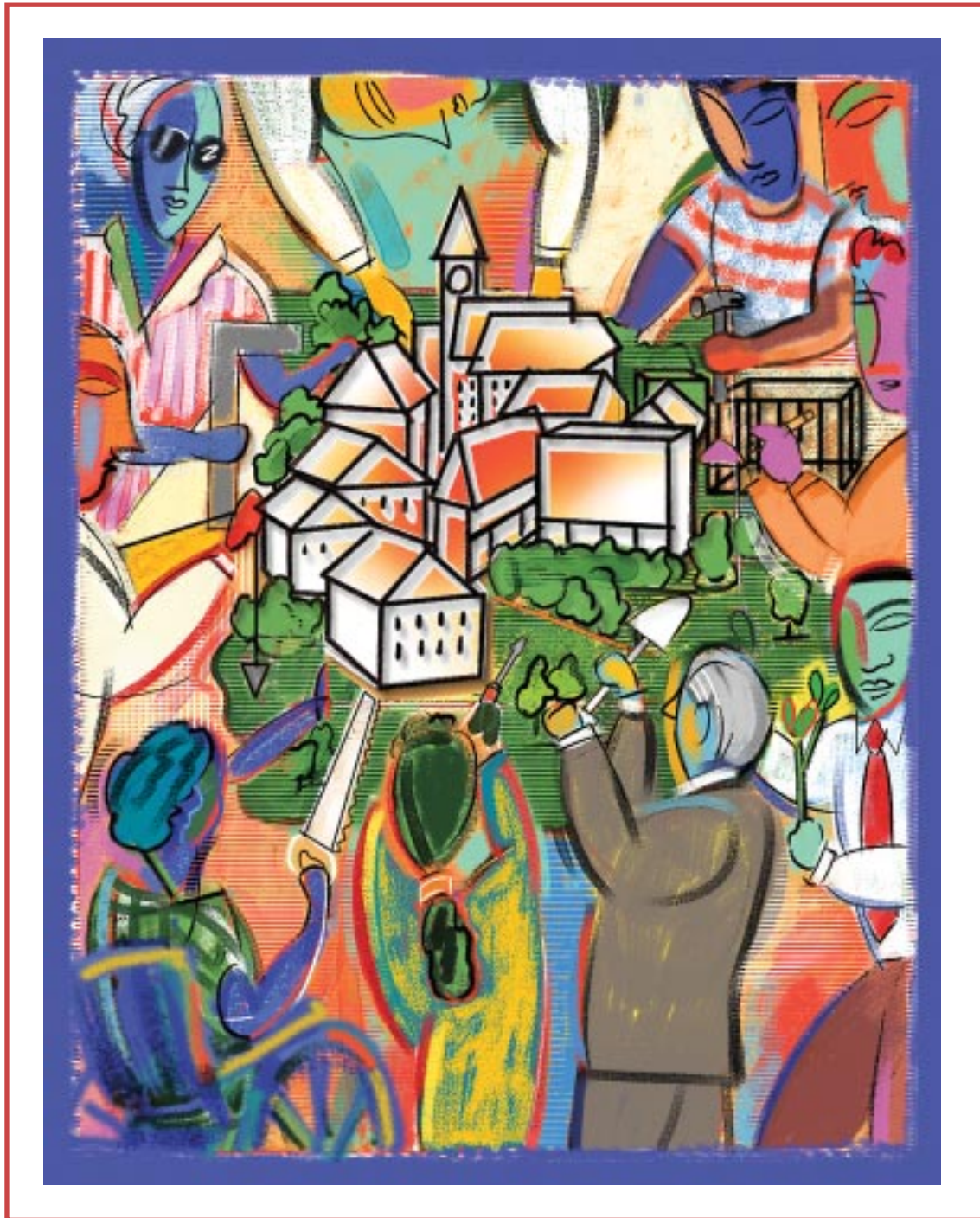




**A Call to Action:
Building a Community-Based
Plan for Delaware**



*Commission on Community-Based
Alternatives for Persons with Disabilities*



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Commission on Community-Based Alternatives For Persons with Disabilities Report to the 142nd Delaware General Assembly

“A Call to Action: Building a Community-Based Plan For Delaware”

Letter from Commission

To: The Honorable Terry R. Spence, The Honorable Thurman Adams and the Members of the 142nd Delaware General Assembly:

The Americans with Disabilities Act of 1990, and the United States Supreme Court decision in *Olmstead v. L.C.* interpreting it, has had a far reaching impact on lives of persons with disabilities (also referred to as consumers) across this country, and especially those who are institutionalized or at risk of being institutionalized. Respecting the rights of all citizens and upholding the dignity of persons with disabilities to live, work, and recreate in the community setting of their choice, our federal government and the Supreme Court have concluded that it is the basic human right not to be warehoused in an institution, but to be able to live in a community with all of the support services necessary to make such community living successful.

Leading the way in Delaware on this issue, the Delaware General Assembly, through the House of Representatives, created this Commission and charged it with developing a plan to facilitate the transition from a society that institutionalizes persons with disabilities, without regard for the needs, desires, and abilities of such persons, to one that recognizes that individuals are entitled to live in the least restrictive environment possible and to be part of the community in which they live.

Hundreds of people throughout the State took the time to give input and insight into how Delaware can better address the needs of persons with disabilities in the community. The Commission members, reflecting relevant constituencies, brought unique perspectives to the issues, and were able, despite an unfortunate inability of the State agencies to take a direct participation role in the process, to create a blueprint for ensuring that persons with disabilities truly will be able to move from institutions and live the type of life to which all Delawareans aspire and desire.

Yet, the Commission’s hard and diligent work, captured within these pages, represents not an end to the process of this planning, but rather a beginning. The plan, while wide-ranging and ambitious, must be implemented. Serious discussions and open dialogue must ensue with the State agencies, providers of services, advocates, caregivers, and consumers, if it is to be successful, and if it is to ensure that the mandates of the *Olmstead* Decision are to be met in this State.

Each of the recommendations characterized as goals and objectives in the Report are important to implement. However, without creating the personal assessments and consumer databases, and changing the dynamics between government and those that it serves and creating a mechanism that ensures that these recommendations are implemented, it is certain that Delaware will neither lead the country in the integration into community settings of individuals with disabilities, nor will it meet the social and moral obligations to its citizens, both those with disabilities and those without.

We, and the fellow members of the Commission, are proud of the spirit of cooperation and achievement that was exhibited throughout the Commission’s review and planning process. Each of the members thanks you for the opportunity to serve this State and looks forward with much anticipation of working with the General Assembly, the Administration, and the citizens of the State of Delaware in implementing this comprehensive plan for the betterment of the lives of all Delawareans.

Rita M. Landgraf
Robert J. Valihura, Jr.
Co-Chairs

Executive Summary

In June of 1999, the United States Supreme Court rendered a historic decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999). The Supreme Court encouraged States to develop plans to ensure that programs and services provided by the state promote community integration for individuals with disabilities rather than unnecessary institutionalization. Since the *Olmstead* Decision, agencies in the State of Delaware have developed plans to address the ruling. However, no cross-disability comprehensive plan or assessment has been implemented in Delaware to accurately assess the number of individuals choosing community supports.

In July 2002, the Delaware House of Representatives passed House Bill Resolution 90, creating a “Commission to Assess and Make Recommendations on Community-Based Alternatives for Persons with Disabilities.” The Commission was created to build on the work

Report Goal Highlights:

Determining Individual Needs and Preferences—Fair Assessments and Process:

A systematic, simplified, standardized, and fair process for assessing the needs, preferences, and recommended supports for individuals with disabilities must be established and implemented. In conjunction with the individual assessment process, a comprehensive database must be created to address the following:

- the number of people currently accessing services and those waiting to access services;
- the methods to support individuals moving from one setting to another; and
- facilitation of greater collaboration among relevant stakeholders.

Aspects of Community Living

Residential

Access to safe, affordable, and appropriate housing options must be available to individuals with disabilities. Individuals with disabilities

that had already been done and address the cross-disability needs of individuals within the State of Delaware.

The Commission consists of 30 Stakeholders. A legislative representative, representatives from advocacy groups, consumers, providers, and invested individuals collaborated to develop the

must be given opportunities to control their own housing, which includes rental and home ownership options. Flexible, diversified supports and services must follow an individual to the location he or she chooses, including the option for his or her family home.

Health Care

Delaware must create a coordinated comprehensive, affordable health care system for individuals with disabilities. Individuals, including children with disabilities must have access to appropriate quality services, specialists, and menus of service that are specific to their disability such as: attendant care or assistive technologies.

Employment

Quality vocational services and supports must center around the individual's strengths, preferences, capabilities, values, and interests just as a job or career would be for anyone. The implications for vocational supports are that they need to be available throughout the course of the person's life, ebbing and flowing in intensity and

duration, as the person's career requires. Compensation for everyone should be based on education, training, skills, and talents regardless of disability.

Transportation

People with disabilities must have a full range of safe, reliable, user-friendly transportation options available in order to access the community. Options are inclusive of accessible fixed route transit services, paratransit services, and personal vehicle ownership.

Education

Education is a significant part of an individual's life and as dictated by the Individuals with Disabilities Act (IDEA) should be provided within the least restrictive environment. Transition from the education system to the adult service system must be coordinated and seamless. The Commission recognizes that education does not stop at a cut-off age and individuals with disabilities must be afforded opportunities and support for continuing education.

Commission for Community-Based Alternatives Report. Frequent meetings were held to develop a draft report. Following the completion of a draft report, public meetings in all three counties in Delaware were held to share the draft recommendations, and comments from the meetings were incorporated into the final report. The

Commission also welcomed and received further comments after the meetings through individual contact.

The Commission shares the viewpoint of researchers that "for many Americans with disabilities, barriers in their communities take away

or severely limit their choices. These barriers may be obvious, such as lack of ramped entrances for people who use wheelchairs, lack of interpreters or captioning for people with hearing impairments, and lack of Braille or taped copies of printed material for people who have visual impairments. Other barriers—frequently less obvious—can be even more limiting to efforts on the part of people with disabilities to live independently, and they result from people’s misunderstandings and prejudices about disability. These barriers result in low expectations about things people with disabilities can achieve.”¹ This way of thinking has further isolated individuals with disabilities. “People with disabilities report getting out in the community less often than their peers without disabilities,” according to the National Organization on Disability.² A paradigm shift is needed not only within the community at large, but also within the service delivery system itself so that individuals with disabilities can experience a quality of life equal to that of any Delawarean. The Commission seeks to support and further the efforts to make a “Livable Delaware” for all, inclusive of people with disabilities, possible.

Whether in an institution or a community-based setting, the focus of service delivery needs to be on the preferences of the individual and his/her family. Individual choice and self-determination respects the experience and knowledge of the individual by valuing these four principles: freedom, authority, support, and responsibility. Individuals with disabilities must have:

- the freedom to exercise the same rights as all citizens,
- the authority to control their resources and make decisions about what is best,

“All human beings, whatever their cultural or historical background, suffer when they are intimidated, imprisoned, or tortured. . . we must, therefore, insist on a global consensus, not only on the need to respect human rights worldwide, but also on the definition of these rights... for it is the inherent nature of all human beings to yearn for freedom, equality, and dignity, and they have an equal right to achieve that.”

The Dalai Lama

- support from the community and agencies in an organized and helpful fashion,
- responsibility so that dollars are used as an investment in a person’s life and not handled as resources to purchase services or slots.³

Systems change must reflect the dignity and respect of every individual within the community,

and afford individuals with disabilities choice and self-determination.

The Commission determined that a system change, which supports individual choice and self-determination, is to be one that ensures *funding and services following the individual*. This system change must exist in order to remove institutional bias. Individuals should not need to “transfer” from one service to the next, as their needs change. Instead, the system should be designed so that an assortment of supports are accessible and available regardless of the funding source or disability.

Costs can only be assessed and actions can only be facilitated when all parties are forthright and collaborative during plan development and implementation. Participation from all stakeholders is vital for systems change within Delaware. The Commission recommends that Delaware establish and implement a policy of *open government* in an atmosphere of mutual respect inclusive of complete stakeholder participation. Collaboration will lead to the development and implementation of the changes and actions suggested in the Report.

The initial action that Delaware must take in order for individuals with disabilities to transition from institutions to the community, or remain in the setting of their choice, is an accurate and thorough evaluation of the individual’s preferences, strengths, and needs so that community services needed by all individuals with disabilities can be obtained. An exhaustive and on-going cross-disability universal assessment will allow the state to analyze and respond to the specific needs of the disability community.

Through research and experience, the Commission also determined that there are broad-based needs by individuals with disabilities in the areas of: Residential, Health Care, Employment, Transportation, and Education.



Without succinct, consistent, and directed support in these areas, individuals with disabilities will face incredible challenges in home and community-based living. The Report contains a series of goals and objectives that identify specific system needs within Delaware and recommends actions that will develop a statewide system that can provide affordable, accessible, and safe options for individuals with disabilities.

The Commission requests that a *formalized oversight group* representing cross-disability stakeholder participation be charged with monitoring and refining the goals and objectives presented in this Report. Stakeholders are inclusive of consumers, families, advocates, providers, and the State. The group must have the authority to implement the recommendations and have support from the administrative and legislative branches within Delaware.

Purpose of the Commission

At the conclusion of its judicial term in June 1999, the United States Supreme Court rendered an historic decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999) (hereinafter, the “*Olmstead Decision*”). In that case, the Supreme Court construed Title II of the Americans with Disabilities Act of 1990 (hereinafter, the “ADA”) to require the States to place qualified individuals with disabilities in community settings, rather than institutions, whenever treatment professionals determine that such placement is appropriate, the affected persons do not oppose such placement, and the State can reasonably accommodate the placement, taking into account the resources available to the State and the needs of others with disabilities. As part of the *Olmstead Decision*, the Supreme Court encouraged the States to develop comprehensive plans to ensure that programs and services provided by the state promote community integration rather than unnecessary institutionalization.

