A Path Forward: Building a Community-Based Plan for Delaware

Commission on Community-Based Alternatives for Persons with Disabilities
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Letter from the Commission

A Path Forward

To: Governor Ruth Ann Minner
Senator, Thurman Adams
Representative, Terry R. Spence
Members of the 144th General Assembly

This report unveils the five-year goals for the Governor’s Commission on Community-Based Alternatives for Individuals with Disabilities. Created by Executive Order 50 and signed by Governor Ruth Ann Minner on September 22, 2003, the Commission has made a significant impact in the community since its inception. Commission members have a unique understanding of the importance of improving state systems and services as we move toward full community inclusion for children and adults with disabilities. This report builds on the Commission’s ongoing accomplishments by outlining the group’s goals for the next five years, and continues movement toward a comprehensive system of community services and supports for individuals with disabilities.

Delawareans with disabilities should be able to access the support and services they need in the community. Community inclusion builds a stronger, more diverse community and is more cost effective than housing and caring for all individuals with disabilities in an institutionalized setting. Institutionalization is extremely costly for governments and taxpayers compared to providing a streamlined system of services in the community through private-public partnerships. With the appropriate supports and services, individuals with disabilities can successfully work, participate in recreational activities, and contribute to their communities. They are also more likely to be educated alongside peers, retain employment, and be more satisfied with their environment.

We believe that Delawareans in the policy-making arena and in the community now better understand the terms and concepts of community inclusion than they did when the H.R. 90 Commission Report was published in 2003. This report included examples of publicly- and privately-funded programs that serve individuals with disabilities in the community. These programs exist and continue to grow because directors, managers, and employees have found that including individuals with disabilities in educational, recreational, social, and occupational settings produce benefits for individuals with disabilities, others without disabilities involved in the program, and the community as a whole. Administrators in schools, vocational and recreational programs, government departments and divisions, and private businesses increasingly find creative ways to provide supports and services to Delawareans with disabilities. Over the last five years, more community leaders and organizations have recognized the value and cost effectiveness of this movement. They are helping Delaware to meet the needs of individuals with disabilities and are receiving a return themselves. We hope you are inspired to find ways to fund, replicate, and promote these types of community supports and services.

The Commission’s work in the next five years will focus on expanding current programs and increasing community options for individuals with disabilities. Many groups must work together if we are to meet these goals, including the Department of Health and Social Services, the Department of Education, the Department of Services to Children, Youth and Their Families, providers of services, advocates, caregivers, and individuals with disabilities themselves. These groups and individuals must collaborate as allies...
to ensure that the mandates of the Supreme Court Olmstead Decision are met in Delaware. During the creation of this report, hundreds of people took the time to give input and insight into how Delaware can better address the community needs of individuals with disabilities.

We look forward to the progress that will be made toward these goals, building on what we have already accomplished. Once again, we thank the members of the Commission, subcommittee members, staff and community advocates for their dedication to our guiding principles and goals. We also extend an open invitation to all policy makers and members of the public who are interested in the Commission’s work to become involved by joining one of the Commission’s subcommittees.

Respectfully,

Rita Landgraf
Vincent Meconi, Secretary, Delaware Department of Health and Social Services
Co-Chairs

Mission of the Commission

To develop a comprehensive administrative and legislative plan 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

History and Purpose of the Commission

In June 1999, with guidance framed by Title II of the Americans with Disabilities Act of 1990 which mandates systematic deinstitutionalization, the United States Supreme Court rendered an historic decision in Olmstead v. L.C., 527 U.S. 581. The Olmstead decision requires states to place qualified individuals with disabilities in community settings when appropriate rather than institutions.

