Options document both captured the key weaknesses in the current system and outlined useful concepts for consideration, they also expressed concern that the state would not be able to move from concepts to actions.

The previous chapter has outlined the barriers to changing the current system of providing services to people with developmental disabilities and their families that the stakeholders identified during the interviews. In direct response to the Options document, the stakeholders reinforced those observations. The stakeholders stressed that the process for implementing actions outlined in Options should be inclusive; in particular, they stressed the importance of including people with developmental disabilities and their families. One stakeholder summarized the need for family involvement:

I hope they continue to include the families in their process. It's easy to not see the forest for the trees sometimes, and having a designated group of family people to bounce things off of would be very helpful.

Furthermore, although the stakeholders' comments about inclusion focused on people with developmental disabilities and their families, the stakeholders also suggested that "it's important to get everyone involved" to really make change happen. One stakeholder underscored what other stakeholders noted about the state's presentation of Options: "The Director should not deliver this to people as the plan. It's not a certainty plan; it's the beginning of a new way of doing things." The stakeholder went on to caution that successful system change is a process, not a completed document.

Multiple stakeholders used the expression "the devil is in the details" to express their recognition that Options is a starting point that provides a context and describes what the system needs, but that it does not take the next step of outlining how to make change happen. One stakeholder summarized this perspective, based on his discussions about Options:

What I'm hearing most people say is everyone from the providers' side, from a philosophical point of view, everyone thinks it's heading in the right direction. The biggest concern is how it actually gets implemented and operationalized.

B. PRIORITIES FOR NEXT STEPS

Options concluded by listing six actions that would be the next steps taken to improve New Jersey's system for the provision of services for people with developmental disabilities and their families. To identify their priorities among the next steps, the stakeholders were asked during the interview to rank order each of the six steps, from 1 (most important) to 6 (least important). They were asked to rank the steps both for the entities they represented and for the statewide system as a whole. The reason for the dual rating was to identify actions that the stakeholders might prioritize differently, depending on the context. Almost every stakeholder gave the same ranking for both perspectives. Each of the following six actions, in order of priority, is followed by the average ranking score given by the stakeholders:

1. Begin service planning and program development in partnership with consumers, advocates, families, and providers (1.84).
2. Develop an expanded waiver (2.32).
3. Redesign case management to meet consumer needs (3.24).
4. Design a consumer-friendly intake process (3.36).
5. Develop a consumer assessment tool (3.86).
6. Create interagency agreements (4.20).

In their discussions of the ranking exercise, the stakeholders noted that it was challenging to identify priorities, because every action was important. The stakeholders who selected service planning as a priority gave as their rationale the need to know what the system will look like before taking actions to finance and support it. In comparison, others thought that program development should take place only after information about the available funds had been obtained.

Among the stakeholders in the developmental disabilities community, DDD has a group of leaders who are committed to improving the system of services for people with developmental disabilities and their families. These stakeholders are positive about the inclusive process used to develop Options. They have recommended that DDD continue to follow this path of inclusion by partnering with people in the developmental disabilities community as it lays out the alternatives to change the system.

IV. STAKEHOLDERS' FORUM SUMMARY

The Stakeholders' Forum, held on March 1, 2003, was convened so that the various stakeholders could come together to discuss the themes identified in the interviews and described in the previous chapters of this report. The attendees included the stakeholders who were interviewed and representatives from the New Jersey Governor's office, the New Jersey Department of Human Services (DHS), the New Jersey Division of Developmental Disabilities (DDD), and the New Jersey Developmental Disabilities Council (DDC). The Stakeholders' Forum was facilitated by the project team from the University of Medicine & Dentistry of New Jersey (UMDNJ) and Mathematica Policy Research, Inc. (MPR). The main purposes of the Forum were to review the results of the stakeholder interviews, and to give stakeholders an opportunity to discuss the results in breakout groups. The appendices provide a list of forum participants, a copy of the agenda, a summary of the topics covered in the breakout group topics, and the discussion guide used by the breakout groups' facilitators.

A. OVERVIEW OF THE STAKEHOLDERS' FORUM AGENDA

The Forum began with presentations from the representatives of the planning group. Three unique perspectives are represented by this group: (1) New Jersey government is responsible for providing services and for policy decisions related to people with developmental disabilities and their families, (2) DDC is mandated by law to advocate for systemic change to benefit people with developmental disabilities, and (3) UMDNJ and MPR are neutral academic and research organizations with public policy expertise. The presentations were intended to ensure that all Stakeholders' Forum participants had the most up-to-date information about the status of reform activities from these different perspectives.

Maureen Babula, the chair of the DDC, began the Forum by underscoring that the purposes of the meeting were to “continue the dialogue” about systemic change, and to work together to improve the quality of services for people with developmental disabilities. Patrick Brannigan, from Governor McGreevey’s office, reminded the stakeholders that many issues compete for public policy makers’ attention and for state financing. He observed that, if those who are committed to developmental disabilities issues remain a “divided community,” they will not be given attention from policy makers. Brannigan also noted that the stakeholders’ process represented an opportunity to get people “to come together and to work together,” and that, by working together, “there’s a strength that sustains the effort” to bring about reforms in the delivery of services to people with developmental disabilities and their families.

Theresa Wilson, DHS’s assistant commissioner, stressed that DHS is committed to reforming the system. After she was introduced and gave her comments, Jim Smith, director of DDD, outlined DDD’s current activities and proposed future actions. He noted that DDD wants a new “pathway” to more effectively provide services to people with developmental disabilities and their families. DDD will develop the pathway by listening to people in the developmental disabilities community. Smith was very candid in his acknowledgement that there had been a loss of confidence in DDD, and he admitted that “we must change.” He also stated that the current system “lacks equity and lacks clarity,” and that it is “leaving too many people behind.”

A presentation by Janice Ballou, a vice president at MPR, summarized the results of the stakeholders’ interviews. These results are described in Chapters II and III of this report. Lois Grau, of UMDNJ’s School of Public Health, gave an overview of the topics for the afternoon breakout groups and the guidelines for these discussions.

The Forum’s afternoon activities focused on the breakout groups. Each group selected a representative, who gave a presentation on the results from the breakout discussions.

B. OVERVIEW OF THE BREAKOUT GROUPS

The following three breakout groups were organized around key themes from the stakeholder interviews. For each topic, the stakeholders were given some suggested issues to consider in their discussions.

1. *Shifting Resources, Shifting Decision Making About Resources*

- What can be done to make the system equitable?
- How would a contribution-to-care approach work?
- How and when should the stakeholders be involved in planning the expanded use of the Home and Community Based Services Waiver?
- How will shifting decision making about the use of resources from the provider to the individual be accomplished?
- How can resources be allocated to support a continuum of care?
- What are the current and future roles of the developmental centers?

2. *Focus on Quality of Lives, not Quality of Services*

- What is quality? Who defines it?
- How can we support consumer choice?
- What should be considered in an assessment used to determine who receives what services?
- How do we help families keep their loved ones at home?
- How do we develop a workforce to support quality lives?
- How can communities be encouraged to include people with developmental disabilities?

3. *Ending the Search, Achieving Information Equity*

- What messages must be communicated to implement reforms to make the system work?
- Who needs to hear them?
- How can key messages be delivered?
- Who is responsible for providing information?
- Who is the best messenger?
- How do we determine whether the messages are received and understood?

Each group was led by a trained facilitator, who guided the discussion. The following assignment was given to provide the groups with a standardized framework for their topics:

1. Develop a priority list of the top three to five issues or actions that must be addressed.
2. Identify individual people or specific agencies or organizations that must be included in any discussion of the subject, and identify the role or contribution that each would make to the discussion.
3. Identify the process to make the issues listed as priorities happen.
4. Describe the desired outcome of the process.

In addition, the groups were asked to spend a few minutes discussing the Stakeholders' Forum process. In particular, they were asked to respond to two questions: (1) How would you like the Stakeholder Forum process to work? and (2) What role can the Stakeholder Forum contribute to advancing system change?

On average, each group consisted of seven people, including people with developmental disabilities; family members; and representatives from government agencies, service delivery agencies, and advocacy groups. Group assignments were made to ensure that the discussions of each of the topics would benefit from having diverse perspectives. An important goal of the Stakeholders' Forum was to give the participants the opportunity to listen to each other, so that they could observe first-hand the areas of agreement and disagreement about issues among different entities in the developmental disabilities community. Each group selected a representative to present a summary of its discussion to all Forum participants during the final session.

The suggested agenda was ambitious, given that the groups met for one hour, and, as a result, none of the groups were able to cover all of the suggested topics. Each summary presentation lasted about 15 minutes and focused on a top-line inventory of what the group had

discussed. The outline of the topics developed and presented by each of the three groups is shown in Appendix G.

1. Breakout Group Themes

The presentations of the groups underscored the general consensus among the participants on issues that also had been identified in the stakeholder interviews. Furthermore, although some specific recommendations in the groups were unique to the groups' particular topics, more frequently, similar themes emerged across the three groups.

a. Resources

Whether the need is for improved communications, services, or overall quality of life, the stakeholders recommended maximizing the efficiency with which current resources are used, rather than financing new efforts to meet those needs. Instead of budgeting funding exclusively for people with developmental disabilities, opportunities should be identified to integrate these people into existing programs.

b. Communication

People with developmental disabilities and their families are dispersed across the state, and an effective communication system is necessary to disseminate program and policy information on such topics as the Medicaid waiver, as well as information about services and building connections within the developmental disabilities community. Regardless of what is being communicated, the message must be clear, consistent, and easily accessible. Communication is a priority because successful systemic reform cannot occur unless people with developmental disabilities and all other participants in the system, such as direct care providers, case workers, and medical professionals, have access to and share the same information.

c. Equity

The stakeholders agreed that there are inequities in the current system, not only in the services that people with developmental disabilities and their families receive, but in the level of information these people are given and in their overall quality of life. Equity can be achieved in a variety of ways, such as providing additional financial resources, offering more flexibility in the choice of services, and improving and more fully integrating systems of care.

d. Choice

All the breakout groups focused on the theme of creating a system that would give people with developmental disabilities more choice about all aspects of their lives. In making decisions about services, having choice also means having a continuum of care options available. These options can range from developmental centers to independent living. Choice also requires a system that is flexible, so that people with developmental disabilities can shift easily from one type of care to another. To give people more choices, the system has to ensure that options exist, that information is available to make informed choices, and that individuals have control of the resources to fund their choices.

e. Inclusion

The process of developing an effective system has to be inclusive. To make reform happen, it is necessary to forge partnerships, and to develop a shared understanding of what actions must be taken. The stakeholders noted that it is particularly important that the reform process include people with developmental disabilities. These people have been isolated and have not been included in decisions that have a direct impact on their quality of life.