Prior to the *Olmstead Decision*, Delaware had no comprehensive cross-disability approach to moving individuals with disabilities from institutions into community settings. Furthermore, Delaware never assessed *all* individuals in institutions to determine whether they would prefer to be in a community-based setting, never made any determination as to the needs or preferences of those individuals concerning those issues, and never made a complete survey of whether those individuals could be, if appropriate support services were available, fully integrated into such community-based living. Nor had the State considered whether adequate services and support mechanisms existed in the community to facilitate such community living for persons with disabilities.



While some progress was made by State agencies in the several years since the Supreme Court rendered the *Olmstead Decision* in moving a number of institutionalized individuals into community-based settings, the State neither surveyed all institutionalized individuals nor reviewed what services needed to be provided in the community to ease the transition of such individuals into community-based living settings.

The Delaware General Assembly, through the House of Representatives, recognizing the importance of this issue—the right of all citizens to be able to live in the setting of their choice—and wanting to ensure that Delaware has a comprehensive plan designed to ensure that persons with disabilities have the ability to live in the community and can do so with the level of support necessary to do so successfully, passed House Resolution 90 creating a “Commission to Assess and Make Recommendations on Community-Based Alternatives for Persons With Disabilities.”

House Resolution 90 charges the Commission with collecting and compiling existing State

Reports and information relevant to planning under the *Olmstead* Decision, supplementing such reports and information by comprehensively assessing existing needs and resources, closely monitoring the availability of Federal and private funds and actively coordinating applications for such funds and, lastly, preparing a comprehensive, multi-year interagency plan to ensure that Delaware programs support community alternatives to institutionalization.

This Report represents the culmination of the work of the Commission over an eight month period to gather such information and to provide such a plan, albeit with some unforeseen limitations in the ability of the Commission to fully carry out its charge, and makes recommendations as to the manner of how the State of Delaware can best ensure that individuals who are institutionalized or at risk of institutionalization can best be accommodated in the community in the setting of their choice.

Mission

Develop a blueprint for a diversified, individualized, cost effective service and support system that enables individuals with disabilities to live and work in the most integrated setting of their choice.

Principles

The following principles are of paramount importance to people with disabilities, their families, and the general public. The principles are inherent in the findings in the report and provide the context and background for the Commission's overall recommendations.

Quality of life: The goal of our service system for persons with disabilities must be to achieve a quality of life (QOL) equivalent to those without disabilities, which includes having access to the same opportunities as those without disabilities including education, employment, transportation, health care, housing, citizen privileges (e.g., voting, signing contracts, owning a home), social and recreational activities, spiritual activities, and all other opportunities afforded to the general public. "Many current 'best practices' emphasize the importance of consumer participation, community presence, meaningful activity, social networks, recreational opportunities, new technologies, and choice for people with disabilities."⁴ Individuals "with disabilities and service providers identified the following principles: 1) QOL for persons with disabilities is made up of the same factors and relationships that have been shown to be important for persons without disabilities; 2) QOL is experienced when a person's basic needs are being met and when he or she has the opportunity to pursue and achieve goals in major life settings; and 3) The meaning of QOL in major life settings can be consensually validated by a wide array of persons representing the viewpoints of persons with disabilities, including their families."⁵

Services must be determined and driven by the individual with a disability and his or her needs: The individual must be the primary focus for service planning and, along with his or her family and significant others, must be an active participant in the delivery, implementation, and evaluation of services. Individuals with disabilities and their families are best able to determine their own needs and should be empowered to make decisions concerning necessary and appropriate services.

Individuals with disabilities must be able to receive support that is continuous, high quality, and community-based: The service delivery

system must ensure persons with disabilities can secure, receive, and rely on services being provided as agreed to by the consumer. Services must be provided in a timely manner, be consistent and dependable, and appropriate for the individual's needs. It is critical that services among multiple provider agencies (both state and private) be coordinated and collaborative in nature.

Evidence-based research in all human services arenas conclusively demonstrates that access to services is maximized when services are developed to meet the needs of an individual with a disability.

System openness and responsiveness: The development and maintenance of a high quality service system for persons with disabilities and their families is achievable only through an open planning, implementation, and evaluation process. The establishment of “open government” practices that ensure consumer input and feedback to enhance practices, policies, and supports is critical. Effective plans for service systems are best achieved with the active involvement of those who will be affected by the services. It is therefore imperative that individuals with disabilities, their families, and their representatives participate in the design, development, implementation, and evaluation of service systems. Collaboration also needs to fully embrace a reciprocal, mutually beneficial public/private partnership with the service provider network, advocacy organizations and councils, the State of Delaware, and the public, including individuals with disabilities and their families.

Mutual respect: True civil rights only occur when all stakeholders interact with each other in an atmosphere of mutual respect. All of the participants involved must interact with one another in an atmosphere of mutual respect; services,

“Science may have found a cure for most evils; but it has found no remedy for the worst of them all—the apathy of human beings.”

Helen Keller, 1927

policy development, and other activities must have a primary focus that will foster independence and dignity for individuals with disabilities.

Funding for services must follow the individual: Funding must support the needs of the consumer regardless of where they reside (institution or community) and should be allocated based on the individual. One of the most challenging system obstacles to flexibility and responsiveness is the “slot-based” funding; an individual should not need to “transfer” from one service to the next as their needs change. Rather, the system should be designed so that an assortment of supports are available to the individual, regardless of funding source, or type of disability. If an individual does choose to change providers, the funding and services must follow the individual. The support needs of the individual must drive the funding, not the funding driving what supports are provided. Leverage of funding through federal, state, and private sector monies should be considered for optimal support in the most cost-effective and efficient way.

The Stakeholders

All planning, implementation, and evaluation of services and supports for persons with disabilities must include the stakeholders who will be affected by decisions related to the system.

Stakeholders include:

- all persons with disabilities;
- the nuclear families, families of origin, extended families, and foster families of persons with disabilities;
- the advocacy groups and representatives of persons with disabilities;
- the provider agencies;
- state and local elected officials;
- local, state, and federal agency representatives;
- representatives of specific communities throughout Delaware;
- representatives of employers and businesses throughout Delaware; and
- representatives of the general public.

The Commission included members from the above stakeholder list, with the exception of Local, State, or Federal agency representatives, in order to develop the most comprehensive product possible. As recommendations of the Report are implemented, the planning and execution of activities must include the participation of the above stakeholders, and those representative stakeholders must have the authority to make decisions for the organizations or individuals who they represent.

History

Title II of the ADA is the touchstone to disability rights in this country and was the provision directly considered by the United States Supreme Court in the *Olmstead* Decision. That provision is particularly broad in its scope, and is sweeping in its pronouncement of the rights of persons with disabilities.

Title II of the ADA provides:

“[N]o qualified individual with a disability shall, by reason of his disability, be excluded from participation in, or be denied benefits of the services, programs, or activities of a public entity, or be subject to discrimination by any such entity.”⁶

Background: The *Olmstead* Decision

The *Olmstead* Decision Confirms the Right to Individual Choice.

As directed by Congress, the Department of Justice promulgated regulations under the ADA, and one such provision implementing the policy of Title II, the “integration regulation,” provides:

A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.⁷

It is with that statutory and regulatory background that the challenge to State mandated institutionalization of persons with disabilities without regard to the desires of the person ultimately arose.

Lois Curtis, a woman with both a mental illness and a cognitive disability, and Elaine Wilson, who also has a cognitive disability, were confined to Georgia Regional Hospital, a state-run psychiatric hospital. Notwithstanding the fact that they had years earlier been cleared by the appropriate treatment professionals for discharge into the community, Ms. Curtis and Ms. Wilson remained confined at the hospital. Relying on the ADA and the integration mandate under the federal regulation, lawyers on their behalf charged that Tommy Olmstead, the Commissioner of Georgia’s Department of Human Resources, and the State of Georgia violated those requirements by failing to provide Ms. Curtis and Ms. Wilson services in the most integrated setting appropriate to their needs. According to these plaintiffs, that setting was the community, not the institution in which they were confined.

A protracted legal battle ensued, ending up in the Supreme Court of the United States. There, in a 6-3 decision, the Supreme Court held that the ADA prohibits the states from unnecessarily institution-



alizing persons with disabilities and from failing to serve them in the most integrated setting.⁸

That victory for Ms. Curtis and Ms. Wilson, according to the Supreme Court, flowed from the Court’s finding in the ADA that unjustified segregation of persons with disabilities is a form of discrimination and from the Department of Justice’s repeatedly held position that unnecessary institutionalization qualifies as discrimination by reason of disability.⁹ Significantly, the Court held that where an institutionalized individual could appropriately live in a community-based setting, Title II of the ADA mandates a state to provide community-based services, unless doing so would fundamentally alter the state’s services and programs.¹⁰

In affirming the integration mandate of the ADA, the *Olmstead* Decision was quite specific in its view that the anti-discrimination provisions prohibit states from placing a person in an inappropriate institutional setting. According to the Court, institutional placement of persons who can handle and benefit from community settings perpetuates “unwarranted assumptions” that persons so isolated are incapable or unworthy of participating in community life.¹¹ Furthermore, the

Court indicated that confinement in an institution severely diminishes the everyday life activities of individuals including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.¹² Ultimately, in order to carry out the mandates of the ADA, the Supreme Court held that the States are required to make reasonable modifications to their existing programs to avoid inappropriate institutionalization.¹³

The Delaware Response: Compliance with the *Olmstead* Decision?

According to the Supreme Court in the *Olmstead* Decision, states could avoid violating their obligations under the ADA if they demonstrate that the state had a comprehensive, effective working plan for placing qualified persons with disabilities in the most integrated setting and a waiting list that moved at a reasonable pace not controlled by the state's endeavors to keep its institutions fully populated.¹⁴ Despite this clear and detailed methodology to meet the most integrated setting requirements under the ADA, Delaware took no coordinated cross-disability or inter-agency action to ensure that the discrimination that results from unnecessary institutionalization would be addressed in due course. Indeed, during the two years following the *Olmstead* Decision, although an Executive Order had been signed by the Governor, Delaware neither promulgated a cross-disability comprehensive plan, nor actively worked on creating a workable process for the reduction in the waiting list for moving individuals from Delaware's institutions into community-based settings.¹⁵

Sensing a need to jump start Delaware's compliance with the requirements under the *Olmstead* Decision, advocates, consumers, and providers in the State sought to begin a dialogue with the State to create some type of broad participation, stakeholder-driven planning process to develop a strategy for the State to meet its obligations

under the ADA and the *Olmstead* Decision and to provide services to people with disabilities in the most integrated setting possible.

Although this process was initiated by the State Council for Persons with Disabilities¹⁶ and actively supported by the Developmental Disabilities Council and other disability advocacy groups, the State neither committed to implementing such a collaborative planning process, nor took any positive public steps, as had been done in over half of the states, to confirm that the State was taking the ADA mandates as articulated in the *Olmstead* Decision seriously.

Although discussions concerning the need for a broad-based, stakeholder-driven comprehensive planning process continued with the State throughout the first six months of 2002, it was now certain that the State would be unwilling to agree on the need for such a process.

The Delaware Litigation: Advocacy in Action.

In the spring of 2002, following the announcement of the proposed budget for the Division of Developmental Disabilities Services which, according to some stakeholder groups, appeared to provide no additional funding to reverse the increasing numbers on the waiting list for community residential living arrangements. The Arc of Delaware, the Homes for Life Foundation, and Delaware People First, along with a number of individual plaintiffs, filed suit on April 8, 2002 against the State of Delaware (hereinafter, the "Delaware Action").

Asserting violations of the ADA and the integration regulation, among other things, Plaintiffs in the Delaware Action are seeking the elimination of waiting lists for services, the provision of community-based services for people who are currently institutionalized at the state-run Stockley Center, and improvements to Delaware's current service delivery system.

The State of Delaware has actively opposed that litigation, and sought to dismiss all of the claims therein. As of the date of this Report, that Action has not progressed past the preliminary motion practice stage of the litigation.¹⁷

The Commission and the Process

With no possibility of a State sponsored Commission being created, advocacy groups approached members of the General Assembly seeking their support for a legislatively-created Commission to begin that coordinated and all-encompassing approach toward ensuring compliance with the ADA and ensuring that programs and services promote community integration rather than unnecessary institutionalization. On the last night of session of the Delaware General Assembly, June 30, 2002, the House of Representatives considered and passed House Resolution 90 that created the Commission.

Under H.R. 90, the Commission's responsibilities include the following:

- Collect and compile existing State Reports and information relevant to Olmstead Planning;
- Supplement such reports and information to comprehensively assess existing needs and resources;
- Closely monitor the availability of Federal and private funds and actively coordinate application for such funds;
- Prepare a comprehensive, multi-year interagency plan to ensure that Delaware programs support community alternatives to institutionalization; and
- Submit a preliminary report to the Joint Finance Committee by February 15, 2003, and a final report to the General Assembly

“Injustice anywhere is a threat to justice everywhere. We are caught in an inescapable network of mutuality, tied in a single garment of destiny. Whatever affects one directly, affects all indirectly.”

Martin Luther King, 1963

within 45 days thereafter which includes the plan; options and costs; legislative and regulatory action needed to support plan implementation; prospects for obtaining supportive Federal or private funds; and recommendations.

Comprising over 30 critical stakeholders from the public and private sectors, the members of the Commission began meeting in July 2002 to address the task confronting them. From the outset, the Commission was fortunate to have the assistance of the Center for Disabilities Studies (CDS) at the University of Delaware and the use of its facilities and staff to help with many of the technical, administrative, and public information obligations of the Commission.

The CDS, under the direction of Michael Gamel-McCormick, and its staff, including Tracy Mann, and University of Delaware Graduate

Assistant, Amy Lynne Sawyer, has been an invaluable resource and has provided expertise and research that the Commission would not otherwise have had available to it. Also, the Commission had the benefit of the staff support services from the State Council for Persons with Disabilities, and truly appreciates the dedication, commitment, and institutional knowledge of its Administrator, Kyle Hodges, who participated throughout the Commission process.