Following the Olmstead decision, the Joint Finance Committee reported gaps in the service delivery systems in Delaware and a federal government interagency planning group published a comprehensive report with over 400 recommendations for facilitating community integration. Furthermore, 39 other states had already formed commissions to develop plans to increase and improve community-based supports and services for individuals with disabilities. In 2002, the Delaware General Assembly passed House Resolution 90 (H.R. 90) creating a “Commission to Assess and Make Recommendations on Community-Based Alternatives for Individuals with Disabilities.” H.R. 90 created the Commission to:

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

By 2002, many community programs serving individuals with disabilities existed across the State of Delaware. The Commission was formed to gather information about these programs and the number and needs of individuals choosing community supports in the State of Delaware, to accurately assess these programs, and to suggest costs and funding options for proposed
new programs. In March 2003, the Commission presented a report in which Commission members requested that a **formalized oversight group** representing cross-disability stakeholders be charged with monitoring and refining the goals and objectives presented in the report. Following successful advocacy of the Commission report and through Governor Ruth Ann Minner’s initiative, Executive Order 50 created a permanent Commission in September 2003. Executive Order 50 charges the Commission with:

1. Ensuring maximum cooperation between government agencies that serve the disabilities community, and between public and private sector entities that serve the disabilities community;

2. Providing recommendations to the Governor and Secretary of the Department of Health and Social Services to refine the state’s plans and other reports/surveys dealing with community alternatives to provide services to qualified individuals with disabilities in the most integrated settings;

3. Supplementing such plans and reports to comprehensively assess existing needs and resources;

4. Providing recommendations to the Governor and General Assembly with respect to funding prioritization among projects designed to provide services to individuals with disabilities; and

5. Monitoring the state’s progress toward implementing existing plans to provide services to individuals with disabilities.

Identifying the barriers to community integration is a major part of the Commission’s charge to make recommendations and assess needs. Barriers are often obvious, such as crosswalks, bus stops, and public areas which lack accessible design for people with physical disabilities. Others are less obvious, imbedded in a community through long-standing misconceptions about individuals with disabilities, such as discrimination in a school or workplace which isolates an individual from his/her peers. The Commission addresses inclusion from a cross-disability standpoint, and the Commission members meet as a group quarterly to better understand the issues and provide a broader perspective. The term disability is used throughout this report. However, Commission members use this term in a broad sense to refer to any condition that can affect activities of daily living to include developmental, intellectual, sensory and physical disabilities, mental illness, and addictions.

The majority of Commission members are engaged in the work of the subcommittees. The current subcommittee topic areas include assessment, housing, healthcare, employment, transportation, Money Follows the Person, and direct workforce development. Subcommittee charges include:

**Assessment** — Develop a cross-disability/condition assessment process, to identify the individualized support and services needed for a person to live in the community. Through the assessment process create a database of comprehensive consumer profiles that will enable greater collaboration, coordination, and planning among government agencies and programs, private providers, and natural support systems to facilitate successful community living. In addition, the database will be utilized to promote future planning of budget needs and services.

**Housing** — Develop a comprehensive plan to ensure that each person in the State of Delaware with a disability/condition has appropriate supports and services to live in safe, affordable housing that is accessible and integrated in the community with appropriate supports and services.

**Healthcare** — Develop a comprehensive plan to ensure that individuals with disabilities/conditions will have dependable, high-quality healthcare in the community and affordable comprehensive health insurance.

**Employment** — Develop a comprehensive plan to ensure that individuals with disabilities/conditions are prepared to search, obtain, and retain employment to establish careers based upon their preferences, interests, and strengths.

**Transportation** — Develop a comprehensive plan to ensure that individuals with disabilities/conditions have access to a full range of transportation options throughout the state. These options should be convenient, reliable, affordable,
and ensure complete accessibility and mobility for individuals with disabilities who live in the community.

**Money Follows the Person** — Develop a comprehensive plan to promote legislation, regulation, policies, and programs to ensure funding designed to follow individuals as they move from long-term care facilities to the community. Additional funding will support persons at risk of being admitted to long-term care facilities to remain in the community with individualized supports chosen by the person at risk. If the individual resides in a long-term care facility, funds will be used to cover the net average cost of service to the individual while there.

**Workforce Development** — Develop a comprehensive plan with yearly-identified objectives that will ensure that individuals with disabilities/conditions have access to reliable, qualified support personnel and that support personnel are valued, compensated, and respected, thereby ensuring ongoing recruitment and retention.