2. Recommendations for the Stakeholders' Forum

All of the groups agreed that the Stakeholders' Forum was a useful process that should be continued. The groups made the following suggestions about the topics and structure of future forums.

a. Topics for Discussion

The stakeholders suggested three possible topics: (1) the future of the developmental centers, (2) identification of the constituents of a continuum of services, and (3) development of a definition of equity.

b. Participation

The stakeholders recommended that more people with developmental disabilities be included in meaningful ways and in meaningful numbers. They also suggested that people with developmental disabilities could have their own forum process. Another consideration for participation in future forums should be the diversity of the selected stakeholders. Scaling down the size of the forums and holding them on a local level was another suggestion.

c. Attendance Support

People who need transportation or who require child care services could find it difficult to attend a forum. A suggestion was made to provide stipends to ensure that a lack of resources would not be a barrier to participation.

d. Meeting Mode

An approach to make future forums more accessible was to consider using teleconferences or finding other ways to communicate the information discussed in the forums.

3. Forum Summary

In conclusion, the stakeholders recognized that “change happens in small increments.” The discussions in the Stakeholders’ Forum underscored both the consensus that there is a need for change and the consensus about the principles that should guide that change. The stakeholders share a sense of what would have to be accomplished to change the system. Although these issues are complex, the stakeholders are committed to a process that will improve the quality of services and the quality of life for people with developmental disabilities and their families.

BIBLIOGRAPHY

- Hall Apgar, Dawn, Paul Lerman, and Tameeka Jordan. “Living at Home: A Closer Look. Summary Report #2 of the Family Support Study.” Newark, NJ: New Jersey Institute of Technology, 2000.
- Hall Apgar, Dawn, Paul Lerman, and Tameeka Jordan. “Living at Home: Summary Report #1 of the Family Support Study.” Newark, NJ: New Jersey Institute of Technology, 2000.
- Harris, Gwendolyn L. “DHS Commissioner Harris Announces Sweeping Changes to Service System for People with Disabilities.” Press release, September 20, 2002. Available online at [www.state.nj.us/humanservices].
- New Jersey Department of Human Services, in collaboration with New Jersey’s Stakeholder Task Force on the Olmstead v. L.C. Supreme Court Decision “Achieving Community Integration for People with Disabilities: New Jersey’s Working Plan.” Draft Department of Human Services working document. Note: The document does not have a date; the group is estimated to have worked and met during 2001. This document reports the minutes of its meetings.

APPENDIX A

MEMBERS OF THE STAKEHOLDERS' FORUM PLANNING GROUP

STAKEHOLDER FORUM PLANNING GROUP MEMBERS

Maureen Babula

Chair, New Jersey Developmental Disabilities Council

Patrick Brannigan

Deputy Chief, Governor's Office of Management and Operations

Carol Grant

Acting Deputy Director, New Jersey Division of Developmental Disabilities

Susan Hammerman

Project Director, Developmental Disabilities Family Support and Information Project, Health Systems and Policy Division, The University of Medicine and Dentistry of New Jersey

Kevin Ryan

Deputy Chief, Governor's Office of Management and Operations

Bernadette West

Assistant Professor, The University of Medicine and Dentistry of New Jersey

Janice Ballou

Vice President and Director of Survey Operations, Surveys and Information Services Division, Mathematica Policy Research, Inc.

Ethan Ellis

Executive Director, New Jersey Developmental Disabilities Council

Lois Grau

Associate Professor and Head, Health Systems and Policy Division, The University of Medicine and Dentistry of New Jersey

Susan Richmond

Deputy Director, New Jersey Developmental Disabilities Council

James Smith

Director, New Jersey Division of Developmental Disabilities

Theresa Wilson

Deputy Commissioner, New Jersey Department of Human Services

APPENDIX B

STAKEHOLDER PARTICIPANTS

STAKEHOLDER PARTICIPANTS

Lowell Arye

Alliance for the Betterment of Citizens with Disabilities (ABCD)

Maureen Babula

New Jersey Developmental Disabilities Council

Tom Bruno

Communications Workers of America Local 1040

Enrico DeGironimo

Developmental Resources Corporation

Ethan Ellis

New Jersey Developmental Disabilities Council

Leila Gold

Coalition of Families for Responsible Care

Eloise Hawkins

New Jersey Division of Developmental Disabilities

Eric M. Joice

Epilepsy Foundation of New Jersey

Richard Lecher

SCARC

Sarah Mitchell

New Jersey Protection and Advocacy, Inc.

Krystal Odell

Allies, Inc.

Diana Autin

Statewide Parent Advocacy Network (SPAN)

Tom Baffuto

The ARC of New Jersey

Diane Conway

New Jersey Association of Community Providers

Lorraine D'Sylva-Lee

Family

Barbara Geiger-Parker

Brain Injury Association of New Jersey

Sherryl Gordon

New Jersey Public Employees Council #1

Jane Horowitz

Spina Bifida Association of New Jersey

Mary Kneuer

Family

Bob Lowe

New Jersey Division of Developmental Disabilities

Kathleen Nugent

Regional Family Support Planning Council #5

Paul Potito

The New Jersey Center for Outreach and Services for the Autism Community (COSAC)

Darlene Reeves
Family

Annette Smith
Regional Family Support Planning Council #4

Stanley Soden
Individual

Regina Tegler
Regional Family Support Planning Council #3

Franklin S. Unkle, Jr.
The ARC of Cape May County

Holly Wescher
Individual

John Rubis
Regional Family Support Planning Council #8

James Smith
*New Jersey Division of Developmental
Disabilities*

Deborah Spitalnik
The Boggs Center

Frank R. Tetto
Family

Loretta Weinberg
New Jersey State Assembly

APPENDIX C

**MEMBERS OF THE NEW JERSEY DEVELOPMENTAL DISABILITIES COUNCIL
COMMITTEE ON QUALITY IN LONG TERM CARE**

**NJ DEVELOPMENTAL DISABILITIES COUNCIL COMMITTEE ON
QUALITY IN LONG TERM CARE**

Maureen Babula
Chair

Bob Allen

Roy Carbone

Ann Gallagher

Virginia Peters

Deborah Spitalnik

Tom Reddington

Joe Young

APPENDIX D

STAKEHOLDER INTERVIEW MATERIALS

**UMDNJ/DDC –
STAKEHOLDERS FORUM
FINAL DISCUSSION GUIDE
October 7, 2002**

Total Time-approximately 45 minutes to an hour

INTERVIEWER:

- **The interview will be framed by a discussion of systemic change (long term planning needs) and DHS options proposal (short term issues).**
- **You are not an expert on this issue; please make sure you ask for and get clarification on any legislation, terms, policies, etc that you do not understand**
- **You are there to listen; if respondent asks questions tell him/her you will write them down and get back to him/her(or someone who knows the answer will. Explain you will need to give his/her name to have this type of contact)**

I. INTRODUCTION (5 minutes)

- A.** I'm (NAME) and I'm here to talk with you as part of the Developmental Disabilities Stakeholder's Forum.
- B.** You should recently have received a letter from Governor McGreevey detailing the objective of this project together with some information about the project. You should also have received a letter from UMDNJ and MPR enclosing a copy of the options plan announced recently by Commissioner Harris of NJ Department of Human Services.

Have copy of Governor McGreevey letter and FAQ to show/leave behind if needed; have a copy of the DHS Options to show/share if needed.

C. Overview of the Interview:

Thank you for taking the time to talk with me about the key issues that need to be addressed to provide quality services to people with developmental disabilities and their families. To make sure all the stakeholders included in the project discuss the same topics, I'll be using a topic guide (**SHOW TOPIC GUIDE BUT HOLD ON TO IT**). In addition to outlining the topics I'll cover today, the guide also has a suggested amount of time we'll spend on each subject.

To give you an idea of the format for this discussion, I'd like to spend about 30 minutes talking about long-term suggestions for changes that are needed in the overall system.

Then, we'll focus on the recent plan of new and expanded options for New Jerseyans with developmental disabilities announced by Commissioner Harris of the Department of Human Services. (show/give copy if needed).

Confidentiality and Taping: All of the interviews we conduct will be confidential—unless you would like to have your comments attributed to you. Our report will talk about the key themes that emerged, not who specifically made a statement. In some cases we may use verbatim comments so the report will reflect the theme in the specific words of the speaker. A section of the report will list the names and organizations of all the participants.

With your permission, I would like to tape record this interview. By taping, I can listen to you and not have to take extensive notes and also, I will have the tape to refer to when I prepare the report.

Have the respondent sign confidentiality agreement.

II. SYSTEMIC CHANGES (LONG TERM CONSIDERATIONS/SYSTEM PLANNING NEEDS) (20-30 minutes)

Let's talk first about changes that need to be made in the overall system.

As you think about these, please focus on what you think would work best for the overall system, not only on what will work for the group or organization or point of view that you may represent.

Also, often changes in a system means there may be trade-offs—to gain something, you may need to give up something. Please think about and comment on the trade-offs you and/or your organization would consider.

Interviewer: Keep R focused on overall system. This may mean discussing trade-offs of what is best for the group he or she represents versus what needs to be done to best meet the needs of all the participants in the system.

- A. First, I'd like to get your opinion about some suggestions regarding how services are provided to people with developmental disabilities and their families.
 - 1. One suggestion is to shift the decisions about the use of resources, who delivers services, and how they are delivered away from the current process and onto the people with developmental disabilities and their families. For example, the HCBS waiver regulations require more consumer control and depend on families to provide some services. It also means much more involvement with Medicaid.
 - a. Who do you think would benefit or be the “winners,” if any, and who would not benefit or be the “losers,” if any, with this approach?

- b. What changes do you think would be needed to make it work? How do you think this would work?
 - c. Do you think this approach will or will not improve the system? Could you please describe why you think that or feel that way?
 2. Next, I'd like you to talk about the best way to use the resources that are available in New Jersey to provide services to people with developmental disabilities and their families. Let's estimate that about 170,000 people need some type of services and currently most of the resources are being used for about 30,000 people.
 - a. What would you do to expand services to more people using the same resources?
 - b. What would you suggest to increase the resources that are available?
 - c. If your suggestions were used, who do you think would benefit or be the "winners," if any, and who would not benefit or be the "losers," if any?
 - d. What if any role do you see for institutions in any plan to shift resources and use different approaches to providing services?
 - e. What are your suggestions for providing services to people with severe disabilities?
 - f. What is your opinion on the ability to provide services in the community? What are some creative ways we might use to support people in the community? What are your suggestions on how to provide integrated community services?
- B. My next questions are about what you would do if you were asked to design a plan to change and improve the system. When you answer my questions, please think from the standpoint of a person with developmental disabilities going through the system.
 1. What is your vision of how a person with a developmental disability would go about getting the highest possible quality of life?