However, no sooner had the Commission undertaken its work, then it was faced with an immediate, and potentially insurmountable, hurdle. The State of Delaware, as a Defendant in the Delaware Action, had been advised by its outside law firm, that active participation on the Commission “would be harmful to the state’s interests” in the defense of the Delaware Action. Based on that advice of counsel, the State directed that its primary officials who oversee Delaware’s services to persons with disabilities, and who had been requested to serve as members, not participate in the Commission.¹⁸

Notwithstanding its inability to directly participate in the Commission’s work, the State of Delaware did, however, provide the Commission with pertinent information and did cooperate with the Commission on providing certain factual information, interviews, and inspections of State facilities. Yet, because of the lack of input from the state, the Commission did not have the capability of having access to knowledge and financial information that would have been helpful in developing a complete plan and fulfilling its desire to provide relatively specific financial information on the long-term savings that would be had or the initial start-up costs which might be incurred by implementing the recommendations made by the Commission.

Notwithstanding the disappointment of not having a key stakeholder provide direct input, the loss of critical insight, information and first-

hand evidence of the State’s internal plans and strategies for addressing the requirements of the *Olmstead* Decision, and not wanting to lose the opportunity to create a far reaching and ranging plan for community-based alternatives, the remaining members of the Commission unanimously agreed to proceed and to carry out their mandate to the extent possible, under the House Resolution.

In attempting to tackle this responsibility, the Commission considered how best to review the issues and struggled to come to grips with the appropriate methodology to ensure that a complete and full review occurred. Following several meetings, the Commission finally concluded that the Commission should breakdown into sub-committees and address the issues using several relevant aspects of community living. Each of those sub-committees then went forward to identify the issues relating to accessibility of community-based living alternatives based on the aspects of community living assigned to the Commission. Those sub-committee focus areas: Residential, Health Care, Employment, Transportation, and Education, were later supplemented by the Commission with two additional sub-committees that addressed overarching topic areas: assessments and funding.

Following the completion of the sub-committee work over a period of several months, in which the sub-committees met frequently, the full Commission met to review, critique, and probe the findings of the sub-committees. This process resulted in a refinement of the issues and recommendations and a delineation of additional areas of concern. Further, work of the sub-committees was resubmitted to the Commission as a whole for its continued review and comment.

As required by the Resolution, and as an invaluable tool to obtain public input into the process, the Commission held three public meetings, one in each of the three counties, to seek out public comment and obtain perspective on planned development and content. Those workshops, well attended by citizens of each county, provided additional information and issues that were not addressed, or addressed insufficiently to date, which was subsequently included in the report.

The Report, the culmination of the work done by the sub-committees and the members of the Commission independently and together, is in fact the blueprint for action by Delaware and the residents of the State.

Commission Report Overview

The themes in the mission statement and principles prompted the development of this Report's structure. This Report includes the following subject areas:

- Determining Individual Needs and Preferences: Fair Assessments and Process
- Aspects of Community Living: Residential, Health Care, Employment, Transportation, and Education
- Funding
- Priority Recommendations, which provide a catalyst for immediate action

Within each of the subject areas, the Report provides a series of goals and objectives that have been developed to express viable and needed

community-based options for people with disabilities in Delaware. Along with goals and objectives, personal stories have been included to illustrate the effect current and past policies and practices have on the lives of Delawareans.

The Commission recognizes that leisure and recreation activities enhance the quality of everyone's life. The Commission has an overriding belief that persons with disabilities must be afforded access to the leisure activities of their choice, as would any person without a disability. Because of the uniqueness and vast nature of an individual's preference for recreation and leisure, it was not included as a major aspect of this Report; however, the Commission remains committed to the need for barrier-free, accessible, individually driven leisure and recreation opportunities.

Determining Individual Needs and Preferences: Fair Assessments and Process

The *Olmstead* Decision ensures that individuals with disabilities in institutions and those at risk are assessed in a fair and timely manner to determine how community living would be possible without limiting options to what is currently provided in the community. All persons with disabilities residing in institutional settings will need to participate in an assessment to help them determine the most integrated setting in which they can and wish to live. The court further found that:

- (a) institutional placement of persons who can handle and benefit from community



Becky Eehalt

In November 2002, Becky Eehalt moved to the Foulk Road II Bancroft group home in North Wilmington. Becky and her family decided that it was time for her to branch out on her own into a community setting and live more independently. Living in her group home is a first step as Becky begins working toward living independently, and she continues to set goals for her future which include employment and living on her own or with her friends.

Community activities are important to Becky, and she participates in a variety of activities including Special Olympics and People First, a self-advocacy organization. A member of the North Stars Team with Special

Olympics, Becky recently participated in the bowling tournament, is participating in the Polar Bear Plunge, and is going to begin swimming in the spring. In Virginia, Becky was active as a junior lifeguard and volunteering with other sports and community activities. She joined People First in December when her roommate asked her to join her for a meeting, and she enjoys working with other people on issues important to her. In addition to these activities, Becky hopes to fulfill her next goal to reaching independence — employment in Delaware.

Becky previously worked for a mailing and administrative services company, and she hopes to find a job where she can use her past employment experiences, gain new skills, and meet new people. She currently participates in a day program three days a week, but is looking for a full-time job to be self-sufficient and independent. “I would like a job, instead of sitting home all day and being bored,” she stated.

Becky is very proud of her home; she lives with three other women and a housemother. Her room is decorated with dolphins, her collections of seashells and teddy bears, and pictures of her family. “My parents think its great,” she said, and they have provided her with guidance and support in moving into her new home. Living in a group home is Becky’s first step in living in a community-based setting, and she believes through continuing her involvement in community activities and finding a job, she will achieve her goals.

settings perpetuates “unwarranted assumptions” that persons so isolated are incapable or unworthy of participating in community life; and

- (b) confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

Currently, a number of assessment forms are used within the State of Delaware. An universal statewide assessment tool and process needs to be established and implemented to effectively provide institutionalized individuals with disabilities and those at risk of institutionalization the choice to receive services in the most integrated setting. The assessment needs to determine the appropriate housing, health services, social support, transportation, and employment/vocational services, which meet the indi-

vidual's needs and preferences. In addition, the assessment process should provide necessary information to individuals regarding community services, so they can make an informed choice. Secondly, assessments must be written and conducted in a fair, objective, unbiased manner. The assessment process should create data that can be used to maintain an accurate database of individual needs and circumstances. An effective case management system needs to be enhanced to ensure the identified needs of the consumer are met in an expeditious and cost-effective manner.

Assessment Goal #1: Establish and implement a practice of assessing all individuals regardless of severity of disability residing in nursing facilities, ICFs (intermediate care facility), and other institutions every 3 months to determine their desire for home and community-based service options.

Objective 1) - Collaborate with the State of Delaware to develop a universal, cross-disability assessment tool to determine the individual's *desire* for home and community-based service options. The Commission has reviewed the *Home and Community-Based Long-Term Care Options Form* (Appendix A) currently used by Delaware agencies and developed the attached prototype, which is more comprehensive for all people with a disability.¹⁹ (Appendix B)

Assessment Goal #2: Establish and implement a practice of assessing all individuals residing in nursing facilities, ICFs, and other institutions every 6 months to determine the needed supports for home and community-based living.

“If civilization is to survive, we must cultivate the science of human relationships—the ability of all people, of all kinds, to live together, in the same world at peace.”

Franklin D. Roosevelt

Objective 1) - Collaborate with the State of Delaware to develop a universal, cross-disability assessment tool to determine needed supports for community living. The Commission has reviewed different assessment forms and developed the *Community Transition Form* based on recommendations from Tony Records, a leading consultant in the disability field²⁰. (Appendix C)

Assessment Goal #3: Contract with non-state agency(ies) to conduct an independent assessment, free from financial or other conflicts. Non-state affiliated agencies must conduct both initial and ongoing assessments.

Objective 1) - Information gathered from the initial Home and Community-Based options form should be used to create a Preference Database containing data on the individuals who desire to live in the community

Objective 2) - Contractors should provide information from *Goal Two* to the State of Delaware, so that a supports database of comprehensive consumer profiles is created which encompasses age, sex, disability, needs and preferences, and other relevant information. This database would enable greater collaboration and coordination of services among all stakeholders.

Assessment Goal #4: The State of Delaware must use the databases created through assessment findings to facilitate the transition of individuals who desire community-based living in as expeditious a manner as possible.

Objective 1) - Establish a practice of stakeholder collaboration to determine a fair and equitable transition process.

- Determine an incremental percent over a 2 year time period to complete the *Community Transition Form (Appendix C)*
- Determine a yearly percent of people to be moved and supported in the community over a 5-year time period. A minimum percent per year should be set which would determine movement of individuals from institutions, licensed nursing facilities, and ICFs to community-based programs and the movement of people currently residing in the community who may desire a less restrictive setting.

Assessment Goal #5: Ensure that a process for assessing individuals with severe and persistent mental illness, cognitive disabilities, and physical disabilities exiting the prison system or involuntary treatment facilities is provided in a timely and appropriate manner prior to release.

Objective 1) - Establish a practice of stakeholder collaboration to determine and implement successful transitions.

Assessment Goal #6: Establish a fair and equitable process of assessing all individuals residing in other settings, such as group homes, natural family settings, or supportive living environments, to determine appropriate preferences and needs.

Objective 1) - Collaborate with the State to establish and improve the process of assessing individuals at least once a year to determine their needs using the same universal *Community Transition Form* discussed in goals one and two. (*Appendix C*)

Objective 2) - Develop a database system that facilitates the provision of adequate supports in a fair and equitable manner. Individuals residing in the community should be evaluated quickly and thoroughly for continuing services needs and changes in the disability, which may require a change in supports.

Assessment Goal #7: Develop and maintain a user-friendly packet of up-to-date information that includes residential, health care, employment, transportation, and education resources. This information should allow for a comprehensive list of available services to be used by service providers and individuals with disabilities, and all other involved stakeholders.

Objective 1) - Before transition occurs, incorporate training in the self-management of disability, self-advocacy and services, which will aid independence in the home and community. Allow individuals to try various community living options, which would enable them to best determine their preferences.

Aspects of Community Living: Residential, Health Care, Employment, Transportation, and Education

Residential

Like many states, Delaware has used various approaches to provide services for people with physical, cognitive, mental, and emotional disabilities. Community-based services do exist, but options have been and are limited in availability and accessibility. Delaware currently has a variety of community-based options, as well a number of institutions: Stockley Center, Delaware Psychiatric Center (DPC), Delaware Hospital for the Chronically Ill, Governor Bacon Health Center, Emily P. Bissell Hospital, and approximately 40+ licensed nursing care facilities. In recent decades persons have moved from institutions to community-based services. However, the types of community options available have been limited and availability of funding for community services has been greatly outpaced by demand.

The State of Delaware's responsibility to provide community-based options to individuals with disabilities should not end at group homes, and instead should grow to include a continuum of options from personal homes and apartments, to foster care, to various individualized settings. Appropriate housing options are necessary for persons with disabilities to remain safe and comfortable within the community. However, persons with disabilities have a difficult time in accessing these housing options for various reasons such as lack of attendant care services, skills training, architectural barriers, and inadequate finances.

"I am living proof of it."

Phil joined the staff of the New Castle County Court of Common Pleas over 22 years ago and has enjoyed the challenging work ever since. Utilizing the court's computer system, Phil checks case information for accuracy for the judges, coordinates the court's schedule with the Capital Police, and is responsible for a variety of other duties as a Court Clerk. The work is both challenging and extremely rewarding, and Phil recognizes employment as a fundamental component of his independence, as well as living in his own home and participating in a variety of community activities.

Phil has been living independently for over ten years since he moved out of his family home with his mother's support and guidance. His condominium is conveniently located near his office, and Phil frequently walked to work before the new courthouse was built a little further away. The DART fixed-route bus system is Phil's regular mode of transportation in the city. Living on his own gives Phil more self-determination, and he stated, "I like

Training and support in such areas as maintenance and home living skills, socialization skills, and self help skills are needed to assist the consumer in gaining a higher level of self-sufficiency. People with disabilities should no longer be "placed" or made to fit into a program or facility. Rather, flexible, diversified supports and services must follow the person to the location he or she chooses, including the individual's family home. Individuals with disabilities must be empowered to control their own housing, which includes rental and home ownership options. Thus, public policies must ensure that individuals with disabilities receive a fair share of all local, state, and national housing resources. Individuals should reside in the setting of their



Phil Saxon

the independence, because I am able to pay my own bills. I am fortunate because I do have a good job and can pay for rent and food, telephone bills, and cable.” His self-sufficiency is very important to him, as is his service to the community, which furthers his independence.

An active community member, Phil not only participates in six sports programs with Special Olympics as a member of the Brandywine Social Club team, he also sits on their Board of Directors and was the 2002 Athlete of the Year for Special Olympics Delaware. As a member of the Board, Phil is responsible for overseeing the Athlete Input Council, which is a forum that Special Olympics athletes utilize to work on issues important to the athletes. As a member of the Board,

Phil also participated in his first Polar Bear Plunge to help raise money for Special Olympics and has continued “plunging” each year. For the Community Legal Aid Society, Inc., Phil is a Community Representative for their Board of Directors. Phil is also a member of People First, a self-advocacy group sponsored by The Arc of Delaware.

Phil is proud of his job, apartment, and community involvement, but does not think he is unique in being able to accomplish these things. “You need support, and you may need help,” he stated, “I was fortunate; I had my mother. But people can do it, but they may need support.” Phil’s family and friends provided him with the encouragement he needed to get his job, move into his own home, and participate in the community, and he is grateful for their support. “I am lucky because I have the support of my mother. She’ll help me, and I’ll help her.” Phil visits his mother on the weekends, and he is now supporting her through maintenance to her home, as well as helping with household errands. “I think people can have a good job like mine and can live by themselves. I think it can be done. I am living proof of it.”

choice and with whom they choose to live, which may include living with people with disabilities or it may not.