## Stakeholders

The planning, implementation, and evaluation of services and supports for individuals with disabilities should include all stakeholders affected by the system changes. Each stakeholder group listed has offered input regarding how plans will affect them. Inclusive planning should continue to involve representatives from all community sub-sets, especially:

- individuals with disabilities;
- nuclear families, families of origin, extended families, and foster families of individuals with disabilities;
- advocacy groups and spokespeople for individuals with disabilities;
- provider agencies;
- state and local elected officials;
- Delaware employers;
- community leaders; and the general public.

## Membership

One of the most important recommendations in the H.R. 90 Commission Report highlighted the dynamics between government and those it serves. Due to a lawsuit, government agency representatives were directed to refrain from participation on the Commission during the H.R. 90 Commission activities. However, after successful advocacy of the Commission Report and through the Governor’s support, the Governor’s Commission on Community-Based Alternatives for Individuals with Disabilities recognized Delaware’s commitment to community-based alternatives for individuals with disabilities and recognized that such services advance the best interests of Delawareans. Executive Order 50 recognized that “the best way to achieve [community inclusion] is for the public and private entities representing Delaware’s disabilities community and those who serve that community to help chart the state’s progress toward those goals.”

Executive Order 50 established a Commission that consists of 19 members. The Commission membership ensures that important stakeholder groups are represented and have decision-making authority to implement recommendations in state agencies based on the Commission’s recommendations. Members are selected as follows:

- two members of the House of Representatives (one selected by each caucus);
- two members of the Senate (one selected by each caucus);
- the Secretary of the Department of Health and Social Services;
- the Director of the Delaware State Housing Authority;
- the Director of the Delaware Transit Corporation;
- the Director of the University of Delaware’s Center for Disabilities Studies;
- the Chair of the State Council for Persons with Disabilities;
Accomplishments

A major accomplishment of the H.R. 90 Commission was establishing the formalized oversight group through Executive Order 50. Governor Minner was very responsive to the H.R. 90 Commission members’ recommendations when creating this new group. Similarly, Commission members have responded accordingly by working in collaboration to not only collect information about community supports and services but to also engage program managers and funders in increasing Delaware’s resources.

In FY 2006, the Delaware General Assembly allocated $250,000 to the Commission. In line with the goals of the Commission, Commission members, with recommendations from subcommittee members, proposed projects and voted on the most appropriate use of the funding. Funding was allocated for the following purposes:

<table>
<thead>
<tr>
<th>Project Description</th>
<th>Amount</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding for Full Commission Staff Support</td>
<td>$50,000</td>
<td>The Center for Disabilities Studies (CDS) is contracted to support the Commission and the Chairs and Staff group. CDS is also responsible for managing the Commission website.</td>
</tr>
<tr>
<td>Medicaid Buy-In Infrastructure Development</td>
<td>$53,000*</td>
<td>The Delaware Division of Medicaid and Medical Assistance began infrastructure development for a Medicaid Buy-In program (See Goal 3, page 11).</td>
</tr>
<tr>
<td>Assessment Subcommittee Consultant fees</td>
<td>$50,000</td>
<td>A consultant was hired to develop a comprehensive assessment strategic plan.</td>
</tr>
<tr>
<td>Respite Care Plan Development</td>
<td>$50,000</td>
<td>The Center for Disabilities Studies with assistance from the Delaware Caregivers Support Coalition will design a lifespan respite care service for the State of Delaware that will be used to demonstrate how a consumer-focused, integrated respite service can be effectively administered statewide.</td>
</tr>
<tr>
<td>Direct Support Workforce Curriculum and Credentialing program</td>
<td>$35,000</td>
<td>The Center for Disabilities Studies will create a strategic alliance of partners to nurture the vision, harness the resources, and create an environment that supports change in the state’s service delivery system, especially as they pertain to the way frontline Direct Support Professionals are trained, advanced, and valued.</td>
</tr>
<tr>
<td>Direct Support Workforce Conference</td>
<td>$12,000</td>
<td>The first statewide conference for Direct Support Professionals, held in May 2006, was attended by approximately 300 people from Delaware and neighboring states and attracted Wilmington News Journal coverage.</td>
</tr>
</tbody>
</table>