Probe: What are the top 2 or 3 improvements that would be on your list?

Where do you see the major road-blocks/bumps in the road to getting this now?
 2. If your suggestion was adopted, who (what groups/organizations) would benefit or be considered the "winners," if any, and what or who would not benefit or be the "losers," if any?
 3. If your suggestion was adopted, from the perspective of a person with a disability, what would be the main difference he/she would experience?

Probes:

- *how this will impact funding, structure/ organization of service delivery, quality of services for people with developmental disabilities and their families.*

III. REVIEW OF DHS NEW AND EXPANDED OPTIONS FOR NJ'S CONSUMERS WITH DEVELOPMENTAL DISABILITIES (20 minutes)

Now let's talk about the New Jersey Department of Human Services recently announced options for consumers with developmental disabilities and their families. In particular I want to look at the "Next Steps", but first:

a. Briefly discuss extent (or not) of information about the DHS document.

Before you received this document in the mail from us, had you read or heard about it ?

Probes:

- *How did you first find out about the document?*
- *Did you see the document itself, or did you read newspaper coverage about the announcement?*
- *Did you hear about it through hearsay, or because people discussed it with you?*
- *Who told you about it or discussed it with you? (Describe position, title, area of interest i.e. political, service provider, consumer, etc.)*
- *Did you receive a different (from our) letter about it?*
- *Where else or who else did you hear about it?*

Interviewer Note: The announcement was made 9/18/02 , and article was in the paper on 9/20/02 and the *Star-Ledger* ran an editorial on 9/22/02.

b. Overall Assessment of DHS Options

What is your overall impression of the DHS options?

Probes:

- *How would you describe your reactions to this document?*
- *What in particular stands out to you? What are the 1 or 2 themes that attract your attention?*
- *What makes you say that?/Why do you feel that way?*

c. Specific Short-Term Priorities

Interviewer: Hand list with summary of DHS Options (page 14).

As you can see, the DHS document organizes information in three ways:

- 1) Five Expected Changes;
- 2) Strategies for Creating Better Services, and
- 3) Next Steps.

Please look at the Next Steps. Take a minute to rank order them from 1 to 6.

Interviewer: Hand grid with list of Next Steps for ranking.

Probe if needed: *Please rank them for importance and then we'll discuss the one or two most important to you.*

Interviewer: Repeat the following as needed for each topic that is mentioned.

Probe:

Why do you feel that way?

Do you think (**STEP(S) R MENTIONED**) will or will not improve services to people with developmental disabilities and their families. (gut level reaction)

Probe:

- *Please tell me (more about) why you think it (will/will not) improve services?*
- *Tell me (more about) if you think this (will/will not) work?*
- *If will not work, what would you suggest to make it work?*

Interviewer: Make sure you are clear on opinions about change(s) on funding, structure/organization, impact on people with developmental disabilities and their families.. Probe – What do you mean by that? Please explain that to me?

Interviewer did R mention another topic? If go back and ask questions about this topic and probe again.

d. DHS Options Summary

Is there anything else about the DHS options that you would like to comment on?

Interviewer: If you still have 5 or 10 minutes left continue with IV, if not go to V “thanks” and then to snowball sample names.”

IV. INFORMATION (5-10 minutes)

A. Need To Know

What information would you like to have/need to have for planning/thinking about changes in providing services?

B. Information Sources

Where do you get information about services and financing of services for families and for people with developmental disabilities?

V. Thank you very much for your assistance. Is there anything else you'd like to add?

Snowball.

I'd like your assistance in identifying other people who you think are "key developmental disability stakeholders"...that is people who you feel should be included in any discussion of issues related to people with developmental disabilities. We want to make sure we have as comprehensive as possible listing of the leaders in this area. Could you give me the names (also get organization/address/phone number) of 4 or 5 people we should make sure to include in this process?

NAME	ORGANIZATION	ADDRESS	PHONE/FAX
------	--------------	---------	-----------

1.

2.

3.

4.

5.

THANK YOU VERY MUCH.

NEW JERSEY DEPARTMENT OF HUMAN SERVICES

NEW AND EXPANDED OPTIONS FOR NEW JERSEY'S CONSUMERS WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

SUMMARY

FIVE EXPECTED CHANGES

1. Design consumer-oriented information and services.
2. Develop a mechanism that collects information about individuals' and families' needs and preferences.
3. Develop a new way of fiscal planning.
4. Develop a capacity to provide an array of services for individuals living at home.
5. Support consumers as they transition through various life cycles: transitioning young and aging consumers.

STRATEGIES FOR CREATING BETTER SERVICES

1. Maximizing revenue and reinvesting in expanded services.
2. Designing an array of family-oriented service options
3. Building upon investments in institutions
4. Working in partnership

NEXT STEPS

1. Develop an expanded waiver
2. Develop Consumer Assessment Tool (CAT)
3. Begin service planning and program development in partnership with consumers, advocates, families, and providers
4. Create inter-agency agreements (DOE/DHS/DHSS-MOUs)
5. Redesign case management to meet consumer needs
6. Design consumer friendly intake process

**NEXT STEPS
PRIORITY RANKING**

Please rank each from 1 (highest priority) to 6 (lowest priority)

ACTION	RANKING FOR SYSTEM	RANKING FOR ORGANIZATION
Develop an expanded waiver		
Develop Consumer Assessment Tool (CAT)		
Begin service planning and program development in partnership with consumers, advocates, families, and providers		
Create inter-agency agreements (DOE/DHS/DHSS-MOU _s)		
Redesign case management to meet consumer needs		
Design consumer friendly intake process		



DEVELOPMENTAL DISABILITIES STAKEHOLDER'S FORUM

CONSENT FORM AND CONFIDENTIALITY AGREEMENT

All of the information from this interview will be kept strictly confidential. We will not report specific individuals' names or the names of organizations. Information will be reported as key themes.

A. PERMISSION TO TAPE RECORD INTERVIEW

- I give my permission to tape record this interview to assist in preparing the report.
- I do not give my permission to tape record this interview to assist in preparing the report.

B. PERMISSION TO INCLUDE NAME AND ORGANIZATION ON LISTING OF STAKEHOLDER PARTICIPANTS

- I give my permission to have my name and the organization I represent included in the report list of stakeholder participants.
- I do not give my permission to have my name and the organization I represent included in the report list of stakeholder participants.

C. PERMISSION TO ATTRIBUTE COMMENTS TO NAME AND ORGANIZATION

- I give my permission to have the comments from this interview attributed to me and the organization I represent with review.
- I do not give my permission to have the comments from this interview attributed to me and the organization I represent.

NAME: _____ DATE: _____

APPENDIX E

STAKEHOLDERS' FORUM MATERIALS

STAKEHOLDER FORUM PARTICIPANTS

Lowell Arye

Alliance for the Betterment of Citizens with Disabilities (ABCD)

Janice Ballou

Mathematica Policy Research, Inc.

Enrico DeGironimo

Developmental Resources Corporation

Ethan Ellis

New Jersey Developmental Disabilities Council

David Frank

Mathematica Policy Research, Inc.

Carol Grant

New Jersey Division of Developmental Disabilities

Susan Hammerman

The University of Medicine and Dentistry of New Jersey

Alice Hunnicutt

Statewide Parent Advocacy Network(SPAN)

Bruce Kastner

The University of Medicine and Dentistry of New Jersey

Bob Lowe

New Jersey Division of Developmental Disabilities

Sarah Mitchell

New Jersey Protection and Advocacy, Inc.

Krystal Odell

Allies, Inc.

Maureen Babula

New Jersey Developmental Disabilities Council

Pat Brannigan

Office of the Governor

Lorraine D’Sylva-Lee

Family

Celine Fortin

The ARC of New Jersey

Leila Gold

Coalition of Families for Responsible Care

Lois Grau

The University of Medicine and Dentistry of New Jersey

Jane Horowitz

Spina Bifida Association of New Jersey

Eric Joice

Epilepsy Foundation of New Jersey

Mary Kneuer

Family

Audrey McDonald

Mathematica Policy Research, Inc.

Kathleen Nugent

Regional Family Support Planning Council #5

Darlene Reeves

Family

Susan Richmond
*New Jersey Developmental Disabilities
Council*

John Rubis
Regional Family Support Planning Council #8

Deborah Spitalnik
The Boggs Center

Franklin Unkle, Jr.
The ARC of Cape May County

Frances Merlin
*The University of Medicine and Dentistry of New
Jersey*

Ana Rivera
The ARC of Gloucester

James Smith
*New Jersey Division of Developmental
Disabilities*

Frank Tetto
Family

Theresa Wilson
New Jersey Department of Human Services

Kathy Palsho
*New Jersey Division of Developmental
Disabilities*



February 19, 2003

Dear NAME:

You are invited to participate in the Developmental Disabilities Stakeholder Forum on Saturday, March 1, 2003 at the Marriott Hotel in Trenton. Included in this mailing are: 1) directions to the Marriott Hotel, 2) an agenda for the meeting, and 3) an RSVP form. As you'll see on the agenda, we will convene beginning at 9:30 and the Forum will start at 10:00 AM. Please contact Jane Dunhamn at 609-292-3745 or jane.dunhamn@njddc.org if you have any special needs or if you require child care at the Marriott.

We look forward to seeing you at the Forum. Your comments, and those of the other stakeholders, provided valuable observations on the actions that need to be taken to provide equitable and quality services to people with developmental disabilities and their families. We look forward to sharing these observations with you on March 1. Please use the attached form to RSVP by **February 26**.

Please contact either of us if you have any questions.