Residential Goal #1: Increase safe, integrated, affordable, and accessible home ownership opportunities.

Objective 1) - Offer tax credits to individuals and housing development organizations for renovations and modifications.

Objective 2) - Investigate mortgage and down payment assistance programs and partnerships with financial institutions and community organizations.

Objective 3) - Establish a program where individuals with disabilities can secure low interest loans and grants for home ownership, as well as home modifications by partnering with financial institutions, and public, and private entities.

Objective 4) - Create and expand “rent-to-own” programs across the state to improve the possibility of home ownership among persons with disabilities.

Objective 5) - Encourage housing authorities to implement the Section 8 program which earmarks at least 10% of those vouchers for individuals with disabilities to use towards mortgage and down payment assistance.²¹

Objective 6) - Secure Section 811 funding to be utilized exclusively for tenant-based vouchers for individuals with disabilities and their families for ownership of property. Currently, nonprofit organizations generally use funds for congregate living arrangements.

Objective 7) - Advocate for visitability laws and universal design in Delaware for newly constructed homes. In a 1999 AARP survey 66% of individual Respondents 45 and older indicated they would support their state passing legislation requiring that more homes be built with home modification features.

Objective 8) - Increase collaboration with housing developers and landlords to educate them on the benefits of accessible design.

Objective 9) - Investigate a partnership with Habitat for Humanity to focus on building accessible homes for individuals with disabilities.

Residential Goal #2: Maximize safe, integrated, affordable, and accessible rental opportunities for individuals with disabilities

Objective 1) - State and local authorities must apply and secure mainstream and fair share vouchers through HUD. Assure vouchers are distributed in a timely fashion through a systematic overview process. This process should also allow individuals to view their placement on the registry.

Objective 2) - Maximize rental opportunities for people with disabilities by educating landlords that they can receive above market value dollars for rentals (e.g., landlords can receive HUD funding from 120 - 140% above fair market value to provide *accessible* housing for people with disabilities.)

Objective 3) - State and local housing authorities must list accessible housing for people with disabilities as a priority in their strategic planning

process resulting in accountability, increased housing opportunities, and compliance with the federal preference for people with disabilities.

Objective 4) - Secure Section 811 funding to be utilized exclusively for tenant-based vouchers for individuals with disabilities and their families for rental of property. Currently, nonprofit organizations generally use funds for congregate living arrangements.

Objective 5) - Investigate the HUD option, which allows an individual to move into a two-bedroom apartment if no one-bedroom apartments are available for the cost of a one-bedroom.

Objective 6) - Examine the priority voucher program targeted exclusively to individuals and families with disabilities. Ensure that it is being effectively implemented statewide.

Objective 7) - Encourage housing authorities to implement the Section 8 program, which earmarks at least 10% of those vouchers for individuals with disabilities to use towards rental assistance.²²

Residential Goal #3: Secure Medicaid waivers that allow for a broad range of residential services and support options which promote choice, independence, freedom to take risks, and cost effectiveness.

Objective 1) - Secure a family support waiver, which would include services and other supports necessary to enable families to remain intact. Investigate kinship and foster care programs that would provide additional choices.

Objective 2) - Advocate that Division of Substance Abuse & Mental Health secure home and community-based waivers which would include residential supports for people with mental illness and their families.

Objective 3) - Review and develop more diverse and flexible residential service programs, funding, and supports which promote meaningful choice across a broader range of options. These options should include:

- additional licensed and unlicensed alternative support service models and funding options,
- supports provided in the family's or consumer's own home, and/or
- a menu of carefully selected and adapted current waiver service options with an emphasis on innovative, effective, and efficient models which promote residential goal number three.

Residential Goal #4: Individuals with disabilities should have the ability to receive continuity of quality, creative community supports within their own homes.

Objective 1) - Establish a practice which allows for funding to be provided based on the support needs of the consumer.

- Preliminary assessment tools have been instrumental in moving the system from a flat reimbursement rate to an individualized rate of reimbursement which matches the funding to the staffing and support needs of the individual. Utilize existing tools *such as* the Inventory for Client and Agency Planning (ICAP) tool currently used for people with cognitive disabilities to develop a more person-centered, cross disability assessment and planning process.

Objective 2) - Use the database (discussed in Assessment Goals 2 and 3) to determine housing and location preferences which promote choice and more effective 'matching' of consumers with housemates (as desired) and providers. Query the database annually to determine the housing needs across disability to monitor trends and advocate for systemic change.

Objective 3) - Establish a task force, including the Human Relations Commission, to ensure that all state, county, and municipalities are in compliance with the Fair Housing Act.

Objective 4) - Promote legislation that will update the state's zoning requirements relating to people with disabilities in group homes.

Health Care

Individuals with disabilities should have dependable, high quality health care in the community, and affordable comprehensive health insurance. People with disabilities have faced many challenges in accessing timely and appropriate health care. Challenges in the community include the inability to obtain appropriate quality services, lack of access to specialists, and healthcare professionals who refuse to serve or limit the options made available to the population with disabilities. Insurance coverage is frequently unavailable or prohibitively expensive and has narrow menus for the specific disability related needs of an individual, such as attendant care or assistive technologies. These narrow menus of services have created an increased pressure on the Medicaid system, which has subsequently increased Medicaid costs.

In order to facilitate community living for individuals with disabilities of all ages, Delaware needs to provide a coordinated health care system. Both the Longwood Study (under the leadership of Easter Seals) and the Goins-Williams study (under the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)) concluded that major gaps in services in Delaware exist in medical care, dental care, and attendant services.

The issue of health care is monumental due to the vast number of individuals in need of services, diversity of their needs, and the need for coordination of services. However, after reviewing both state and federal initiatives and programs relating to health care, the Commission has identified the following critical areas that need to be initially addressed in Delaware.

Health Care Goal #1: Develop a comprehensive, flexible, consumer driven health care service system that would more effectively facilitate community living.

Objective 1) - Implement House Bill 30 as mandated. This legislation passed in July 2001 and is funded by the Delaware Health Fund Advisory Committee (DHFAC). HB 30 provides for a state mandated personal attendant services program, which has been very successful. However, there are provisions in the bill which have not been implemented. For example, regulations need to be developed, services to individuals with mental illness need to be included.

Objective 2) - Expand the scope of House Bill 30 by taking people off the waiting list and allowing attendant services to be provided outside of the home (e.g. place of employment, school, other alternate settings). Attendant services provided outside of the home are consistent with the initiative of Delaware's Medicaid Buy-In Infrastructure Grant.

Objective 3) - Increase availability of cross-disability respite care options and services throughout the state.

Objective 4) - Increase incentives that would create a larger health care work force such as:

- Increase compensation for community-based workers, equal to wages received by

“I want to move back into the community.”

David Cox

After breaking his neck in 1998, then 29-year-old David Cox was in and out of nursing homes until moving to the Delaware Hospital for the Chronically Ill (DHCI) in Smyrna in 1999. Two years later David left DHCI to live with his family in Hartly, Delaware. His mother was providing him the support he needed to continue living in the community until sadly she became ill and passed away in August 2002. After his mother's death, a personal care attendant visited three times a week while David was still living at home, however, daily treatments for pressure sores on his feet necessitated more consistent, dependable services.

Without supports from family or reliable attendant care, David was forced to return to DHCI in August of 2002 in order to receive the daily treatment he needed for his feet. The attendants David had used before returning to DHCI in August were inconsistent and did not provide

workers in equivalent positions working in institutions;

- Provide compensation to service providers for currently “unbillable” tasks, such as paperwork, travel, and mileage reimbursement;
- Increase training opportunities for personal attendants and direct care staff; and
- Develop and implement certification programs that would allow for increased wage opportunities and career advancement.
- Endorse the House Joint Resolution No. 3 “Workforce Issues Resolution” which will further investigate these issues and apply detailed recommendations for enhancement.

for any after hours services that he occasionally required. David believes he would never have had to leave his home if he had reliable, consistent personal care attendants with backup services in case of evening or emergency situations. For many individuals with disabilities without consistent backup services, medical situations after 9 pm often result in expensive emergency room trips or waiting all night for care, leading to other medical complications that require more extensive, expensive services.

David continues to live on a skilled care unit at DHCI, although his pressure sores have healed, and he does not require the high level of care provided by the staff in the unit. Once the pressure sores were treated David no longer requires the extensive services provided in a nursing facility, however, while living at DHCI, David has not been able to prepare for moving back into the community. He receives \$44 each month from his Social Security benefits while the remainder goes to DHCI to pay for his institutionalization. The resources spent to provide services to David could more effectively provide for him to live in a community setting and provide cost savings to the state service programs, especially since he does not require the expensive services of the facility he currently resides in.

David is cognizant of the supports that he will need to move back into the community. A consumer-driven personal care attendant program where David coordinated his own attendant services would provide him with the level of care needed without the expense of the skilled care nursing unit in which he currently resides. A more consistent, flexible, and dependable attendant—preferably one that David could personally employ using a Medicaid or other waiver—may have prevented his moving back to DHCI in August because he would have been able to receive the services he needed on a consistent basis.

Moving back into DHCI was not an easy decision for David; he knew he needed medical care for the pressure sores on his feet, but he did not need the high level of skilled care provided in the unit in which he currently resides. David hopes to return to living in the community and is working with Independent Resources, Inc. in Dover on finding an accessible and affordable place to live and hopes to return to community-based living in the spring of 2003. For David Cox the goal is not primarily independence from the nursing home, but creating interdependence through specific, specialized supports he personally coordinates and controls in a community setting of his choosing.

Objective 5) - Evaluate the possibility of Medicaid reimbursement for family members as personal care attendants. Utilizing family members as personal care attendants would expand the labor force. Reimbursing family members as personal care attendants would expand the community capacity and ease the transition of people with disabilities into the community.

Objective 6) - Develop a back-up/emergency system for the state's personal attendant services program. If timely personal attendant services are not provided, this leads to unnecessary trips to the emergency room and therefore increased costs of care.

Objective 7) - Establish an administrative oversight system that will monitor personal care services and protect all parties.

Objective 8) - Utilize dollars provided through DHFAC for programs in which general fund dollars have been cut. For example, \$44,000 was cut from the Division of Services for Aging and Adults with Physical Disabilities' state funded attendant services program/personal care programs.²³

Objective 9) - Amend the Nurse Practices Act (24 DEL.C.CHAPTER 19) to allow attendants to provide services that a person would be able to perform if he/she did not have a disability. This amendment would save money since skilled nursing care costs far more than personal attendant services. Other possible amendments would be to provide for nurse delegation and amend the current exemptions provision.

Objective 10) - Research and evaluate how the Medicaid Personal Care option could be implemented in Delaware. Delaware is one of 19 states that do not utilize this option.

Objective 11) - Access appropriate assistive technology (AT) services which can reduce or prevent unnecessary Medicaid costs and secondary disabilities that may result from inappropriate services. Assure collaborative work by experts at the initial assessment and follow through with training, and “goodness of fit” evaluations which are more efficient overall. Initially providing individuals with appropriate AT will reduce improper use or compatibility of AT, and may help reduce duplication of services or harm to the consumer as a result of inappropriate assessments.

Objective 12) - Support and secure disability representation on any legislative committee established to review Medicaid programs and reimbursement formulas.²⁴

Objective 13) - Examine accountability and liability issues which impact doctors and insurance companies in the provision of services to people with disabilities.

Health Care Goal # 2: Develop a specialized infrastructure that would provide a “one-stop” service program and coordinated wrap around services where individuals with disabilities can receive health care services on an ongoing or as-needed basis. This service program would facilitate transition, as well as provide appropriate focused services for individuals at risk of institutionalization.

Objective 1) - Develop a pilot project that would address the one-stop approach for more prevalent disabilities (e.g. spinal cord injuries, acquired brain injury, stroke, and cancer).

- Evaluate best practices from Magee, Kennedy Krieger centers, and A.I. Dupont Hospital for Children.

Objective 2) - In conjunction with the Medical Society of Delaware and A.I. Dupont Hospital for Children, develop an education and training program for health care specialists regarding the needs of individuals with disabilities.

Objective 3) - In conjunction with the Medical Society of Delaware, develop a coordinated system in which individuals with disabilities would be able to receive general health care and dental services on an ongoing or as-needed basis. Include participation of the service sites in the Delaware Health Care Commission’s Information Network in the process.²⁵

Objective 4) - In conjunction with the Medical Society of Delaware, conduct a survey to determine the physical accessibility and alternative communication availability of Delaware’s health care offices, including access to medical equipment such as X-Rays, examination tables, or sign language interpreters.

Objective 5) - Evaluate Delaware’s Diamond State Long Term managed care programs for the capacity, quality, flexibility, and depth for all people with disabilities to ensure the program is meeting the needs of individuals.

Objective 6) - Coordinate programs and educate individuals with disabilities, including residents in institutions, on health care services and options available in Delaware. Target health promotion programs that incorporate training in the self-management of disability, self-advocacy, and services that will aid in health maintenance. The State should consider coordinating with stakeholders on self-advocacy education and training programs.

Objective 7) - Develop an effective case management system to ensure the identified health care needs of the consumer are met in an expeditious and cost-effective manner. Assessments must be completed before transition and conducted consistently in the community or chosen placement (see Assessment Section for further detail).

Health Care Goal # 3: Develop an infrastructure for medically fragile children and those with behavioral health disabilities to remain in the state.

Objective 1) - Locate, research, and evaluate the current Delaware Department of Education (DDOE) findings regarding medically fragile children being sent out of state and costs associated with sending these children out of state.

Objective 2) - Access to a First State School model should be available statewide to address the educational and medical needs of chronically ill children.

Objective 3) - Evaluate the State's plan which states in a November 14, 2002 News Journal article that the Division of Services for Children, Youth, and Their Families will be saving \$818,000 by keeping children in State.²⁶

- Are the individuals now remaining in the state receiving the same services?
- What services are being provided and where?
- What are the profiles of these children?
- What are the costs of related services associated with in state versus out-of-state treatment?