* $20,000 was initially allocated to support an accessible crosswalk pilot project, which was later determined to be unfeasible. This money was reallocated to fund the Medicaid Buy-In Infrastructure project.
Other accomplishments from 2003 to 2007 include:

- The Money Follows the Person subcommittee was established as a result of Senate Resolution 26. The subcommittee was charged with undertaking all necessary steps to fund, facilitate, and complete a study on the feasibility of implementing the “Money Follows the Person” initiative in the State of Delaware. A federal grant was awarded to Delaware in 2007 through the combined efforts of the Division of Medicaid and Medical Assistance, the subcommittee, and partner organizations. State funding was secured in June 2007 through the Delaware General Assembly for $352,800 to match the federal dollars to begin implementation. See page 9 for the Money Follows the Person section.

- The Delaware General Assembly allocated $223,700 for the Medicaid Buy-In program. This goal was the priority of the employment subcommittee. See page 11 for the Employment section for more information.

- Expanded and improved transportation options in 2004, including Night Bus Service and Flexible Service programs, a transfer system between counties, a new DART policy against cell phone use by drivers, a DART ADA Compliance Team, and a resource list available at www.dartfirststate.com/directory/.

- The Employment subcommittee helped increase training for hiring managers and reporting of the State’s usage of State Personnel Office programs.

- A comprehensive strategic plan for the assessment of individuals with disabilities in Delaware was created by the Assessment subcommittee and will be considered in coordination with Housing subcommittee recommendations and the Delaware State Housing Authority’s Discharge Planning subcommittee.

- Funding was increased for fiscal year 2008 to eliminate the existing waiting list for Personal Attendant Services (PAS).

Executive Summary

In June 1999, the United States Supreme Court rendered an historic decision in *Olmstead v. L.C.*, 527 U.S. 581. The Supreme Court encouraged states to develop plans to ensure that programs and services provided by the states promote community integration for individuals with disabilities rather than favoring institutional services.

In September 2003, Governor Ruth Ann Minner signed Executive Order 50, creating the Governor’s Commission on Community-Based Alternatives for Individuals with Disabilities. The Executive Order affirms that Delaware is committed to community-based alternatives for supports and services and that these community-based programs should effectively foster independence and fully engage participation in society. The Commission’s overall purpose, throughout the ongoing planning process, is to ensure that all citizens, including those with disabilities, have the ability to live:

- close to family and friends,
- as independently as possible,
- engaged lives that include productive employment, and
- in settings where they can participate in community life.

The initial goal of the Commission was to develop a five-year Comprehensive Administrative and Legislative Plan with identified priorities, goals, objectives, action steps, and fiscal notes. The plan is intended to be a living, evolving plan that responds to the needs of individuals with disabilities and their families. The Commission, through its subcommittee structure, is charged with continuously updating the plan, monitoring progress toward achieving the goals and objectives of the plan, and adapting to unforeseen issues. It is the intention of the Commission to be an ongoing body to identify and adopt planning priorities annually.
This current plan includes guiding principles which frame the 10 goals for the State of Delaware to strive toward accomplishing in the next five years to enhance community-based services for individuals with disabilities and their families. The 10 goals reflect the priorities of the public, advocacy groups, and Commission members for the next five years. It is expected that as circumstances and realities change, these priorities will be modified to meet the needs of individuals with disabilities and families.

### Guiding Principles

The following principles are of paramount importance to individuals with disabilities, their families, advocacy groups, and the citizens of Delaware. These principles are critical to implementing the goals and objectives of the Commission’s plan and in providing services and supports to individuals with disabilities. The principles provide the background for understanding the goals, objectives, and action steps of the Commission.

**Guiding Principle 1** — Service delivery systems should provide supports that are designed to meet the needs of individuals with disabilities as they transition from one living environment to another and from one support service to another.

**Guiding Principle 2** — The lives of all individuals, including those with disabilities, change; therefore they will have different support needs at different times in their lives.