Regards,

Lois Grau
UMDNJ
graulo@umdnj.edu
732-235-5269

Janice Ballou
Mathematica Policy Research
jballou@mathematica-mpr.com
609-750-4049

**NEW JERSEY DEVELOPMENTAL DISABILITIES
STAKEHOLDERS FORUM
PROPOSED MARCH 1, 2003 AGENDA**

9:30-10:00	MEET AT THE MARRIOTT HOTEL TRENTON, NEW JERSEY (SEE ATTACHED DIRECTIONS) COFFEE
10:00 -10:05	OUTLINE DAY AND GOALS FOR FORUM
10:05-11:00	REVIEW FINDINGS OF STAKEHOLDER INTERVIEWS
11:00-12:00	DIVISION OF DEVELOPMENTAL DISABILITIES PRESENT STATUS OF CURRENT ACTIONS AND PROPOSED FUTURE ACTIONS
12:00-12:45	LUNCH
12:45-1:45	BREAKOUT GROUPS
1:45-2:30	REPORTS FROM EACH OF THE THREE BREAKOUT GROUPS
2:30-3:00	SUMMARY AND NEXT STEPS

OVERALL GOAL OF STAKEHOLDER FORUM

- *Forge partnerships to optimize resources*
- *Be inclusive*
- *Develop an agenda of priorities for system change*

NEW JERSEY DEVELOPMENTAL DISABILITIES
STAKEHOLDERS FORUM
SATURDAY MARCH 1, 2003

PLEASE RSVP BY FEBRUARY 26, 2003

By Fax: 609-799-0005 ATTENTION JANICE BALLOU

By Phone: 609-750-4049

By Mail: Use the enclosed postage paid envelope

By Email: jballou@mathematica-mpr.com

_____ YES, I WILL BE ATTENDING SATURDAY MARCH 1

_____ NO, I AM NOT ABLE TO ATTEND SATURDAY MARCH 1

NAME:

ORGANIZATION:

PHONE:

CELL PHONE:

EMAIL ADDRESS:

Contact Jane Dunhamn at 609-292-3745 or jane.dunhamn@njddc.org if you have any special needs or if you require child care at the Marriott.

MARCH 1, 2003 STAKEHOLDER FORUM BREAKOUT GROUPS

OVERALL GOAL OF STAKEHOLDER FORUM

1. Forge partnerships to optimize resources
2. Be inclusive
3. Develop an agenda of priorities for system change

FRAMEWORK FOR BREAKOUT GROUPS

A. TOPIC DISCUSSION

To frame the discussion, each of the three groups, will address the following with respect to the topic and report their recommendations back to the full group:

1. Develop a priority list of the top 3-5 issues/actions that must be addressed.
2. Identify who (as specific as possible—either individual people and/or specific agencies/organizations) must be included in the discussion and their role/contribution to the discussion.
3. Identify the process to be followed to make it happen.
4. Describe the desired outcome.

B. STAKEHOLDER FORUM PROCESS DISCUSSION

Each group should take a few minutes to discuss the Stakeholder Forum process and answer the questions: How would you like the Stakeholder Forum process to work? What role can the Stakeholder Forum contribute to advancing system change?

BREAKOUT GROUPS

The following lists three topics with preliminary suggestions of what could be included in the group discussion. Breakout group members may use these suggestions or develop their own list of what to discuss under each topic.

1. Shifting Resources, Shifting Decision Making About Resources
 - What can be done to make the system equitable?
 - How would a contribution to care approach work?
 - How and when should the stakeholders be involved in planning the expanded use of the HCBS waiver?
 - How will shifting decision-making about the use of resources from the provider to the person be accomplished?
 - How can resources be allocated to support a continuum of care?
 - What is the current and future role of the developmental centers?
2. Focus on Quality of Lives, Not Quality of Services
 - What is quality? Who defines it?
 - How can we support consumer choice?
 - What should be considered in an assessment used to determine who gets what services?
 - How do we help families keep their loved ones at home?
 - How do we develop a workforce to support quality lives?
 - How can communities be encouraged to include people with developmental disabilities?
3. Ending the Search, Achieving Information Equity
 - What messages must be communicated to implement reforms to make the system work?
 - Who needs to hear them?
 - How can key messages be delivered ?
 - Who is responsible for providing information?
 - Who is the best messenger?
 - How do we determine whether the messages are received and understood?

MARCH 1, 2003 STAKEHOLDER FORUM BREAKOUT GROUPS

OVERALL GOAL OF STAKEHOLDER FORUM

1. Forge partnerships to optimize resources
2. Be inclusive
3. Develop an agenda of priorities for system change

FRAMEWORK FOR BREAKOUT GROUPS

A. TOPIC DISCUSSION

To frame the discussion, each of the three groups, will address the following with respect to the topic and report their recommendations back to the full group:

1. Develop a priority list of the top 3-5 issues/actions that must be addressed.
2. Identify who (as specific as possible—either individual people and/or specific agencies/organizations) must be included in the discussion and their role/contribution to the discussion.
3. Identify the process to be followed to make it happen.
4. Describe the desired outcome.

B. STAKEHOLDER FORUM PROCESS DISCUSSION

Each group should take a few minutes to discuss the Stakeholder Forum process and answer the questions: How would you like the Stakeholder Forum process to work? What role can the Stakeholder Forum contribute to advancing system change?

BREAKOUT GROUPS

The following lists three topics with preliminary suggestions of what could be included in the group discussion. Breakout group members may use these suggestions or develop their own list of what to discuss under each topic.

1. Shifting Resources, Shifting Decision Making About Resources
 - What can be done to make the system equitable?
 - How would a contribution to care approach work?
 - How and when should the stakeholders be involved in planning the expanded use of the HCBS waiver?
 - How will shifting decision-making about the use of resources from the provider to the person be accomplished?
 - How can resources be allocated to support a continuum of care?
 - What is the current and future role of the developmental centers?
2. Focus on Quality of Lives, Not Quality of Services
 - What is quality? Who defines it?
 - How can we support consumer choice?
 - What should be considered in an assessment used to determine who gets what services?
 - How do we help families keep their loved ones at home?
 - How do we develop a workforce to support quality lives?
 - How can communities be encouraged to include people with developmental disabilities?
3. Ending the Search, Achieving Information Equity
 - What messages must be communicated to implement reforms to make the system work?
 - Who needs to hear them?
 - How can key messages be delivered ?
 - Who is responsible for providing information?
 - Who is the best messenger?
 - How do we determine whether the messages are received and understood?

2003 NJ DEVELOPMENTAL DISABILITIES STAKEHOLDER FORUM
GUIDELINES FOR BREAKOUT GROUP FACILITATORS

MATERIALS YOU WILL HAVE:

1. List of participants in your group
2. Handouts: 1) Outline of Task for the Group 2) Suggested topics for discussion
3. Flip Chart
4. Tape recorder

KEY RESPONSIBILITIES:

1. Listen
2. Keep the group on track/on topic/on time
3. Use neutral probes to assist, if the group gets stuck
4. Take your own notes, if possible, it's most important to focus on facilitation

REMEMBER THE GROUP NEEDS TO ACCOMPLISH TWO TASKS: 1) COMMENTS ON THE BREAKOUT TOPIC AND 2) COMMENTS ON THE FUTURE OF THE FORUM

STEPS IN FACILITATION (and approximate time):

1. Introductions (5 minutes)

Introduce yourself and have members of the group introduce themselves

2. Provide Guidelines for the Discussion (5 minutes)

--Amount of time they have is about 45 minutes

Tell them you'll let them know when there are 15 minutes left, 10 minutes left, and when they need to wrap up

--Have them delegate a spokesperson who will report back to the group and delegate a person to record on the flip chart (unless you want to do it)

--Give out handouts

1) Remind group they have to respond to the 4 categories listed

2) Remind group that the questions listed under the topic are to start their thinking –they may use them or develop their own set of questions

3. Let the discussion begin (45 minutes)
4. Remind them of time; Probe as needed
5. Discuss future of Stakeholder Forum (5 minutes)
6. RETURN TO MAIN ROOM AT 1:45

APPENDIX F
RECRUITMENT SCRIPT AND PACKET

September 19, 2002

«Name»
«Title»
«Company»
«Address»
«CityStateZip»

Dear «Salutation»:

Thank you for your commitment to persons with developmental disabilities. I am writing to support the Developmental Disabilities Stakeholders' Forum which is sponsored by the New Jersey Department of Human Services and the Developmental Disabilities Council.

The Forum, described in the enclosed material, is designed to facilitate a dialogue among stakeholders – those who provide services and the people and families served. The University of Medicine and Dentistry of New Jersey, School of Public Health and Mathematica Policy Research, Inc. are managing the effort.

I encourage you to participate in the Forum. We need the broadest level of participation possible. We have a unique opportunity to forge a productive and inclusive discussion about emerging reforms. More importantly, we can develop ideas on how to improve the quality of care for our developmentally disabled community.

This is an opportunity to work together to maximize our resources as we create an effective system of care for people with developmental disabilities. I certainly look forward to receiving recommendations from the Forum and thank you for your support.

With all good wishes,

James E. McGreevey
Governor

Enclosures



September 17, 2002

Dear Name:

As described in Governor McGreevey's letter, the UMDNJ School of Public Health and Mathematica Policy Research, Inc. are directing an important effort to talk with key stakeholders to identify the most important issues that need to be addressed to provide quality services to people with developmental disabilities and their families. In the next week or so you will be contacted by someone from the project team to make an appointment to talk with you for about an hour at the place and time that is most convenient for you. Or, if you would prefer, you can contact us at 1-800-385-8046 to make an appointment.

Please contact either of us if you have any questions. We look forward to including you in this unique effort.

Regards,

Lois Grau
UMDNJ
graulo@umdnj.edu
732-235-5269

Janice Ballou
Mathematica Policy Research
jballou@mathematica-mpr.com
609-750-4049

DEVELOPMENTAL DISABILITIES STAKEHOLDERS' FORUM

PARTICIPANT INFORMATION

WHAT IS THE DEVELOPMENTAL DISABILITIES STAKEHOLDERS' FORUM ?

The Developmental Disabilities Stakeholders' Forum is a process to listen to ideas and to prioritize actions that are needed to provide quality services to people with developmental disabilities. There are some key issues that are currently facing the State of New Jersey related to the system of supports and services to people with developmental disabilities and their families. For example, the state is developing a plan to meet its obligations under the Supreme Court's *Olmstead* decision; the use of Medicaid funding through the Home and Community-Based Services (HCBS) Waiver offers an opportunity for new resources for community support; and the state is anticipating its first federal evaluation of waiver-funded community services by the Centers for Medicare and Medicaid (CMS). These and other related topics are complex and interconnected. That is why representatives from the McGreevey Administration, including the Department of Human Services and the Division of Developmental Disabilities, along with the New Jersey Developmental Disabilities Council, are coordinating their efforts to obtain the best information possible about immediate and future needs.

WHY ARE THESE INTERVIEWS BEING CONDUCTED?