Objective 4) - Research and evaluate before and after school care programs to ensure they are available for students with disabilities.



Objective 5) - Establish fair and equitable child-care practices and reimbursement rates for children with disabilities that reflect the child's support needs.

Health Care Goal # 4: Mental Health Insurance Parity—Mental illness is the number one cause of disability in the United States according to the World Health Report, published in 2001.²⁷ The current laws toward the treatment of mental illness are discriminatory. Amendments in Delaware's legislation are needed to reflect the science based evidence indicating mental illness as a medical problem deserving of the same quality care as other physical illnesses.

Objective 1) - Implement current House Bill 100 legislation (141st General Assembly) and expand to include all mental illnesses recognized by the National Institute of Mental Health and Substance Abuse. Include language that calls for the use of universally accepted science-based medical necessity criteria for treatment of specific illnesses.

Objective 2) - Examine the APS Healthcare, Inc. Medical Necessity and Level of Care Determination Criteria to determine if it appropriately meets the needs of persons with mental illness.

Objective 3) - Amend Delaware’s FY 2003 State Mental Health Plan to develop a comprehensive, individualized community-based mental health system. Assure the assessment tool is appropriate for individuals that have barriers to understanding the utilized tool (e.g., people with cognitive disabilities, people who are deaf, people who do not speak English.)

Objective 4) - Mandate that the DSAMH pursue Medicaid Waivers that will provide case management services to persons with mental illness who have been carved out of the DSAMH services.

Objective 5) - Enforce current law²⁸ which mandates a 45 day payment for “clean” claims²⁹, so that insurance companies pay for legitimate mental health treatments. Promote legislation to develop independent oversight of denied insurance claims and denial for treatment. In addition, hold insurance companies accountable for unfounded denials of treatment and non-payment of claims.

Objective 6) - Eradicate the use of police transport of individuals who present symptoms of mental illness to hospitals. Institute an alternative transportation system that is humane and void of treating persons with a mental illness as criminals.

Objective 7) - Provide appropriate case management services for individuals with mental illness being released to the community from prison and other court mandated residential settings.

Objective 8) - Mandate that Child Mental Health in the Department of Services for

Children, Youth, and their Families (DSCYF) work with the Division of Substance Abuse and Mental Health (DSAMH) to develop seamless wrap-around services, including case management for those who age out of DSCYF programs. Include those to be released from juvenile corrections and youth residential settings.

Health Care Goal #5: Research and evaluate health care programs that implement the self-determination philosophy in order for individuals with disabilities to manage and have control of their own lives.

Objective 1) - Research best practices, demonstration projects and costs for cash allowances for people living in the community.³⁰

Employment

Just as the general population in the United States is expected to work, so should there be an expectation that people with disabilities work. The question is not “whether” someone should work, but “what supports will they need” in order to go to work. A system designed around this paradigm shift would eliminate many barriers that currently exclude people from receiving employment services and would promote greater creativity and flexibility in service provision. Quality vocational services and supports are driven by the individual. They should be centered around the individual’s strengths, preferences, capabilities, values, and interests—as defined by the individual—just as a job or career would be for anyone. An individual’s job needs to be viewed from a long-term perspective, as a career. Often, people have a tendency to assume that a person with a disability placed in a job will stay in that job forever. In fact,

Tonya*

June of 2000 was a pivotal year for Tonya. She moved out of the institution she lived in for almost thirty years to a group home, began a full time job, and according to those close to her, she blossomed. Since she started working at The Opportunity Center, Inc. (OCI), an incredible learning experience has continued—first for Tonya in her transition into the community—and second for staff who have substantially benefited from getting to know and work with Tonya.

Tonya was six years old when she was moved into a large institution, and life for her in the group home is significantly different. Living closer to her family was a significant factor in her moving to a group home; Tonya and her family appreciate the shortened distance between them. Working at OCI has also allowed Tonya to meet other people since moving from the institution.

Tonya was originally placed in an area focused on cleaning services at OCI, however, the staff soon found that a more appropriate place for Tonya was working in a more open setting where she could work with others, as well as work on more interactive jobs. While she enjoys being independent, the opportunity to assist others is also very important to her, and she is often found assisting her coworkers on tasks. Living and working in the community has provided Tonya the freedom to make her own choices. Working through Tonya's preferences was

important in developing the proper place for her to work, and the staff continues working with Tonya to develop her future career goals.

For the staff at OCI, Tonya's transition was a time of learning innovative and new ways to support an individual with a disability in the workplace. "She kept the staff creative, developing new supports. Her transition into working for OCI was not straightforward—yet it reminded us to embrace the challenges and be creative. She is responsible for a lot of that," stated one of her managers. Developing workplace supports that were individualized to Tonya's preferences and needs has been fundamental to her success.

Tonya enjoys her employment at OCI and proudly displays her ID badge for others to see. She treasures her coworkers and the friends she has made, and never fails to walk by the offices to say hello to everyone each day. Many of the staff at OCI would say that Tonya's joining their staff in 2000 has had significant benefits that have extended to the staff of OCI, as well as the larger community. The importance of individualized, creative supports adapted to an individual's strengths, preferences, and needs was reaffirmed to the staff at OCI through working with Tonya. "Everyone who meets Tonya says she is a star," expresses her manager, "as well as a blessing to work with".

*Pseudonym given to protect her privacy as requested by her family

the typical person changes jobs every 5 to 7 years or at least 6 times in their lifetime, which should be no different for a person with a disability. The implications for vocational supports are that they need to be available throughout the course of the person's life, ebbing and flowing in intensity and duration, as the person's career requires.

Individuals with disabilities can be competitively employed or form their own businesses in their communities. They should be supported to make informed choices about their work and careers and have the resources to seek, obtain, and be

successful in community employment. The majority of adults with disabilities are either unemployed or underemployed, despite their education, ability, desire, and willingness to engage in meaningful work in the community. Few individuals with disabilities have had the opportunity to earn money, acquire benefits, advance their careers, or plan for retirement. Without appropriate education, career development, job training, job coaching, technological assistance and support, people cannot enjoy the benefits of employment. All persons with disabilities should have the opportunity to be prepared

for careers and have jobs based upon their preferences, interests, and strengths.

Vocational supports should fit the needs of the individual—not the other way around. In other words, the system should be designed to accommodate the many and varied needs of the individuals being served. This might include vocational staff to support people in jobs that are on a night shift, jobs that have flexible hours, or to provide supports in the evening that will support someone in their day job—such as helping them do their laundry so they will be well-groomed for work the next day or shopping with them to purchase an alarm clock that will ensure they wake up in time for work. To truly provide quality vocational supports and services, there needs to be mutually respectful relationships between the individual, the individual’s family, the provider, and the state. These relationships need to be based on roles that are considered to be of equal importance to the success of the individual’s career.

Employment Goal #1: Develop a flexible system that provides individual interventions that maximize employment outcomes for people with disabilities over their lifetimes.

Objective 1) - Change existing programs, services, and regulations to allow for supports to be provided over the person’s employment life.

- Maximize the use of the Division of Vocational Rehabilitation Services’ post-employment funding.
- Develop funding for follow-along services for every population. Using The Division of Developmental Disabilities Services’ current follow-along services as a model, to investigate Medicaid waivers as a source of funding for these follow-along services for *all* people with disabilities.

“If I could work, I would.”

Immediately following a car accident on August 1, 1982, Paula Talarowski was flown to the Shock Trauma Center at the University of Maryland Hospital. The accident resulted in a spinal cord injury that paralyzed then fifteen-year-old Paula from her waist down. She left the hospital in September of 1982 when she was transferred to A.I. DuPont Children’s Hospital for four months of rehabilitation and schooling. Paula then began rehabilitation at John G. Leach School in New Castle while attending William Penn and after completing her rehabilitation she transferred to Newark High School for two years and graduated with her diploma at age 21. Like many high school graduates, Paula Talarowski was unsure of what to do after graduating from high school, so she began with clerical job training through the Institute for the Development of Human Resources.

Soon after finishing her training, Paula acquired a position as authorization clerk at the Bank of Detroit’s Newark office. Working up to six hours each day, Paula answered merchant phone requests for purchase authorizations, as well as customer service calls from bank customers. Paula enjoyed working with her coworkers and customers, as well as improving her computer skills at her job. However, in 1992 the Bank of Detroit closed their Delaware offices, and Paula had to begin looking for a new job.

For the next three years without success, Paula continued looking for employment when one of her former teachers from Leach School recommended her for an intensive job-training program. From June through

Objective 2) - Organize services into integrated, interdisciplinary teams with a fixed point of responsibility across all disabilities. Essentially, utilize the successful Program of Assertive Community Treatment (PACT) model with all populations. Components of this model are cur-



Paula Talarowski

August of 1995, Paula was trained in word processing, faxing, customer service, and other administrative responsibilities. That fall she applied for and received a position with a major financial institution in Delaware. Paula was scheduled to work from 4:00 pm to 12:30 am, however, after only two weeks she had little choice but to leave

the position. Working at the company had affected her entire life; her health suffered, transportation issues in the evening abounded, and these two weeks she worked in 1995 dramatically affected her social security benefits. The company had offered to move Paula to a different department with different hours, however, Paula's many attempts to pursue this were left unanswered, and eventually she stopped calling.

At this company Paula was paid more than she could receive without affecting the amount of her social security checks, despite her informing the company of social security regulations. Because she was overpaid in that position, her current and future social security checks for the next ten years have been significantly reduced. The monthly payments she received prior to the cuts did not begin to cover her cost of living, and the reduced amount has made it even more difficult. In order to supplement her reduced income, Paula decided

to cash in savings bonds, which in turn also affected her Social Security and Medicaid benefits. Now she is overly concerned about the affect of a job on her benefits, although she desires to be independent. "I would eventually love to find something to do. You know sitting, it just... it gets to you after a while not doing anything. It would get me out and being around other people and stuff," she stated.

Paula has lived at home with her parents since she graduated from Newark High School in 1988. A close-knit family, the Talarowskis are Paula's support system for many of her needs, however, Paula has a strong desire to be self-sufficient. Her social security benefits are used to pay for her medical supplies each month, as well as some of her personal items. Paula said, "I would love someday to get a place of my own, but with the kind of money I have right now I can barely live month-to-month on it. That's basically what I am doing—living month to month."

Reflecting on employment and the obstacles she has overcome since graduating from high school, Paula's attitude is positive in regards to the challenges she has had in finding and maintaining a good job. Paula's story indicates a situation that often deters people with disabilities from going to work—fear of losing health coverage. She does hope someday to have a job that will not affect her medical and social security coverage and allow her to live independently. Not having a job has not hampered her spirit and willingness to live her life as fully as she can. She is involved in the community through Special Olympics, attends semi-professional local wrestling matches, and uses her computer to improve her typing and computer skills and keep in touch with her family and friends.

rently being used by DSAMH in Delaware's Continuous Treatment Team system for people with mental illness.

- Add vocational staff to the existing and newly formed Continuous Treatment Teams for people with mental illness and to all future implementation of cross-disability Teams.

- Develop a rating system that will be predictive of the service-need level of individuals to be served. Use that rating to determine a fee that providers will be paid to provide all the vocational supports the individual needs in order to get and stay employed. The rate should not change regardless of which provider is used. The rate may change if the

individual's needs become less intensive or more intensive. *See Assessment Section.*

Objective 3) - Review and amend existing systems of service delivery, payment, and regulations to eliminate barriers to employment success.

- Amend the Division of Services for Substance Abuse and Mental Health (DSAMH) plan to include funding for employment supports.
- Investigate the amendments to the Rehabilitation Act³¹ to determine if the State of Delaware can lessen restrictions on the number of hours, types of supports, and other services.
- Establish the Medicaid buy-in for health insurance to remove the potential disincentive of an individual losing health coverage if they go to work. Permitted by the Federal Ticket to Work legislation, this option must be implemented by the State of Delaware.
- Provide reasonable accommodations that promote employment opportunities, for example worksite modifications, interpreter services, and other supports as needed by the individual.
- Continue to provide benefits counseling beyond the end of the CLIMB (Consortium Leadership for Individuals Managing Benefits) grant. Plan now for how this service will be continued beyond this federal grant, which was secured by the Division of Vocational Rehabilitation.
- Extend hours of job support services to be available when they are needed, for example for individuals who work second and third shifts, and that individuals can receive support services that are not directly job-related but support them in maintaining their jobs.

Employment Goal #2: Compensation must be fair and equitable for individuals with disabilities.

Objective 1) - Evaluate and update studies on wage parity issues to ensure continuous, fair compensation. Wages must be the same for people with disabilities and people without disabilities who are in the same level of employment. Compensation for everyone should be based on education, training, skills, and talents regardless of disability. Anecdotal evidence suggests that men with disabilities make less than men without disabilities and women with disabilities make less than men with disabilities.

Objective 2) - Compensation based on piece-meal activities must be evaluated on a continuous basis to ensure the process is fair and equitable.

Employment Goal #3: Increase the number of employers who provide fair and equitable opportunities for people with disabilities to become gainfully employed.

Objective 1) - Establish an employer roundtable under the jurisdiction of the Workforce Investment Board to focus on the employment of people with disabilities and to build the employer-employee network.

Objective 2) - Establish linkages and/or continue to partner with the Delaware Economic Development Office, the State Personnel Office, and the Delaware Department of Labor for the purpose of promoting employment opportunities for people with disabilities.

Objective 3) - Continue to work with the Ticket to Work and Work Incentives Improvement Act Work Group to design and implement a public awareness campaign on the value of employing people with disabilities.

Employment Goal #4: Extend and improve provider capacity.

Objective 1) - Attract and retain quality, skilled staff to work in the field, across disabilities and disciplines.