**Guiding Principle 3** — Supports and services should provide individuals with disabilities with the right to choose, direct, and manage their own affairs. Whether in a long-term care facility or a community-based setting, service delivery should focus on the preferences of the individual and his/her goals. Individual choice and self-determination respects the experience and knowledge of the individual by valuing these four principles: freedom, authority, support, and responsibility.

**Guiding Principle 4** — Individuals with disabilities should have basic rights that include:

- the freedom to exercise the same rights as all citizens;
- the authority to control their resources and make decisions about their lives;
- support from state government services, providers, agencies, family members, and friends in an organized, comprehensive fashion;
- flexible use of funding so that dollars are invested in services and supports and are not restricted to facilities or programs; and
- the right to receive services and supports in the least restrictive environment.

**Guiding Principle 5** — The Commission is supportive of universal healthcare measures designed to deliver medical and long-term supports to all individuals based on need, regardless of disability status.

**Guiding Principle 6** — In order to continue to enhance and develop quality services, reliable collecting and reporting of outcome data are essential. Outcome data about public services and programs should be available to facilitate both performance-based management and budgeting to produce a higher quality of services.

### Strategic Plan: Fiscal Years 2008–2012

The work outlined throughout this plan and the formation of goals, objectives, and action steps were constructed within the Commission’s subcommittee structure. The Commission, as the formal body, reviewed the subcommittees’ proposed goals and objectives, and was then charged with their prioritization and adoption.

### Public Comment

Community members were invited to participate in the goal prioritization process by submitting comments regarding the draft goals and objectives at one of three public meetings held in each county, by voicemail, by e-mail, by mail, or at
a meeting hosted by an advocacy organization. Public comments were collected and reported by University of Delaware Commission staff members contracted by the Commission.

The Commission reviewed the public comments at the June 14, 2007, meeting to determine if the plan needed amending. Consensus was that the comments would be integrated into the work of the subcommittees, which would further evaluate and act upon the public comments during fiscal year 2008. A number of revisions, additions, and clarifications to definitions were made to the report in response to public comment. Commission members appreciate the time and effort by members of the public in order to ensure a comprehensive plan. A full report of the public comments can be obtained at the Commission’s website, www.udel.edu/ccba.

The following narrative provides a perspective on the work of each subcommittee, including background of the development of corresponding goals, objectives, and action steps. The report will also highlight current or state of the art initiatives pertaining to an identified area.

Housing

**Goal 1: Ensure a sufficient number of safe, affordable, integrated, and accessible housing options for individuals with disabilities.**

Appropriate housing options are necessary for individuals with disabilities to remain safe and comfortable within the community. Overwhelmingly, individuals want to live in their own homes and communities. Individuals with disabilities and those who are aging are confronting housing challenges and affordability gaps that limit choices and/or make it very difficult to maintain independence and involvement within the community. The overriding goal of the Commission is to create and support livable communities that have appropriate and affordable housing, adequate and available mobility options, and support services that facilitate personal independence and continued engagement in society. The major challenges reported by individuals with disabilities and the agencies that support them in exiting long-term care facilities are the availability of appropriate housing and serving the individuals on the long waiting lists for Section 8 housing.

The stock of affordable, accessible housing units must be consistently identified and maintained. A system needs to be created to more effectively match individuals with disabilities to those housing opportunities. This system should be easily and readily accessible to individuals with disabilities.

Quality housing plays a major role in creating livable communities. In order for individuals with disabilities to have access to community living, a range of in-home services and supports must be present. These supports include personal attendant services (PAS), in-home medical, non-medical, assistive technology, personal care services, and access to behavioral healthcare. Personal attendant services are presently funded through both general state revenue and tobacco-tax revenue sources. As the waiting list continues to grow funding may prove to be inadequate.