The purpose of these interviews is to listen to key leaders among the multiple groups who provide or use services for people with developmental disabilities and their families. The main focus of the interviews will be to assess immediate needs and to identify and discuss reforms that can be made to cost-effectively enhance the quality and availability of services and supports to people with disabilities and their families. The New Jersey Developmental Disabilities Council, which has funded this project, is uniquely positioned to sponsor these interviews because of its mandate to advocate for and seek systemic change.

WHO WILL BE INTERVIEWED?

Leaders from the key entities that are involved in providing and using services and supports to people with developmental disabilities will be asked to participate in the Stakeholders' Forum.

HOW WILL THE RESULTS BE USED?

The results will be used to guide a discussion that will focus on assessing current reforms being made by the State and on establishing priorities for future changes that need to be made to the system. This discussion will be the centerpiece of a forum to take place after the interviews are conducted when the participants will meet and review a summary of the results. Governor McGreevey is very interested in using this information in planning state policies and programs.

WHO IS CONDUCTING THE INTERVIEWS?

The interviews will be conducted by the UMDNJ School of Public Health and Mathematica Policy Research, Inc. (MPR).

WHAT DO I HAVE TO DO TO PARTICIPATE?

In the next few weeks a representative from MPR will be contacting you to set up an appointment for an interview. The interview will be conducted in-person and will take about 45 minutes to an hour. You can also call 1-800-385-8046 to set up an appointment.

WILL MY ANSWERS BE CONFIDENTIAL?

Yes, the information reported will refer to key themes and will not identify any specific individual.

WHO CAN I CONTACT FOR MORE INFORMATION?

Lois Grau (732-235-5260) at UMDNJ and Janice Ballou (609-750-4049) at MPR

*New and Expanded Options for New Jersey's Consumers
with Developmental Disabilities and Their Families*



James E. McGreevey
Governor

Gwendolyn L. Harris
Commissioner
NJ Department of Human Services

Theresa C. Wilson
Deputy Commissioner
NJ Department of Human Services

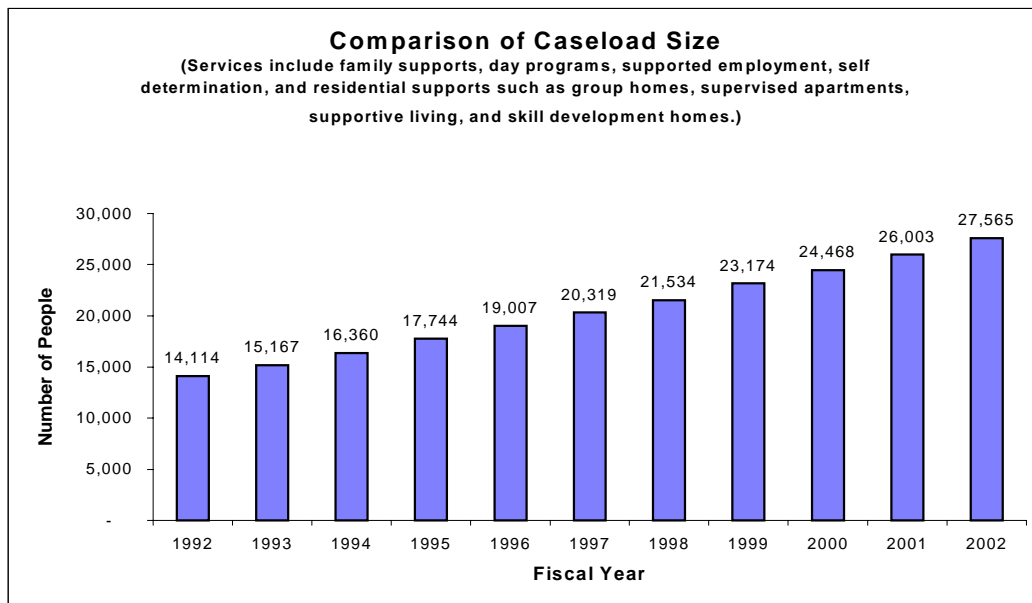
James W. Smith
Director
Division of Developmental Disabilities

September 19, 2002

New and Expanded Options for New Jersey's Consumers with Developmental Disabilities and Their Families

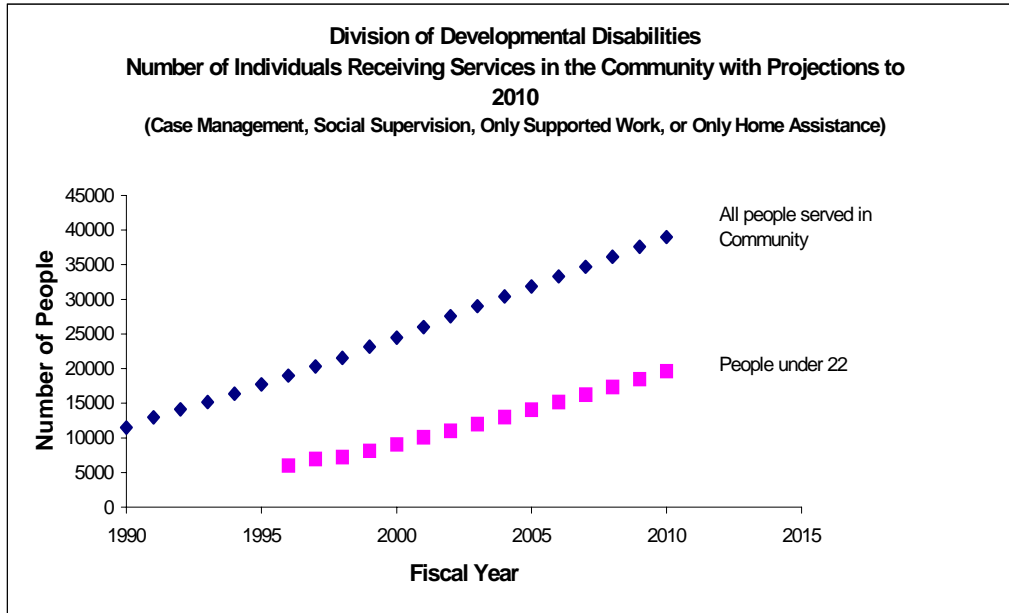
Overview

Thousands of persons with developmental disabilities live in the state of New Jersey today. They suffer from severe chronic disabilities that develop before the age of 22 and cause substantial functional limitations. Developmental disabilities include mental retardation, autism, cerebral palsy, epilepsy, spinal bifida, and other neurological impairments. The New Jersey Department of Human Services, Division of Developmental Disabilities (the Division) provides services to 30,800 such persons, including 3,300 individuals who reside in residential facilities known as developmental centers. The remaining nearly 27,500 receive services in the community through a variety of means including group homes, day program services, boarding and nursing homes, and services and supports to individuals living with their families.



New Jersey faces several major challenges in meeting the needs of this vulnerable population. The Division's caseload has experienced tremendous growth in recent years. Just a decade ago, a little over 14,000 persons with developmental disabilities relied on the State for services. Last year, the caseload almost doubled to more than 27,000, but the average age decreased.

Forty percent of the Division’s caseload is now under the age of 22 and living at home. This figure is likely to grow to 50% by the end of the decade. Yet, current Division services are largely oriented to adults. Unless the person with a disability lives in a residential setting, families are provided few options for accessing services to meet their actual needs.



In the current system, the Division utilizes a waiting list for residential services. The waiting list is the only formal mechanism to access services. While consumers “wait” there is no systematic way to provide alternative services to support them and their families while living at home. This population, the majority of the caseload, is greater than 18,000 consumers.

The Division’s large and aging developmental centers remain difficult to staff and manage while ensuring quality care for their residents. Governor McGreevey's FY'03 budget provided \$27M in new funding to address quality of care issues in the developmental centers. This funding provided for new direct care and professional staff, training, and new equipment. However, a continued commitment is needed to ensure these facilities meet high standards of care.

New Jersey lags behind other states in leveraging additional financial resources that would allow the Division to improve existing services and develop new programs. The Division needs to obtain

“There are certain functions of the State that are not discretionary. Caring for people with developmental disabilities is among them.” - Governor James E. McGreevey

additional federal revenue through 1) broadening the use of Medicaid waivers, 2) better enforcement of Medicaid eligibility requirements, and 3) seeking a greater contribution toward services from consumers living in group homes. Maximizing federal revenues would enable the State to serve more New Jerseyans in need with the same level of State resources.

New and Expanded Options for New Jersey's Consumers with Developmental Disabilities and Their Families lays out an ambitious, yet workable, plan to provide better, more appropriate services to individuals and families – services that are truly oriented around their needs. Together, working with consumers, families, providers, and other partners, New Jersey can build and sustain a system of care that provides more options and greater choice, is fiscally sound, and results in high quality institutions and community programs.

“We can accomplish a lot together.” – Leila Gold, Family Member

Services Today

INSTITUTIONAL CARE

The Division operates seven large and aging developmental centers, housing more than 3,300 consumers. Centers include North Jersey, Woodbridge, Green Brook, Hunterdon, New Lisbon, Vineland, and Woodbine. It is difficult to manage and retain appropriate levels of qualified staff to ensure the provision of good care at these centers. Moreover, the physical infrastructure of these centers suffer from years of deferred maintenance. Deteriorating conditions have largely gone unaddressed over the years, with exceptions occurring during periods of failed federal government inspections and threats of sanctions.

During the past two years, the federal Centers for Medicare and Medicaid Services conducted inspections of New Jersey's developmental centers, along with our counterparts across the country. Since March of 2001, five of New Jersey's developmental centers have undergone these reviews. Continuation of federal funding and certification has been threatened each time. Federal certification not only insures a consistent standard of care, but also provides half of the cost of providing services for consumers.

Two facilities, Woodbridge and New Lisbon, were decertified. Recently, certification was restored to New Lisbon due to efforts to replace outdated equipment and increase staffing. Woodbridge, however, remains decertified and anticipates a review in the late fall of this year.