- Continue and expand the University of Delaware's Center for Disabilities Studies' successful provider training.³²
- Develop a certification that would include specific educational requirements that would enhance the prestige and desirability of working in the disabilities field.
- Develop a curriculum track within the vocational high schools that has disability-related careers as an option.
- Develop other incentives to attract people to the field such as tuition forgiveness, low interest college loans, and other benefits to working in the disabilities field.
- Provide a living wage that is competitive with the market and provide a clearly defined career path to which employees can aspire. Consideration should be given to bringing salaries of community provider staff in closer line with state salaries. Many community program direct care staff receive a minimum wage whereas direct staff within institutions receive starting wages above a minimum for similar work.
- Endorse House Joint Resolution No. 3 the "Workforce Issues Resolution" which will further investigate these issues and apply detailed recommendations for enhancements.

Objective 2) - Ensure a match between service demand and provider capacity. Utilizing the joint planning process and work with existing providers to extend their capacity which would enable a greater economy of scale resulting in more cost-effective services.

Employment Goal #5: Demonstrate the economic benefit to be realized by the federal and state government and indirectly, by taxpayers, of having more individuals working. The economic benefits can be seen in reductions of monetary benefits and health benefits paid to unemployed people with disabilities (SSI and SSDI). In addition, benefits can also be seen in increased revenues to the state because these individuals are working, earning a livable wage, paying taxes, and possibly utilizing employer-paid health benefits. For example, the Delaware Division of Vocational Rehabilitation has estimated the annual savings in public assistance payments in fiscal year 2002 was \$363,708.

Objective 1) - Secure the services of an independent contractor to determine a way to quantify the cost benefit ratio of investing in a broader system of employment supports for people with disabilities.

The variables may include the following:

- Savings from reduction in SSI and SSDI payments,
- Savings from reduction in health benefits to be paid by employers,
- Increase in tax base due to employees paying taxes,
- Increase in amount of state funds being used to expand the support system, and
- Increase in Medicaid funds able to be secured from the federal government.

Transportation

A significant barrier to moving individuals with disabilities into community-based settings is the transportation infrastructure. As a result of unprecedented demographic changes, our society has been transformed from a town-centered environment, with multiple mass transit options, to decentralized suburban sprawl, focused solely on the automobile. The result of this de-urbanization has been to spread out employment opportunities, human services providers, and cultural and social opportunities.

This decentralization has led to the need for more mass transit services to distant and remote locations. Yet, ironically, as this spread out continues unabated, mass transit services are cut back. Limited access to the community is further exacerbated for individuals with disabilities due to the lack of adequate public transportation services. While at one time governmental or health care services were located mostly in the urban core, the State's largest and most comprehensive health care provider is located more than 20 minutes away from downtown Wilmington, and County services in New Castle County have been moved out of the City of Wilmington into an isolated corporate industrial park. Public transportation services are even further limited in Kent and Sussex Counties.

In order for people with disabilities to have the freedom to access the community, a full range of transportation options must be made available. "One in four individuals with disabilities who were not working or not working full-time indicated that the lack of affordable, convenient, accessible transportation prevented them from being able to get a job."³³ People with disabilities tend to utilize public transportation services provided by DART through fixed route and



paratransit services. Delaware is fortunate to have DART, the consolidated mass transit authority, which is trying to meet the transportation needs of the growing (and sprawling) community including people with disabilities. Delaware is among the handful of states that provide transit services throughout the state, and is the only statewide provider of paratransit services in the nation. While not required under the prevailing law, DART provides paratransit services beyond the 3/4 mile radius of the fixed route system required by the ADA which is a significant benefit for persons with disabilities.

According to DART, paratransit ridership is increasing on a yearly basis, a fact that can be attributed to the success of its program in providing convenient and reliable transportation services to people with disabilities. Yet, even though Delaware has an extensive paratransit system, more work needs to be done to ensure complete accessibility and mobility for people with disabilities and to assist in meeting the obligations under the *Olmstead* Decision. While DART attempts to stretch its budget to meet its obligations to the public, delays, system gaps, and inconveniences to people with disabilities continue to occur.

Transportation Goal #1: Ensure that reasonable transportation choices are available for all citizens, including people with disabilities.

Objective 1) - Provide additional fixed route mass transit services for all citizens of Delaware including weekend and weekend evening services, weeknight services, inter-county services, and more frequent services.

Objective 2) - Provide more comprehensive paratransit services for people with disabilities including Sunday paratransit service, weeknight and Saturday night paratransit services later into the evening, and more frequent inter-county paratransit services. Develop and implement a system providing for a more efficient, timely transfer process between local paratransit services and inter-county paratransit services, for example refrain from diverting inter-county paratransit buses for local services.

Objective 3) - Maximize opportunities for personal vehicle ownership and use for people with disabilities. Ensure that information is available concerning vehicles that can be adapted and or equipped with a number of features that ensure safe access and transport for consumers. Those features include such things as ramps or lifts, securement systems, and other modifications that facilitate independent driving.³⁴

- Ensure that expertise, labor, and service for vehicle modification is available in Delaware.
- Implement a drivers' education program for people with disabilities which includes the use of a modified vehicle.

Objective 4) - Ensure that non-medical emergency transportation services are available to people with disabilities. Develop a statewide program for off-hours paratransit services for non-medical emergencies experienced by people with disabilities.

Objective 5) - Ensure that affordable medical care transportation services are available to people with disabilities. Review the new system of providing services for Medicaid transportation to ensure that the system is effective and meeting the needs of the population served.

Objective 6) - Ensure that there is single source available for information concerning transportation options. Increase DART travel training and outreach to individuals with disabilities.

Transportation Goal #2: Ensure that reliable, user-friendly, and timely transportation services are available for people with disabilities.

Objective 1) - Revise the paratransit eligibility form to make it less imposing on the potential user.

Objective 2) - Review the paratransit scheduling system to ensure that timely services are provided for paratransit users. Develop and implement system of driver "in waiting" or "on call" to ensure that all routes scheduled and booked on the previous day are covered regardless of driver availability or work attendance. Other recommendations to reduce delays and improve efficiency include limiting overbooking and/or pile on booking, ensuring that every paratransit user who makes a reservation is accommodated, reducing the time required to be ready prior to when bus is scheduled to arrive, and refocusing service goals to emphasize timely service and delay minimization.

Objective 3) - Ensure better communication between the paratransit provider and its users.

- Provide cell phones to drivers for them to call the riders directly when they are running late or waiting for user.
- Develop and establish a direct line of communication between the paratransit user and the paratransit daily scheduling coordinators.

- Provide paratransit users with real time and online access to scheduling, routing, and bus location information.
- Provide a customer ombudsman as primary contact for dispute resolution and consumer issues. Also, develop a communication policy which addresses real time issues occurring on the bus using the 800 MHz radio system.

Objective 4) - Provide for a more efficient direct communication system between the paratransit driver and the paratransit daily scheduling coordinators to prevent duplication of services and to ensure that users are not being charged with a “no show.”

Objective 5) - Develop a same-day paratransit services program to ensure accessibility for people with disabilities. Recognizing that fixed route users have the freedom of determining on a daily basis what transportation services they need and will use, a reasonable system of same-day scheduling and use of paratransit services for people with disabilities must be developed and implemented.

Transportation Goal #3: - Develop policies that enable fixed route and paratransit drivers to properly serve people with disabilities.

Objective 1) - Drivers should not be overworked. For example, hours and difficulty of routes should be balanced among all of the drivers.

Objective 2) - Paratransit drivers must have, at a minimum, the same pay scale as fixed route drivers.

Objective 3) - All drivers should receive annual sensitivity training in addressing the needs of people with disabilities. All drivers should also receive training, with periodic updates, on the use of accessible and safety equipment.

Objective 4) - Driver employment performance reviews should include consumer evaluations on the driver’s treatment of people with disabilities.

Objective 5) - All drivers should be provided with written notice of changes in DART policies and procedures.

Objective 6) - Maintain a high level system of background checks and qualifications prior to employment to ensure the safety and well being of the passengers.

Transportation Goal #4: Ensure that fixed route and paratransit transportation vehicles are appropriate to the mobility needs of people with disabilities.

Objective 1) - Ensure that all fixed route and paratransit vehicles are continually modified to keep up-to-date with technology, and advancements to provide safe and fully accessible transportation for people with disabilities.

- Annually review technological advances in fixed route and paratransit transportation vehicles and equipment. Routinely retrofit and/or replace vehicles to ensure that the State of Delaware has the most appropriate vehicles and equipment to best accommodate people with disabilities, for example installing folding seats, accommodating all types of motorized carts, scooters, and power chairs, and installing a transponder system to meet the needs of people with visual impairments.

Objective 2) - All fixed route buses must be fully operational, accessible, and safe at all times. Develop and implement a daily inspection program which ensures that all buses have fully functioning equipment, including operational doors, lifts, and safety straps. Those that are deemed unoperational or unsafe must be immediately retired from service until repaired.

Transportation Goal #5: Ensure that transportation destinations are accessible to people with disabilities.

Objective 1) - Ensure that fixed route stops are safe and have reasonably accessible paths of travel for persons with disabilities. Investigate each fixed route stop on every route to determine whether the bus stop and the path of travel for destinations located within reasonable proximity of the fixed route stop have accessible pathways, curb cuts or ramps and safe crosswalks. Construct, rebuild, or replace pathways, curb cuts, or ramps and crosswalks where necessary.

Objective 2) - Ensure that destinations within reasonable distance from fixed route stops are accessible to persons with disabilities. Inventory public accessible and high traffic generator destinations within reasonable distance from each fixed route stop to determine whether those destinations are accessible to persons with disabilities. Where necessary, contact the owner of each such destination and encourage that owner to rebuild or replace pathways, curb cuts, or ramps and crosswalks where necessary.

Objective 3) - Ensure that paratransit destinations open to the public are accessible to persons with disabilities. Inventory regular paratransit destination stops to determine whether those destinations are accessible to persons with disabilities. Where required, contact the owner of each such destination and encourage that owner to rebuild or replace pathways, curb cuts, or ramps and crosswalks where necessary.

Objective 4) - Ensure that ingress and egress to homes of people with disabilities are fully accessible to residents. Develop a broad-based program to assist in the installation of disability specific external home modifications, for example ramps, railings, and accessible pathways.

Education

The Commission dedicated its work to researching and recommending enhancements in the area of community-based supports to individuals with disabilities throughout his/her lifespan. Education is a significant part of an individual's life and as mandated by IDEA should be provided within the least restrictive environment.

Education Goal #1: The Commission is in full support of the ongoing activities being conducted by the Partner's Council for Children with Disabilities (known as PCCD). The PCCD consists of at least thirty members appointed by the Delaware Secretary of Education and recommended by the PCCD. The membership includes representatives of higher education, school district administrators, teachers, state and private agency service providers, parents, and advocacy groups.

Delaware is dedicated to implementing the education reform initiative, improving student achievement, and providing access to a high quality education for all students. Children with disabilities represent one of the most diverse groups within our overall student population. The following seven priority areas have been identified by the PCCD as the focus of their work and are being addressed the State Improvement Plan:

Improve student performance

- By having an instructional support system, techniques, and other adaptations in place so all students progress in the general education curriculum.

- By ensuring that the curriculum is individualized to meet the needs of the students which would include components of a functional curriculum.

Increase student placement in the least restrictive environment

- By ensuring that new school building plans include classrooms that are inclusive and facilities are fully accessible.

Improve student behavior

- By providing school staff with the knowledge and supports they need to address the needs of children who are at risk. The discipline provisions in the IDEA have not proven to be a hindrance in the discipline of students with disabilities according to the General Accounting Office.³⁷

Increase family involvement

- By actively involving families in decision-making.

Increase student completion of high school

- By providing engaging opportunities for students to progress through high school, as well as, demonstrating the secondary and employment opportunities available to students after high school graduation.

Improve general supervision

- By developing and implementing a process in all local education agencies which will enhance student performance.

Improve availability of family friendly information

- By providing information in diverse methods and languages.

“Once your child gets out of school, it is like you are on your own.”

The Gordon Family

As twenty-five year old Chris Gordon from Georgetown has transitioned from school to adult services, he and his family have worked to continue Chris’ involvement in the community. Since options for community living outside of their family home have been limited, the Gordons have provided supports and services to ensure Chris’ preferences and needs are being fulfilled.

While attending Howard T. Ennis School in Georgetown, Chris was involved in educational, social, and community activities through his school program. After graduation four years ago, Chris’ community involvement has been limited to people from Kent and Sussex Industries (KSI), Special Olympics, and family driven activities. According to his mother, services for adults with disabilities are much more limited than those available in schools. “Once your child gets out of school, it is like you are on your own,” she stated.

In addition to the work of the PCCD, the Commission would like to highlight the following goals as they pertain to the education of individuals with disabilities.

Education Goal #2: Ensure effective and meaningful transitions are the norm rather than the exception.

Objective 1) - Develop a quality transition program that will provide for a seamless move from educational to adult services.

Chris works a regular schedule at KSI in Milford, Delaware. A van picks Chris up each morning at 7 am, and brings him home in the afternoon between 4 and 5. Without the company's van services, Chris' Mom is not sure how Chris would get to work, especially since access to public transportation is limited in Georgetown and she herself is employed. For Chris' other activities, his parents provide the needed transportation to ensure he gets to do the things he enjoys.

A very important part of Chris' life is his involvement in Special Olympics with the Landsharks team; he recently participated in the bowling tournament, and he is also participating in basketball and track training. His involvement in Special Olympics started when Chris was in elementary school in New Castle County, and upon their move to Georgetown, Chris' parents were instrumental in bringing the Special Olympics program to Ennis school for the benefits of Chris and his peers. Chris' parents and sister are also all involved in Special Olympics as well. They enjoy watching Chris in competition and the other social events Special Olympics provides to athletes and families. "After he graduated, its up to the parents, you know, take them to practice, take them to the events, so. . . we are doing that," she stated.

Dancing is another love of Chris', and the Gordon family often heads to the Midway Slots in Harrington for dinner and dancing to live bands. "Being out in the community" through Special Olympics or dances "has helped all the way around," his mom stated. Chris enjoys being with his friends, and since finishing school the opportunity to see many of them has been limited to the friends who also participate in Special Olympics.