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### Home Modification Tax Credits

**Contributor: Rita Landgraf**

Government initiatives can be implemented to facilitate livable communities. Programs in Georgia and Virginia offer state tax credits to persons with disabilities who make changes in their homes that allow them to continue to live there. The Olmstead Supreme Court ruling has been the catalyst for Indiana, New Hampshire, North Dakota, and Washington to fund home modifications for individuals with disabilities in order to prevent institutionalization. Georgia offers tax credits to individuals with disabilities who include certain accessibility features in a new home or renovate an existing home. Virginia offers a tax credit to anyone for similar features added to an existing home. The Housing Subcommittee will continue to explore the feasibility of government incentives for home medications for individuals and families in Delaware.
The concept of universal design, in which housing is designed to be accessible for individuals with disabilities, is not only critical to those with disabilities, but also enables the aging population to age-in-place, thus maintaining and enhancing independence. Private and public sectors in the housing development, construction, and rehabilitation industries should not only retrofit homes when the need arises, but should design and build new homes that meet specifications of universal design.

The Housing subcommittee has identified a need to advocate for visitability laws which mandate that housing barriers are removed. One approach is to subsidize the visitability requirements for housing through state or local funds. Another approach is to eliminate rules that discourage shared housing units, commonly referred to as “mother-in-law suites” or “accessible dwelling units.” This option has allowed many individuals to receive supports while maintaining a high level of independence.

Collectively, housing advocates can work at the federal level to advocate for tax incentives or low-interest loans to help low-income homeowners renovate to create accessible environments. Mandates are needed to include more aging-in-place/accessibility features in subsidized housing units, to support federal incentives to encourage public and private builders to develop innovative designs, and to provide adequate government funding for a range of affordable housing options.

Public policies must ensure that individuals with disabilities receive a fair share of all local, state, and national housing resources. Community-based options for individuals who are aging and those with disabilities should not end at group homes or assisted-living facilities. Instead, these opportunities should be expanded to include a continuum of options from personal home ownership or rental opportunities to small congregate living arrangements.

See page 1 of the insert for planned Housing subcommittee objectives and action steps.

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**Money Follows the Person**

**Goal 2: Implement Money Follows the Person (MFP) program.**

The “Money Follows the Person” (MFP) initiative, included in the Deficit Reduction Act of 2005, is currently being implemented by the Centers for Medicare and Medicaid Services. As a component of the New Freedom Initiative, MFP is a nationwide effort to remove barriers to community living for individuals of all ages with disabilities or chronic illnesses. MFP is a system of flexible financing for long-term care services and supports that allows Medicaid funds to be spent on home- and community-based services as an alternative to institutionalization. MFP supports a growing consensus that long-term supports must be transformed from an institutionally-based and provider-driven system to a person-centered and consumer-controlled system.

The Supreme Court’s Olmstead Decision has direct implications for state Medicaid programs and the state’s ability to serve individuals with disabilities in home- and community-based settings. MFP allows the state flexibility to expand services to individuals to prevent institutionalization and to support those individuals exiting long-term and intermediate care facilities.

The Commission advocates that the support needs of the individual must drive the funding, rather than the funding driving which supports are provided. In June 2006, the State Senate passed Resolution 26, establishing a subcommittee of the Governor’s Commission to “undertake all the necessary steps to facilitate and complete a study on the feasibility of implementing the ‘Money Follows the Person’ initiative in the State of Delaware.” Funded through the support of various public and private agencies and individuals, the report was completed by the Lewin Group in February 2006. The MFP coalition is made up of stakeholders representing the disability community, the Delaware Department of Health and Social Services, the Delaware Division of Medicaid and Medical Assistance, AARP, and
representatives from the state legislative branch. In the fall of 2006, the subcommittee initiated a coalition responsible for developing and submitting a grant proposal for funding to the Centers of Medicare & Medicaid Services (CMS). CMS approved the Delaware proposal in May 2007, awarding Delaware and 31 other states funding to implement a demonstration project for the next five years. Major objectives of the demonstration project are:

- To shift the amount of Medicaid funding supporting institutional care to a greater proportion of community-based care. Delaware currently spends 65% of its long-term care funding for institutional settings.
- To expand opportunities for consumer choice and self-directed services. Delaware’s MFP operational protocol will include developing policies and procedures to offer consumers self-direction and ensure that individualized, required supports are established.
- To develop a true continuum of services. Successful rebalancing can only be achieved with effective collaboration between public, private, and consumer organizations.
- To monitor program outcomes and ensure consumer protections by developing annual benchmarks.
- To monitor progress in areas of accessible housing, transportation, and workforce development by creating annual benchmarks.