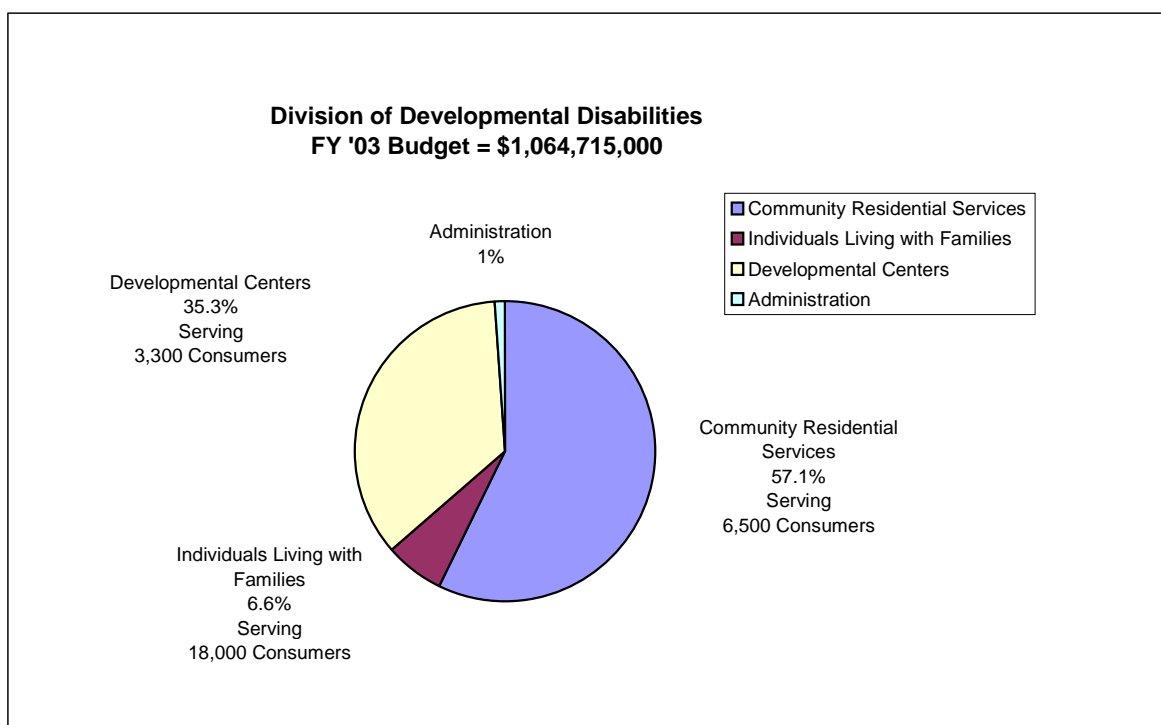
Governor McGreevey's FY'03 budget provided \$27 million in new funding to improve services to individuals in the developmental centers. The administration remains committed to serving people with disabilities and providing a high standard of care.

The Division has funded initiatives in the last two years to expedite and support the movement of eligible consumers to the community complying with the Olmstead decision. This federal mandate stipulates provisions be made for residents capable of living in the least restrictive community settings.

COMMUNITY SERVICES

For the past twenty years, the Division has been moving from a system of institutional care to one based primarily in the community. Currently only 10% of the caseload lives in Developmental Centers. This mirrors the national trend: moving away from large institutional settings to the integration of individuals with developmental disabilities into community life.

New Jersey, similar to elsewhere in the nation, began its evolution to community services with an emphasis on residential placements. It was a familiar service model since it provided 24-hour care for individuals. Over the last decade, the Division has invested heavily in its residential services' budget, primarily group homes. In 1996, the community services budget was \$357M. The community services budget is now \$677 million, a 90% increase.



The Division uses a waiting list to place individuals in group homes and other residential services. The waiting list remains the primary way people access services. Initially intended to categorize individuals according to need and respond to a growing demand for residential placement, the list has only expanded over the years. Unfortunately, the waiting list is not an effective mechanism for organizing a system of services in a timely fashion, nor does it allow families to request supports more tailored to their needs, especially while the individual is at home. Most services are delivered based on the chronological order of the waiting list. There is no comprehensive assessment conducted to determine actual need or consumer preference for types of services that might be most appropriate.

As increasing numbers of individuals have been added to the list, the Division has sought to respond to this growing demand through funded

“Many parents of developmentally disabled adults have told us they would prefer to keep their loved one at home rather than have them live in a group home.” - Commissioner Gwendolyn L. Harris

residential initiatives since FY '99. The Division planned to eliminate the waiting list by placing 500 people each year. However, the Division has not been able to achieve its annual placement goal. Three major barriers have been identified:

1. Regardless of the number of consumers that are placed, 600 new consumers have been added to the waiting list each year;
2. Agencies face community hurdles in designing and planning for facilities, (e.g. site acquisition, cumbersome zoning requirements, local community opposition, and exorbitant costs);
3. Providers report that current Division requirements are too rigid and limit their ability to look at the needs of families at home, or to offer broader options to serve families. As currently structured, agencies are not permitted the flexibility to plan and create alternative non-residential services.

Despite these three major barriers, the bulk of resources continue to support an emphasis on the traditional group home model. Eighty-seven percent of the community services budget is allocated to residential services supporting 6,500 consumers.

“All additional revenues need to be reinvested in expanded services.” Tom Buffuto, Executive Director, ARC of New Jersey

Few supports and services are in place to assist families in caring for relatives at home. New Jersey ranks 37th among other states in the amount of money spent on services to families in their own homes. Less than 7% of the total Division budget is dedicated to serving these 18,000 consumers. The Developmental Disabilities Planning Institute of the New Jersey Institute of Technology (June 2002) reports that consumers would choose other options if available:

- 91% view the waiting list as an insurance policy
- 67% reported that when the time came that they could no longer care for their relative, they preferred arrangements be made for that family member to live with another relative
- 60% would delay placement if adequate services at home were available

Families indicate a number of reasons for delaying placement. For example, forty-nine percent of the sample reported that they want to keep their family together. Thirty-eight percent believed that they can provide better care.

Several factors contribute to the continued growth of the waiting list despite consistent efforts by the Division to move people into placement. The list is inaccurate. The study commissioned by the Department showed that out of 1,842 persons on the urgent portion of the list, 34% were not waiting for residential services. It was found that some individuals had already been placed, or duplicated in the database, or could not be found. Moreover, many people request to be added to the waiting list with anticipation of placement at some time in the distant future. With initiatives occurring each year, however, these individuals may be offered placement before they are ready or willing to accept them. Of the 3, 948 people on the urgent waiting list, 25% of families in each of the last several initiatives have declined placement. Absent other alternatives such as

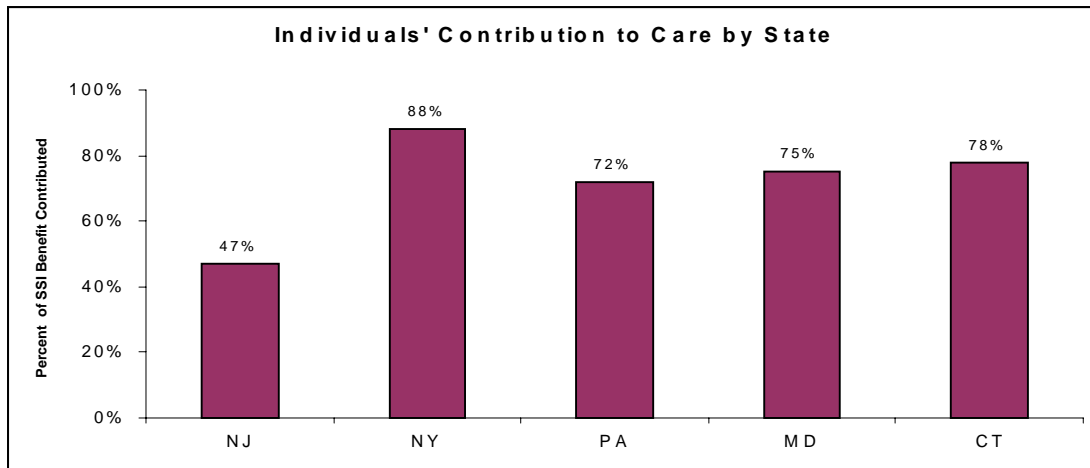
services and supports to individuals living in their own homes, the list often indicates the family's need for a future insurance policy.

RESOURCES AND REVENUES

The Division has not capitalized on the opportunity to draw down the maximum federal reimbursement available through the existing Home and Community Care Waiver. The Waiver authorizes Medicaid reimbursement for residential, day programming and other support services. However, the State does not require that consumers become eligible for Medicaid prior to receiving Division services. For every person who is not made Medicaid eligible, or loses Medicaid eligibility, another person is not served. At any point in time, 10% to 15% of individuals in current Waiver services, primarily residential and day programs, are not Medicaid eligible. Since the federal government reimburses 50% for eligible recipients, New Jersey is losing major resources that could be *reinvested* to serve more people.

For every person who is not made Medicaid eligible, or loses Medicaid eligibility, another person is not served.

Revenues could also be enhanced with a change in the Division's current fee policy. Currently, the Division permits consumers to retain substantial amounts of income from federal benefits, like Supplemental Security Income (SSI) and other income. New Jersey is an outlier in the use of SSI benefits. SSI payments from the federal government are given to individuals with disabilities to support their room and board expenses while the residential programs already



include these necessities. Other states have adopted policies requiring individuals to contribute larger percentages toward their care, while still allowing consumers to retain funds for personal needs.

In New Jersey, most individuals under the current fee structure keep about 50% of their SSI benefit averaging \$700/month despite the fact that they may live in a group home that provides for nearly all of their needs. When an individual accumulates more than \$2000 in cash assets from any source, Medicaid eligibility is lost. The State must then assume 100% of an individual's costs, rather than being reimbursed for 50%. New Jersey must reconsider its current policy. Under revised rules, additional funds could be generated and reinvested in expanded services for more individuals and families.

Our Vision for the Future – An Evolving System

To provide more services and supports to a larger number of individuals and their families, ensuring quality services in both institutions and community settings.

The Division will adopt a service system that recognizes the demographics of its current caseload and creates services based on individualized needs. The current caseload is younger, the needs of residents in group homes are changing, and family caregivers are aging. The current system with its reliance on group home development and placement fails to effectively respond to the majority of individuals and their families and to support families in their care-giving responsibilities.

The system must continue to evolve from developmental centers to community-based services. However, greater attention must be paid to the service needs of individuals living with their families, where the majority of the individuals on the Division's caseload live. Currently, 18,000 individuals on the caseload live at home. The new system will need to assess these individuals earlier and develop service capacity to meet the needs that are identified. This is a direction which has been utilized in other States. The concept of person-centered planning and individualized service planning has been the philosophical direction of developmental disabilities systems across the nation. (Braddock, D., Hemp, R., Rizzolo, M.C., Parish, S. and Pomeranz, A., "The State of the States in Developmental Disabilities: 2002 Study Summary.")

The developmental disabilities system in New Jersey needs to have a fundamental shift in service delivery away from the exclusive development of group homes toward the development of an array of services which support individuals and families in their communities.