Chris' parents had hoped the Chris would be settled into a community living situation after graduating from school. As Chris was entering his teen years his parents began thinking about the transition for Chris from their home, but they have been told only in emergency situations can people be placed into community-based housing. Chris is currently living at home, and his parents are able to provide the supports he needs, and for now, Chris and his parents are comfortable with the situation. Moving into the community could limit Chris' opportunities for transportation to Special Olympics or other events, thinks his mother. However, Chris' mother hopes to have him settled into a community living situation while they are still able to support him through the transition and ensure his preferences and needs are met, and he is able to continue doing the things he loves.

Objective 2) - Assistive technology devices must stay with the young adult leaving the school system where appropriate.

Education Goal 3: Education does not stop at age 18, nor age 21. Individuals with disabilities must be afforded opportunities and support for continuing education.

Objective 1) - Ensure that all local institutions of higher learning have adequate resources and supports available which support physical and intellectual accommodations for people with disabilities.

Funding

Funding in Delaware: A need for change

The Commission intended on providing specific dollar amounts needed for each of the objectives and recommendations included in the report. However, without State agency participation, the Commission concluded that it would not be feasible to provide an accurate representation of funding needed to effectively

promote community integration of individuals with disabilities. In addition, the Commission believes that recommendations should be targeted on creative methods to secure alternative funding in both flush and tight economic times that will not dramatically increase the state's budget. Therefore, the funding recommendations provided in this report are broad, and based on needed systems change.

Efficient system change can best be seen when funding supports the needs of the consumer regardless of where or with whom they reside (institution, community) and is allocated based on the needs of the individual. Marital status or family status must not be a factor in determining the individual's funding. One of the most challenging system obstacles to system flexibility and responsiveness is "slot" based funding. An individual should not need to "transfer" from one service to the next, as their individual needs change, which is the current system. Rather, the system should be designed so that an assortment of supports that are needed by the individual are available and accessible, regardless of funding source or disability. Cost-effective, efficient funding that follows the individual can be leveraged by including federal, state, and private sector monies.

The Commission recognizes that the State offers community-based services. These include, but are not limited to, the following:

- Waiver programs that provide an array of services for the elderly, and individuals with mental retardation, physical disabilities, acquired brain injury, and AIDS
- Assisted Living Waiver
- Social Services Block Grant services
- Money management program, personal attendant services, homemaker and personal care services through DSAPPD

Brenda and Matt Petke

After finishing school at the Benedictine School in Ridgely, Maryland, Brenda Phipps started working at MBNA in their Credit Department. Matt Petke, an acquaintance and classmate of Brenda's, also followed in her footsteps from the school to MBNA to work in the Landscaping Department a few years later. While they had briefly had met while in school together, they did not know each other well enough to ever imagine they would be where they are now. Through their involvement with The Arc of Delaware, Matt and Brenda became friends, began dating, and within a few years, became husband and wife. Married since June 24, 2001, Matt and Brenda are happily living in their home in Pike Creek and are thankful for the friends and family that supported them individually and continue to support their life together.

In 1990, Brenda began working at MBNA in the Credit Department where she worked for a little over a year before moving to the Legal Department. Working at MBNA, Brenda enjoys the administrative responsibilities she fills for the department. Matt started working in the Landscaping department at MBNA in 1993, and he currently works in Inventory Management at the ware-

- Continuous Treatment Team services (CTTs) through the DSAMH
- Prescription Assistance Program (also known as the "Pill Bill")
- Community Access Program to transition individuals from institutional settings to the community

Currently, several state initiatives secure federal funding that support community integration, including among others, the following:

- Approximately \$600,000 has been awarded for the DSAAPD Nursing Home Transition Grant (Passport to Independence) over three years (FY 03–FY 05) to develop a universal assessment and conduct an independent



house. Although they went to the same school and worked at the same company, Brenda and Matt did not become friends until they met when their individual involvement in The Arc brought them together.

Working with people from The Arc of

Delaware has helped tremendously, both Matt and Brenda say, including giving them the guidance and support to be more independent. Their involvement in The Arc of Delaware sponsored self-advocacy group, People First, has also impacted their life by providing them opportunities to be in leadership roles within the organization: Brenda, as past president, and Matt, as past vice president. Through People First, Matt and Brenda have been involved with various activities designed to educate other people with disabilities about independence and how to advocate for their own needs. Being a self-advocate for her own needs, Brenda says, has taught her to be more confident, which has

given her more freedom to make her own decisions, as well as work through the decisions that affect her and her husband. Learning to advocate for their own needs and their family's needs allows both of them the opportunity to be more responsible, and they both recognize their friends from The Arc, their coworkers, and their family and friends for giving them the guidance and support necessary to be independent.

After finishing school, they both resided in different living situations, which included group homes, with a roommate, or on his or her own; however, Matt and Brenda have found living together in their own home the best living situation for both of them. Support from Matt's family, as well as their friends and coworkers, has made living on their own possible. They also have the unconditional love from a very special friend, their K9 Partner for Life support dog. "It's not always easy," Matt says about living on their own, "but my family and friends are always there if we ever need anything." Matt and Brenda have found they compliment each other very well, and hope to continue their involvement in People First, as well as traveling and spending time with their family and friends.

survey of nursing home residents. At present, the survey does not appear to be exhaustive of all nursing home residents. The goal is to transition 15 residents into the community. Independent Resources, Inc. (IRI) is collaborating with DSAAPD and has secured an additional \$270,000 to transition 15 individuals. IRI's initiative will target New Castle County.

- The Delaware Division of Social Services (DSS) secured \$500,000 in FY 02 for the Ticket to Work and Workforce Incentives Improvement Act's Medicaid Buy-in Infrastructure Grant. In addition, Delaware has applied for additional funding for the next phase of the grant process in FY 03. The dollars are being utilized to determine need and develop the appropriate state infra-

structure so that Delaware can implement the Medicaid Buy-in in the future. The Medicaid Buy-in will enable individuals with disabilities to work without losing Medicaid health benefits.

- The Delaware Division of Developmental Disabilities Services (DDDS), in collaboration with the Delaware Assistive Technology Initiative (DATI) has secured 1.2 million over 3 years to develop an improved assistive technology access infrastructure. DATI, as an organization, has \$348,000 in federal funding for FY 03 and FY 04, however, funding is not guaranteed after FY 04.

- The Personal Mobility and Vehicular Transportation Task Force was created by budget epilogue language and has \$100,000 to provide recommendations regarding assistive technology needs and barriers as it relates to vehicular modifications and mobility. Any remaining funds will be provided for a low-interest loan program to obtain a 3-to-1 federal match.

However, the programs fall short in the number of individuals being served and, in some cases, scope of services. The result is that programs do not respond to the needs of all individuals with disabilities.

President George W. Bush's New Freedom Initiative (Executive Order # 13217) allows flexibility and creativity for states in establishing and expanding programs to meet the many needs of persons with disabilities. A collaborative effort between state agencies, the General Assembly, advocacy organizations and consumers is needed to utilize this initiative and develop appropriate and economical programs in Delaware to achieve this goal. President Bush in January 2003 proposed a \$1.75 billion, five-year program aimed at moving people with disabilities from institutions into the community. Under the proposed program, the federal government would pay the full cost of Medicaid for a year for people who moved from institutional to community-based care returning to a 50/50, federal/state match in subsequent years. Since states and the federal government typically share Medicaid costs, the initiative would boost state efforts to help people with disabilities live in community-based settings. The initiative includes \$350 million for 2004 and \$1.75 billion over five years. The implementation of President Bush's most recent initiative presents unparalleled opportunity for the State of Delaware to maximize federal funding and redirect previously committed state funding for expanded services to assist in the transition process.

Other States: *Leading the way.* . . .

The Commission reviewed various state plans and is highlighting the state of Mississippi for its comprehensive plan which includes clear objectives, fiscal allocation and a firm commitment from elected and government officials, advocacy groups, and other relevant stakeholders.

The Mississippi legislature passed House Bill 929 and the Governor signed the bill into law on March 23, 2001, which formalized the ongoing work of the Mississippi Access to Care workgroup. The legislation mandated the development of a comprehensive state plan to provide services to people with disabilities in the most integrated setting appropriate. The plan created in response to the legislation, provide detailed information on: the estimate of the number of people with disabilities in the state who need or will need services, the estimate of appropriations necessary over the course of the proposed schedule to implement the plan, and set forth the goal of no later than June 30, 2011, for the state to have community services available for all people with disabilities that are recommended by professionals and requested by persons with disabilities.

The Commission recommends a firm commitment from Delaware to utilize the Mississippi plan as a model. The commitment by Mississippi is remarkable given its economic situation vis-à-vis Delaware. Mississippi's per capita gross domestic product (GDP) is \$23,655 compared to Delaware's per capita GDP of \$46,325 in fiscal year 2000, almost double that of Mississippi (Appendix D).

Other states in the honorable mention category include:

Missouri - The 2000 Missouri legislature enacted a law requiring that an individual eligible for

Medicaid-funded nursing home care be given the opportunity to have those Medicaid funds follow him or her to the community to be used for the personal care option that best meets the individual's needs. The per capita GDP of Missouri was \$31,985 in fiscal year 2000.

Texas - The State of Texas' extensive plan includes an inventory of available services, state budget requests, and proposed statute changes, and identification of the agencies responsible for implementing the recommendations. The plan includes recommendations to expand all waiver programs, increase outreach to people with disabilities about community care options, help nursing facility residents make the transition into the community, provide temporary rent subsidies for consumers who are awaiting federal housing assistance, train staff, and implement a data collection system. The per capita GDP of Texas was \$35,593 in fiscal year 2000.

Ohio - The State of Ohio increased the number of Medicaid Home and Community-Based Services waiver program slots from about 11,000 in FY 1992 to nearly 38,000 in FY 2000, a 242% increase. In 2001, Ohio spent \$480.6 million for waiver programs and added funding almost 5,000 new slots in the 2002-2003 budget. The per capita GDP of Ohio is \$32,828 in fiscal year 2000.

Funding Recommendations:

Objective 1) - Allow all State and Federal dollars to follow the individual from the institution to community-based settings with the appropriate supports (e.g., assistive technology, nutritionist, personal attendant services). A universal assessment is needed to determine what individualized supports are needed, as well as the costs.

Objective 2) - Aggressively identify any programs which are 100 percent State funded, but could be Medicaid reimbursable. Subsequently,

pursue the federal match. For example, DDDS's Family Support Services are currently 100 percent State funded, but could be a Medicaid funded program with an approved waiver that provides 50% federal funding.

Objective 3) - Locate and secure a steady stream of revenue-based funding to support home and community-based services (e.g., the Health Care Fund or the Transportation Trust Fund).

Objective 4) - Research "ability to pay policies" to secure additional revenues for community-based services

Objective 5) - Sell off all the land and facilities at Stockley which are not needed. Dedicate the proceeds to the improvement and expansion of community-based services.

Objective 6) - Consolidate the three state-operated institutions (DHCI, Bissell Hospital, and Governor Bacon Center) into one which will generate additional revenues from the unused property/buildings which can be dedicated to community-based services. Obtain and examine related studies which have recommended this approach in the past. Insure that stakeholders are involved with the process and consumers are adequately assessed with regard to personal choice and identification of support needs.

Objective 7) - Secure private/non-state funding (e.g., Longwood Foundation, Crystal, MBNA Helen Graham Grants Committee, and the Developmental Disabilities Council) for demonstration, pilot, or development projects.

Objective 8) - Support the DDDS, in collaboration with the Center for Disabilities Studies, federal grant application to provide funding for a self-determination/family support program.

Priority Recommendations

Establish and implement a policy of open government in an atmosphere of mutual respect inclusive of complete stakeholder participation. Decision makers from all sides of the partnership should engage in joint planning and collaborative implementation.

Communication among all stakeholders is essential for effective, efficient, and focused outcomes.

Objective 1) - Host regular—at a minimum annual—updates on DHSS Division activities and plan enhancements. This procedure would be similar to the federal requirements which require the Division of Vocational Rehabilitation and Developmental Disabilities Council to update the public community of annual plans. Reporting on outcomes should be public, providing information on baseline data *and* timely, accurate, unduplicated information on community-based program progress and financial data.

Objective 2) - The State of Delaware Department of Education (DOE) should be used as a model for “open government.” Delaware’s DOE appears to have a clear sense of open government by being open to public comment and responsive to exchange of information, for example DOE circulates changes of policies monthly to interested stakeholders.

Implement an independent needs assessment and create a comprehensive database

A universal, cross-disability assessment is needed to determine individualized supports and service capacity for individuals with disabilities in Delaware. Through the assessment process create a database of comprehensive consumer profiles, which would enable greater collaboration and coordination of services among consumers,

“This is my appeal. Let us unite in a revolution to eliminate primitive practices and stereotypes, and to establish a culture that focuses the full force of science and democracy on the systematic empowerment of every person to live his or her potential.”

Justin Dart, 1998

providers, and supports.

See Determining Needs and Preferences Section

Issue a Gubernatorial Order for the continued monitoring of progress

Create a formalized group responsible for implementation and monitoring of Delaware’s progress in implementing the recommendations in the report. This group should include all stakeholders and have the authority to implement the recommendations with support from the administrative and legislative branches.

Conclusion

In 1990, the most significant civil rights law since the Civil Rights Act of 1964, the ADA, was enacted. Over three years ago, the Supreme Court reaffirmed the civil rights provided by the ADA by rendering that unnecessary isolation of individuals with disabilities is a form of segregation and discrimination. As President George W. Bush stated in his announcement of the New Freedom Initiative, “though progress has been made in the last decade, too many Americans with disabilities remain trapped in bureaucracies of dependence, denied the tools they need to fully access their communities.”³⁵ Isolating individuals with disabilities from their community is unjust and unacceptable, and prohibits everyone in the community from benefiting from a diverse society. Living in the community as equals is a fundamental element of civil rights. As Martin Luther King said in 1957, “The denial of these sacred rights is a tragic betrayal of the highest mandates of our democratic tradition.”

The work of this Commission, and the work that has preceded it, provides an opportunity for continuing the movement toward a fully inclusive society. Implementing community-based options is socially, morally, and fiscally responsible. The hope of this Commission is that the blueprint will be the catalyst for stakeholder collaboration in implementation of community-based options for all people with disabilities.

List of Commission/ Committee Members

Regina Byers, consumer
Ray Brouillette, Easter Seals
Doyle Dobbins, DeArf
Micki Edelson, parent
Cathie Field-Lloyd, Opportunity Center
Michael Gamel-McCormick, Center for
Disabilities Studies, University of Delaware
Brian Hartman, Community Legal Aid Society,
Inc. Disabilities Law Program
Kyle Hodges, State Council for Persons with
Disabilities
Marie Johnson, Community Legal Aid Society,
Disabilities Law Program
Janet P. Kramer, MD
Rita Landgraf, Chair State Council for Persons
with Disabilities, caregiver
William Love, The Arc
Patricia Maichle, Developmental Disabilities
Council
Tracy Mann, Center for Disabilities Studies,
University of Delaware
Rita Marocco, Alliance for the Mentally Ill in DE
Cathy McKay, Connections
Daniese McMullin-Powell, Consumer, Acting
Director Freedom Center for Independent
Living
John McNeal, Independent Resources, Inc. (IRI)
Beth Mineo Mollica, Delaware Assistive
Technology Initiative
Terry D. Olson, Martin Luther Homes of
Delaware, Inc.
Al Rose, Developmental Disabilities Council
Amy Sawyer, Center for Disabilities Studies,
University of Delaware
Elizabeth Schantz, consumer
Mike Shriver, MBNA Support Services
Jody Tate, consumer
Representative Robert J. Valihura, Jr., R-Delaware
North
Jamie Wolfe, Consumer

AWARENESS FORM - TITLE XIX HOME AND COMMUNITY BASED LONG-TERM CARE SERVICES OPTION

I have read, or have had read to me, the following:

The Department of Health and Social Services offers a program of home and community based long-term care services to individuals who are currently either living in a long-term care institution or at risk of living in an institution. Instead of living in an institution, you may be eligible to receive long-term care services in your home. In order to be eligible for this program, the following conditions must be met.

1. I must want to accept home and community-based services instead of nursing facility placement.
2. I must be financially eligible for Title XIX services.
3. It must be proven by criteria developed by the Department of Health and Social Services/Division of Social Services/Medicaid that I am in need of intermediate or skilled nursing care services.
4. I understand that I will not be eligible for this Option if the cost of the care I need to be maintained safely in the community as determined by the Division of Social Services/Medicaid would exceed that of institutional care.
5. If I am accepted for this Option, I understand that all services on my behalf must be approved and authorized by the Division of Social Services/Medicaid Case Manager.
6. I understand that I will not be eligible for the Option if the maximum number of clients to be served under the Option has been reached.

I understand that I have the choice of either institutional or home and community based services if the above stated conditions are met.

I do do not wish to apply for the Title XIX Home and Community Based Long-Term Care Services Option.

Client/Representative

Date

HOME AND COMMUNITY-BASED SERVICE OPTIONS FORM

Completed Every 90 Days and on Admission

I have read, or have read to me the following: (This means that there was a face-to-face meeting with a state representative and myself)

The Department of Health and Social Services offers a program of home and community-based care services to individuals who are currently either living in a long-term care institution or at risk of living in an institution. In order to determine the most integrated home and community-based setting appropriate to your needs, the following criteria must be met or considered:

YES NO

		<i>I do not oppose home and community-based services.</i>
--	--	---

		<i>I want information on home and community-based services that may include, but is not limited to:</i>
		<i>* Housing</i>
		<i>* Work Options</i>
		<i>*Transportation</i>
		<i>* Health care</i>
		<i>* Education</i>
		<i>* Health Insurance</i>
		<i>* Medicaid waiver</i>

I am am not applying for home and community-based services.

Signed:

client/representative

date

state representative & job title

date

The NEXT REVIEW will be: _____ (date)

COMMUNITY TRANSITION FORM

YES NO

		Have you received and signed the Service Options form?
		Did you receive information on home and community-based services if you asked for it on the Service Options Form?

If questions above were answered with “yes”, then proceed:

Stakeholders Involved In Decision Making and Transition Process:

Individual and/or legal representative: _____ (required)

Friend or Family Member(s): _____

Advocate: (ex: Center for Independent Living) _____

Appropriate State Agencies: _____

Community Service Provider(s): _____

YES NO

		Is this the first form Transition Form you have completed?
		If no, are you pleased with the pace of arrangements?

If you aren't satisfied with the pace of the arrangements, please explain: _____

Present Residence: _____

What services are you currently receiving at your present residence?
 (MDS Form or other assessments attached: _____)

YES NO

		Have you had the opportunity to view and experience community-based options?
--	--	--

If yes, what community options have you experienced?

What services do you need to move? *(For any area checked, describe in detail what is needed)*

Health Care:

- Assistive Technology: _____
 - Medications: _____
 - Medical Supplies: _____
 - Additional Comments:* (specialized medical needs?) _____
-
-

Support:

- Personal Attendant: (who are they, have you met them, how many hours needed?) _____
-
-

- Financial Management: _____
 - Housekeeping: _____
 - Additional Comments:* _____
-
-

Housing:

- Roommate: _____
 - Selection of Apartment: _____
 - Furniture: _____
 - Moving Truck/Help: _____
 - Group Home: _____
 - Foster Home: _____
 - Additional Comments:* _____
-
-
-

Transportation:

- Drive Self: _____
- Public Transportation: (has application been filled out?) _____
- Additional Comments:* _____

Employment Supports:

- Daytime activities: _____
- Specific Employment: _____
- Additional Comments:* _____

Possible Sources of Funding:

- Self: _____
- Medicaid: _____
- Additional Comments:* (how will you pay?) _____

Perceived or Potential Barriers to movement into the community and resolutions:

What are they?

Resolutions:

Possible risks to safety and health, and how can they be accommodated?

Possible safety/health risk

Accommodations:

Additional Comments:

This form will be reviewed on: _____ (date)

_____ (name, position) **Will Coordinate Services**

_____ (phone number & address)

Highlights of the Mississippi Access to Care Plan

As set forth in their plan, the Commission thought several areas were illustrative of the work that can be accomplished in Delaware. In particular, the Commission noted these several areas:

Transition from Institutions

Fiscal Year	#Individuals	State \$
2003	60	\$400,000
2004	75	\$500,000
2005	90	\$600,000
2006	105	\$700,000

Service - Expand model home ownership programs such as "Home of Your Own" by increasing the funding to cover down payment and closing costs for individuals from the Mississippi Development Authority

Fiscal Year	State \$
2003	\$50,000
2004	\$50,000
2005	\$50,000
2006	\$50,000

Service - Expand community waiver programs

MR/DD Waiver - currently serves 1,700 people,

Increase to an additional 1,600 individuals by FY 2011 - By FY 2011, 3,300 people will be supported by this waiver. Total new state monies \$6,624,00 . Total all funding (federal and state) = \$25,872,000

Fiscal Year	#Individuals	State \$	Total \$
2003	500	\$2,070,000	\$8,623,000
2004	250	\$1,035,000	\$4,312,000
2005	250	\$1,035,000	\$4,312,000
2006	100	\$ 414,000	\$1,725,000

Elderly and Disabled Waiver - Increase the number of individuals receiving service by 750 individuals /year for the next 5 years . Total numbers served by 2007 3,750. New state monies = \$13,200,000. Total all funding (federal and state) = \$55,000,000

Fiscal Year	#Individuals	State \$	Total \$
2003	750	\$2,640,000	\$11,000,000

Independent Living Waiver - Increase services to an additional 500 people/year each year for the next 5 years and expand the menu of services offered. Currently serves 650 people. Total increase of numbers of people served in 5 years is 2,500. Total new state monies = \$11,900,000. Total all funding (federal and state) = \$42,500,000

Fiscal Year	#Individuals	State \$	Total \$
2003	500	\$2,380,000	\$8,500,000

Endnotes

- 1 Freedom Resource Center. *What is independent living?* (n.d.). Retrieved January 25, 2003, from <http://www.macil.org/freedom/intro%20to%20il.htm>.
- 2 National Organization on Disability. (2000). *The 2000 N.O.D./Harris Survey of Americans with Disabilities*.
- 3 National Program Office on Self Determination. (n.d.). *About self-determination: the four principles*. Retrieved January 25, 2002 from http://www.self-determination.org/information1248/information_show.htm-doc_id=1507.htm.
- 4 Dennis, R., Williams, W., Giangreco, M., & C. Cloninger. (1993). Quality of life as context for planning and evaluation of services for people with disabilities. *Exceptional Children*, 59(6), 499-513.
- 5 Goode, D. (1990) as paraphrased in Dennis, et al, 509.
- 6 Title II of the Americans with Disabilities Act of 1990, 42 U.S.C. §12132 (2002)
- 7 28 CFR § 35.130(d).
- 8 *Olmstead v. L.C.*, 527 U.S. at 606-7.
- 9 *Olmstead v. L.C.*, 527 U.S. at 596-7.
- 10 *Olmstead v. L.C.*, 527 U.S. at 597.
- 11 *Olmstead v. L.C.*, 527 U.S. at 660.
- 12 *Olmstead v. L.C.*, 527 U.S. at 601.
- 13 *Olmstead v. L.C.*, 527 U.S. at 603.
- 14 *Olmstead v. L.C.*, 527 U.S. at 605-6.
- 15 Although Governor Thomas Carper had signed Executive Order 79 on May 17, 2000, which was an attempt to meet the requirements of the *Olmstead* Decision, during the following year, the State did not meet the deadlines imposed in that Order. Moreover, rather than a coordinated effort across agencies lines and intra-agency planning, the plan that resulted from that Executive Order was fragmented with three separate Department of Health and Social Services' plans and did not include broad based participation from the public, service providers or, unfortunately, the consumers for whom the plan was ostensibly written: institutionalized persons with disabilities.
- 16 The State Council for Persons with Disabilities (SCPD) was originally established in 1980 as the Advisory Council for the Coordination of Services to the Handicapped under Title 16, Chapter 94 of the Delaware Code to promote better coordination of State services related to persons with disabilities. The name was changed in 1990 to the State Council for Persons with Disabilities. In July 1992, Governor Michael N. Castle dismantled the Department of Community Affairs (the former administrative home of SCPD) and transferred the Council and the Office of Handicapped Services to the Department of Administrative Services, Division of Administration. On July 10, 1995, legislation was passed that changed the name of the Office of Handicapped Services to the Office of Disability Affairs. On July 3, 1997, legislation was passed that updated the activities and expanded the membership of SCPD. SCPD's membership consists of state agencies, state advisory councils, advocacy organizations, and consumers. Its duties and responsibilities are currently mandated by Title 29 Del.C. Section 8813.
- 17 The Commission expresses no view concerning the Delaware Litigation. Rather, the Commission encourages the State to begin an open dialogue with the providers and institutionalized persons with disabilities to resolve the differences between the parties. The Commission hopes that this Report will be the catalyst to bring about that discussion and the vehicle through which the State can start the process of meeting its obligations under the ADA and the *Olmstead* Decision.
- 18 Those executive branch officials who had originally agreed to participate on the Commission, but who were subsequently directed to refrain from participation, expressed their personal disappointment and their continuing commitment to being advocates for persons with disabilities.
- 19 The Commission recognizes that DSAAPD is currently addressing the assessment issue and coordinating the transition of a sample of individuals through its Nursing Home Transition Grant.
- 20 Tony Records and Associates, Inc. 7109 Exeter Rd. Bethesda, MD 20817 (301) 652- 4040, TRAconsult@mindspring.com.
- 21 *Mississippi Access to Care Plan*, submitted to the Mississippi Legislature on September 30, 2001 in response to House Bill 929, page 20. Retrieved from <http://www.mac.state.ms.us/>.
- 22 *Mississippi Access to Care Plan*, page 19.

- 23 Jackson, P. (2002, November 14). State freezes jobs to reduce deficit. *The News Journal*, p. A10.
- 24 Greto, V. (2002, December 21). Pharmacies, state reach Medicaid deal: Happy Harrys, RiteAid ok compromise on reimbursement rate. *The News Journal*, p. B1.
- 25 The Delaware Health Information Network functions under the direction of the Delaware Health Care Commission. Information can be found at www.dhin.org.
- 26 Jackson, p. A10.
- 27 President's New Freedom Commission on Mental Health Interim Report to the President, October 29, 2002. Available on www.mentalhealthcommission.gov.
- 28 18 Del. C. sections 311, 2304 (16), and 2312
- 29 as defined by 6 DE Reg. 593 (proposed)
- 30 Best practices are available on the Centers for Medicare & Medicaid Services: Promising Practices in Home and Community-Based Services: <http://cms.hhs.gov/promisingpractices/default.asp>.
- 31 For more information on the Rehabilitation Act of 1973: Rehabilitation Services Administration, <http://www.ed.gov/offices/OSERS/RSA/Policy/Legislation/narrative.html>.
- 32 For more information on the University of Delaware's Center for Disabilities Studies' Community Education: www.udel.edu/cds/ or call 302-831-6974.
- 33 Kaye, S. (1997). *Disability Watch: The status of people with disabilities in the United States*. Volcano, CA: Volcano Press, Inc.
- 34 *Assessment of the unmet need for accessible vehicles, home modifications, and assistive technology among individuals with disabilities in Delaware*. Delaware Assistive Technology Policy Committee Progress Report, January 2003. For more information on the Delaware Assistive Technology Initiative: <http://www.asel.udel.edu/dati/> or call 800-870-DATI.
- 35 President George W. Bush in the foreword to the New Freedom Initiative. Available at: <http://www.whitehouse.gov/news/freedominitiative/freedominitiative.html>.