FIVE EXPECTED CHANGES

1. Design consumer-oriented information and services.

The Division will expand education and outreach efforts to broaden consumer awareness about services and supports available in their communities. The new system will develop and phase-in an eligibility process which enhances information and supports available to individuals and families. This more consumer-oriented process recognizes that individual and family needs are not static. In partnership with providers, services will be developed in response to the changing needs of consumers.

2. Develop a mechanism that collects information about individuals' and families' needs and preferences.

In order to plan for individualized service needs, it is necessary to gather common information and determine the needs of individuals utilizing a common understanding of the level of individual needs. An assessment tool will be developed which looks at both the individual's abilities to provide for their own self-care needs and the families' care-giving role.

3. Develop a new way of fiscal planning.

The Division has relied on a budget that provided for the development of residential services for 500 individuals on the waiting list each year. This single-focused method of budgeting provided little flexibility to provide an array of services to meet the service needs of these other individuals on the caseload.

The budgeting process in the future needs to support the development of an array of services to different segments of the caseload including:

- Waiting List individuals;
- Individuals leaving special education at 22 and transitioning to adult life activities
- Individuals living with aging family caregivers and individuals currently aging in residential services;
- Individuals living with their families and in need of services to improve their quality of life and support families in their care-giving;
- Individuals and families who have recently become eligible for Division services and who need information and support.

4. Develop a capacity to provide an array of services for individuals living at home.

Once the system has better information and an assessment of the needs of individuals on the caseload, it will be essential to develop and fund an array of services that can meet these needs. It will also be necessary to have an effective case management system which supports individuals living at home. The majority of case management is currently provided to individuals living in residential services.

Surveys of families as well as current requests for family supports provide the best background for the development of needed services. These surveys indicate that to assist an individual in their own home and to provide the needed supports for families, an array of enhanced services needs to be in place. Although many of these services currently exist, we have not assessed the amount of services an individual actually needs to be adequately supported in their own home for as long as possible, nor have we focused on the development of service capacity to meet these needs.

“This is an admirable start and I look forward to working with all stakeholders to continue to make more improvements.”
Ethan Ellis, Executive Director,
Developmental Disability Council

Therefore, working with community partners, the Division will develop and fund the increased capacity required to do this. Consideration will be given to include enhanced in- and out-of-home services, special needs and recreational respite, assistive technology, day programming (including employment opportunities) and access to transportation. All of these services are focused on improving the quality of life of the individual and supporting the caregiver.

Recognizing that consumers with disabilities can be supported to live at home if appropriate services are available, the services most often requested will be expanded and enhanced. These include the following:

Respite

Respite is provided when a family member is seeking time away from home or a caregiver needs a break or support. In-home respite is provided in the person’s own home and can vary from several hours, to an evening, to several days. Out-of-home respite is provided out of the family home in a more specialized facility or recreational environment, such as a day or overnight camp or an after-school program.

Day Programming and Employment Opportunities

Provide opportunities for more individuals to develop skills, participate in using community resources and make a contribution to their communities through employment and volunteer work.

Personal Care

This service is for individuals who need physical assistance with bathing, grooming, feeding or transferring to vehicles.

Assistive Devices

These devices assist individuals to remain in their homes and community through the use technology for speech, lifting, mobility, etc.

Access to Transportation

Access to transportation is important for ensuring that individuals can get to and from programs and leisure activities.

Each of these services will be planned and developed in close partnership with community providers, families, advocates and consumers. Several task forces will be formed to incorporate their ideas and best practices into the improvement of these services. As the Division seeks to build capacity to provide more services for individuals living at home, it will also seek to build the capacity of residential provider agencies to ensure compliance with federal standards. Based on the Division's experiences in fulfilling Center for Medicare and Medicaid Services' certification standards, proactive steps will be taken to assist group home and other residential providers in preparing for anticipated federal inspections of our community programs.

5. Support consumers as they transition through various life cycles: transitioning young and aging consumers.

The current system with its residential care emphasis has not focused adequate attention on those individuals with developmental disabilities who have been largely supported by federal education funds while they were eligible for special education. At the age of 22, individuals are no longer eligible for these services. The new system will collaborate with the educational system to assess the needs of these individuals at an earlier point in time and begin to plan services as they move to adult life.

Too often individuals who have been actively engaged in school programming during the day do not have an adequate transition plan. Day programming or employment options have not been put in place or funded and the individual is at home with their families with little or no support. Under these circumstances, families may see the residential waiting list as their only option

The new system will prioritize and fund needed services for individuals transitioning to adult life and will pay special attention to individuals who are aging.

Strategies for Creating Better Services

Governor James E. McGreevey and Commissioner Gwendolyn L. Harris have pledged to improve the way services are delivered to New Jersey citizens, especially vulnerable residents. As such, the Department of Human Services must explore a range of strategies and options designed to strengthen supports to individuals and families in need. For the state's developmental disability community in particular, the Administration has seized on the opportunity to bring to fruition several strategies that can lead to creating a high-quality system of care in both the community and institutions:

- *Maximizing Revenue and Reinvesting in Expanded Services*
- *Designing an Array of Family-Oriented Service Options*

- *Building Upon Investments in Institutions*
- *Working in Partnership*

Maximizing Revenue and Reinvesting in Expanded Services

Difficult economic and budgetary times should not necessarily translate into a loss of services and supports to families in need. Conversely, New Jersey has an opportunity to explore a number of alternative funding strategies including:

Claiming for more individuals under the Community Care Waiver.

The Division's Community Care Waiver authorizes Medicaid reimbursement for individuals, but New Jersey currently fails to require all persons served by the Division to become Medicaid eligible. The State will now require Medicaid eligibility to be determined prior to services being delivered. This will be a significant change, resulting in many more dollars being made available for services. It is estimated that this change could potentially yield an additional \$10 million dollars annually to reinvest in services.

Non-Residential Waiver

The existing Community Care Waiver does not encompass services to families living at home including, personal care, respite care and assistive devices. These services are needed to meet the needs of individuals living with their families. The Division is in the process of developing an enhanced waiver that would provide a 50% federal reimbursement for these services, which now cost the State \$35 million with no federal match.

Redesign Consumer Fee Structure

At present, consumers can retain more than 50% of their income from federal benefits, such as Supplemental Security Income (SSI), despite the fact that they may live in a group home that provides for all their needs. The State of New Jersey takes 47 percent of an individual's SSI payment toward the cost of care in a residential placement.

Other states require that between 72% to 88% of an individual's SSI income be contributed toward their costs of care in a community residence. Because New Jersey consumers keep more of their SSI dollars, they often lose Medicaid eligibility when they have more than \$2,000 in assets in the bank.

New Jersey will now seek a higher percentage of individual SSI contributions for residential services provided by the Division. The SSI percentage will be increased to more closely match the national average and could generate an additional \$5 to \$10 million annually.

Design an Array of Family-Friendly Service Options

A *Consumer Assessment Tool* will be developed. This tool will assist the Division in assessing people's actual needs and most appropriate types of services. The utilization of an assessment instrument will provide a more responsive service system.

It will not abandon residential options, but will make them part of a broader menu of services. The lack of services fuels more demand for the more expensive group home option (now estimated at \$60,000 per year vs. \$18,000 for various day and community program services). Enhanced and expanded services as cited above are currently being explored for individuals living at home.

“Creating a more responsive developmental disability system will make it possible for the State to meet the needs of individuals and their families who are currently in the system, and for the first time allow us to reach to those communities who have traditionally been underserved.” – Deborah Spitalnik, Executive Director, Boggs Center on Developmental Disabilities, UMDNJ

Build Upon Investments in Institutions

Despite problems associated with an aging physical infrastructure, New Jersey *has* made progress with improving conditions in its developmental centers. The McGreevey Administration has worked diligently to respond to regulations and other compliance issues mandated by the Federal Centers for Medicare and Medicaid Services. More than 700 staff have been added over the last year as part of an additional commitment of funds totaling \$27 million. These funds were also used to upgrade equipment and technology.

The Division will continue to transition those consumers who are ready for discharge from developmental centers. Any reduction in the current census will result in better consumer-to-staff ratios. The Division will continue to focus its efforts to improve the quality of care offered in all of the State's developmental centers.

Work in Partnership

New Jersey is fortunate to have a strong and vibrant community of consumers, advocates, providers and families concerned about the systems that serve people with developmental disabilities. As the Division moves forward with its efforts to provide more services that speak to the demands and needs of consumers, it will remain committed to work in partnership with every facet of this community.

The Division will also explore inter-departmental and inter-agency agreements to expand available services, especially for the growing portion of the caseload under the age of 22. Since this cohort will constitute 50% of the caseload by the end of the decade, it will be imperative to plan for anticipated needs of this population. Conversations are currently underway with the State Departments of Education (DOE) and Department of Health and Senior Services (DHSS) to achieve inter-departmental collaboration including the pooling of funds where appropriate.

For example, the Division is very interested in working with the DOE to determine how federal funds for students with disabilities can be better utilized for young adults transitioning out of local school districts into the State's developmental disability system.

The Division will also partner with providers as it builds capacity to expand services to support individuals living at home.

Next Steps

Implement a series of components during the remainder of this fiscal year:

- Develop an expanded waiver
- Develop Consumer Assessment Tool (CAT)
- Begin service planning and program development in partnership with consumers, advocates, families, and providers
- Create inter-agency agreements (DOE/DHS/DHSS – MOUs)
- Redesign case management to meet consumer needs
- Design consumer friendly intake process

Moving Forward

A confluence of factors in New Jersey creates an opportunity to continue efforts to improve the system serving people with developmental disabilities. Changing consumer needs and preferences, as well as a national trend supporting individuals living with their families, makes it possible to develop a more responsive system in partnership with our consumers, families, advocates and providers. By taking advantage of new ways to maximize federal revenues, additional dollars can lead to reinvestment in new and expanded services, particularly for individuals living at home. With several promising strategies identified, a commitment to a collaborative multi-year effort will bring this vision to a reality.

Interview Scheduling Script
DEVELOPMENTAL DISABILITIES STAKEHOLDER'S FORUM

Hello, may I please speak with _____.

I. IF NO GATEKEEPER

Hello, my name is _____ and I'm calling from Mathematica Policy Research in reference to a letter recently sent to you from Governor McGreevey's Office regarding the Developmental Disabilities Stakeholder's Forum. Today we are calling to schedule an interview at a time and place that is convenient for you. We will be conducting these interviews throughout the next 5 or 6 weeks and would like to schedule your appointment now. Which day and time would be best for you?

YES.....IF INDIVIDUAL PROVIDES DATE GO TO SCHEDULE CALENDAR AND DETERMINE AVAILABILITY, THEN RECORD ON CONTACT SHEET

Please tell me where you would like to meet, and our interviewer will come to your location. Thank you very much.

NO.....IF INDIVIDUAL REFUSES TO PROVIDE DATE ASK REASON AND RECORD ON CONTACT SHEET.

We believe that your experiences will contribute to the success of the Forum, so we will attempt to make any accommodation necessary to meet with you. Could you please tell me the reason why you are unable to schedule an interview at this time?

A. IF RESPONDENT UNFAMILIAR WITH FORUM, OFFER TO FAX OVER COPY OF MATERIALS WHICH INCLUDE THE GOVERNOR'S LETTER, THE INVITATION LETTER, AND THE PARTICIPANT INFORMATION FORM.

I'd like to provide you with a copy of the materials that were included in the letter from the Governor's Office. Could you please tell me your fax number?

B. IF SIMPLY WISHES TO SCHEDULE ANOTHER TIME.

You can call 1-800-385-8046 to set up an appointment, or I can call you back at a more convenient time. Could you please tell me when would be the best time to call back?

II. IF GATEKEEPER

My name is _____ and I'm calling from Mathematica Policy Research in reference to a letter recently sent to _____ from Governor McGreevy's Office. This letter contained information about the Developmental Disabilities Forum including an invitation to participate in an interview to identify the most important issues that need to be addressed to provide quality services to people with developmental disabilities and their families. Today we are calling to schedule an interview. Could I speak with _____?

A. IF NOT CONNECTED DIRECTLY, DETERMINE IF GATEKEEPER CONTROLS SCHEDULING

We are conducting these interviews throughout the next 5 or 6 weeks. Please tell me which day and time would be best for _____ to schedule an interview?

YES..... IF INDIVIDUAL PROVIDES DATE GO TO SCHEDULE CALENDAR AND DETERMINE AVAILABILITY, THEN RECORD ON CONTACT SHEET.

Please tell me where you would like to meet, and our interviewer will come to your location. Thank you very much.

NO.....IF GATEKEEPER REFUSES TO PROVIDE DATE ASK REASON AND RECORD ON CONTACT SHEET.

We believe that _____ will contribute to the success of the Forum, so we will attempt to make any accommodation necessary. Could you please tell me the reason why you are unable to schedule an interview at this time?

B. IF GATEKEEPER UNFAMILIAR WITH FORUM, OFFER TO FAX OVER COPY OF MATERIALS WHICH INCLUDE THE GOVERNOR'S LETTER, THE INVITATION LETTER, AND THE PARTICIPANT INFORMATION FORM.

I'd like to provide you with a copy of the materials that were included in the letter from the Governor's Office. Could you please tell me your fax number?

C. IF SIMPLY WISHES TO SCHEDULE ANOTHER TIME.

You can call 1-800-385-8046 to set up an appointment, or I can call you back at a more convenient time. Could you please tell me when would be the best time to call back?

APPENDIX G

**STAKEHOLDERS' FORUM:
SUMMARY OF BREAKOUT GROUP DISCUSSIONS**

During the Stakeholders' Forum, which was held on March 1, 2003, the participants were divided into three breakout groups: (1) Shifting Resources, Shifting Decision Making About Resources; (2) Focus on Quality of Lives, not Quality of Services; and (3) Ending the Search, Achieving Information Equity. Each group met for about one hour and then gave a verbal summary of the topics that had been discussed. As described in the instructions to the breakout groups, which are given in Appendix F, the goal of each group was to organize its comments around four topics: (1) issues to address, (2) people who should be included in the discussion of these issues, (3) the process required to resolve the issues, and (4) the desired outcome. The remainder of this appendix presents the unedited verbatim summary of what was discussed in the breakout groups, and of what the group members listed on the charts they used when giving their verbal presentations. Because of the limited time provided for the breakout groups and presentations, the groups did not discuss in depth the details associated with the recommendations outlined in these summaries.

BREAKOUT SESSION 1: SHIFTING RESOURCES, SHIFTING DECISION MAKING ABOUT RESOURCES

List/Prioritize the Top 3-5 Issues/Actions that Must Be Addressed

1. Identify existing community resources
2. Provide information on the resources that exist and how to access them
3. Maximize available funding streams
4. Maximize existing community resources
5. Focal point of state government to control funding and reimbursement
6. Role of stakeholders in reworking the waiver
7. Increase knowledge about the waiver
8. Money following the person: individual control over the dollars to allow people to choose their provider in or out of the DD system
9. System of equity based on functional assessment
10. Identify a baseline of services that's available to everyone
11. "Front end information" to support informed decision making

Identify Who (as Specific as Possible—Either Individual People and/or Specific Agencies/Organizations) Must Be Included in the Discussion and Their Role/Contribution to the Discussion

1. People with developmental disabilities and with a diversity of backgrounds
2. Local government—council/mayor
3. Governor's office (state commissioner's office)—integrate with—government
4. Child care providers
5. Legislators
6. Faith-based organizations

7. Schools/systems
8. Non-profits
9. Parents
10. Media

Identify the Process to Make It Happen

1. Workshops/seminars—local officials/town meeting
2. Resources need to stay in the developmental disabilities system
3. Make sure resources are used for services that are needed—an “a la carte menu” where people can select what they need
4. Structural continual dialogue on the subject of equity
5. Consensus building to make it happen

Describe the Desired Outcome

1. Accountability
2. Develop both short-term and long-term plans
3. Short-term claim for existing resources; phase-in programs using limited resources; take small steps; put your toe in the water and don't be afraid to try new things; don't wait to re-work the whole system
4. Provide opportunity grants for communities on the local level to develop programs
5. Pursue new funding sources, such as additional waiver money
6. Long-term develop a flow-chart indicating how to involve new partners
7. Long-term work on redefining individual versus family support

Future Stakeholder Forums

The group agreed that there should be future forums. Suggested forum topics were (1) the future of the developmental centers, (2) identifying a full continuum of possible services, and (3) defining equity.

BREAKOUT SESSION 2: FOCUS ON QUALITY OF LIVES, NOT QUALITY OF SERVICES

Note: This group did not organize its comments around the suggested topics. The spokesperson for the group described the group's approach as being more "philosophical" than "engineering."

List/Prioritize the Top 3-5 Issues/Actions that Must Be Addressed

What is meant by quality of life must be defined. The group determined that it is a person's surroundings. It's the people, programs, and environment in which a person lives. Quality of relationships defines a person's quality of life. Quality of life for a person with a disability is the same as for those who do not have a disability.

- The key is having an environment that enables the individual to "shine." Quality of life needs to be defined by an individual, and it may vary from individual to individual. People want support for what they want to do; they do not want to be "fixed." They want to be able to contribute to society in any way that they can. A key issue is ensuring a person's rights. In particular, a person should have choices. A different approach is needed to look at personal outcomes, not at the services that need to be provided. However, choice has no meaning if there are no services or programs available from which to select. Also, the individual needs a mechanism to use to make choices. Whatever system is built for people with developmental disabilities, we need to build in a process for assessing what people want. Choice needs to be empowered, and that may mean the person has control over what is purchased or what you need to make a marketplace.
- People operate on all cognitive levels. We do not do a good job of listening to people who are cognitively impaired. Learning to listen to people with cognitive disabilities is an area for future development that needs to be addressed.
- There are currently barriers for people with developmental disabilities to get generic services. We need to understand what these barriers are. Are these barriers a lack of knowledge? A need for training? A lack of money?
- There is a need to better disseminate information to families. Uneven information distribution limits the choices and options that people have. If we want to expand choices, we need to help people learn how to make choices. There is a need to work with the educational system to do this.

- Quality is also related to assessment. The level of care may not be the only key variable you want to look at in an assessment. There is a need to focus on the individual and his or her situation. There is a need to understand the family situation and the stress on the individual.
- As part of the service shift, there is a need to look at the family and the community as a resource, not just as another need. There is a need to look at the total environment to understand the service area.
- There are also issues related to the workforce. There is a need for available workers. Also, once workers are acquired, we must develop systems so the workers can share our values. The system will work only if the workers have some vision.
- Quality is measured by (1) personal outcomes, and (2) supporting choice, and (3) it is individually determined.
- An important shift needs to be made. The focus has been on the service delivery system and how people with developmental disabilities are different. We need to recognize that people with developmental disabilities are us; that we're the same group of individuals and share similarities.

BREAKOUT SESSION 3: ENDING THE SEARCH, ACHIEVING INFORMATION EQUITY

List/Prioritize the Top 3-5 Issues/Actions that Must Be Addressed

- A key topic that people will need information about is Medicaid and issues related to the waiver.
- There needs to be a system to provide information to families and consumers. This system needs to have both quantity and quality. There is an ongoing need for information that is consistent and accessible. A communication plan should use what currently exists, and it should be responsive to what families and individuals need and want. The Division of Disability Services can be “key player” for information about state services, especially for I & R. Key criteria for the communication system
 1. Need a single point of entry (that is, telephone number) for the Division of Developmental Disabilities that provides consistent, accurate, up-to-date information. At this number, people can get referrals. Additional resources may be needed to make it happen.
 2. There should be a standard information package from the Division of Developmental disabilities that everyone can get. These standard packets should be available wherever a person accesses the system, such as health care, education, and service agencies.
 3. Not only families need access to information. It is needed throughout system (from management/administration to case managers, etc.)
 4. There needs to be a core set of information that is basic and everyone needs; however, there also has to be a mechanism to get information out that is current and up to date. For example, now there are rumors about Medicaid because people do not have information they can use.

Identify Who (as Specific as Possible—Either Individual People and/or Specific Agencies/Organizations) Must Be Included in the Discussion and Their Role/Contribution to the Discussion.

1. State departments of education, human services, labor, health
2. County offices for the disabled, IL centers
3. Community groups, religious organizations
4. Social service network

Process to Make it Happen

No items listed here.

Desired Outcome

The desired outcomes for improved communication are: (1) to have lots of information, (2) to have quality information, (3) to have consistent information, and (4) to have it readily available.

Future Stakeholder Forums

Stakeholder Forums should continue. People with developmental disabilities should be included. An idea was to provide a stipend to support people attending future stakeholder forums. There should also be a forum for people with developmental disabilities so they can talk with each other. Continue the forum on a smaller basis—that is, have forums on local basis. Ensure diversity in participation. Utilize other means of communicating or conducting forums (for example, teleconferences). Include people with developmental disabilities in a meaningful way and in meaningful numbers.