The demonstration project funding focuses on shifting systems to enhance service delivery in the community-based on specific needs of the individuals being served. In addition, this funding will enable a minimum of 100 individuals currently residing in long-term care facilities to have access to community-based services. This demonstration project will help to identify gaps in the current services and supports system and identify ways to improve the system for all users. This will have a lasting impact on all individuals with disabilities and those who are aging.

MFP reflects a long-awaited commitment to independence, choice, and dignity. MFP allows for states to create and fund a system that promotes long-term care within the community, affords states some flexibility in the variety of services offered, and enables states to allow the consumer authority in the direction of these services. The MFP initiative in Delaware reflects the state’s commitment to fostering self-determination with strong community partnerships and participation among older community partnerships and participation among older individuals and those with disabilities.

See page 3 of the insert for planned MFP subcommittee objectives and action steps.

Community Ombudsman

Contributor: Jamie Wolfe

Like the long-term care ombudsman that assists nursing home residents with complaints and concerns, the community ombudsman would assist individuals who are having problems with their home and community-based services. This individual would be responsible for investigating complaints when a service user is not receiving supports that he or she is entitled to under the home and community waivers. In addition, the ombudsman could facilitate conflict resolution between the service user, the provider, and the state agency. The ombudsman will work with the funding source to assure a provider that meets the needs and wants of the service user is identified in a timely manner and that services are provided so institutionalization will not occur. Other states that have a comparable program include Pennsylvania, Connecticut, Arkansas, Minnesota, South Dakota, and Utah.

In order for this program to be successful, a Community Bill of Rights must be established to outline the specific rights entitled to an individual receiving home and community-based services. Modeled after the nursing home residents’ bill of rights, the Community Bill of Rights will list items pertaining to community services. For example, the bill could include provisions to responding to the needs of individuals in non-medical emergencies. The goal of the Community Bill of Rights is to ensure individuals can stay in their homes and receive the proper supports to avoid unnecessary institutionalization.
Employment

**Goal 3: Establish a Medicaid Buy-In Program.**

**Goal 8: State will provide funds and resources for long-term support for all people with disabilities to maintain employment.**

The majority of individuals with disabilities who want to work are frequently discouraged from doing so by barriers in the current system. The Ticket to Work and Work Incentives Improvement Act of 1999 seeks to address many of these barriers. Individuals with disabilities often choose not to be employed because they are concerned about a potential loss of healthcare coverage if they return to work. The Act expands Medicare and Medicaid coverage for certain categories of employed individuals with disabilities. The Act also provides for improvements in employment supports from government agencies. These provisions indicate a commitment to enabling individuals with disabilities to be productive members of the workforce.8

Stakeholders continue to express concern over the limitations and complexities of the current employment system for individuals with disabilities. In general, society has low employment expectations for individuals with disabilities, in spite of multiple examples of individuals who have highly successful careers. Government disincentives to work, such as connecting income to healthcare benefits eligibility, have perpetuated these myths. These low expectations often begin early in life and are repeated and encouraged as individuals mature. Especially important, however, is the message that is now being sent to employers that individuals with disabilities can be productive and successful employees.9

Some of the government complexities can be addressed by planning, designing, and creating improvement strategies to make the Medicaid state plan and/or waiver programs provide more effective support to potential employees with disabilities. Some services that can be offered could include: improvements to personal care, transportation, durable medical equipment, community-based treatment, or a supportive employment waiver. Coordination between the activities of other state agencies in support of working individuals with disabilities and the state Medicaid program is critical in building comprehensive supports.10

The Medicaid Buy-In (MBI) Program is intended to assist individuals with disabilities by allowing them to work without losing health benefits. MBI is a catalyst, which enables individuals with disabilities to participate in the world of work while still receiving Medicaid coverage. Recipients would contribute to the cost of the plan based on a sliding fee formula. In addition, many employed individuals would only require Medicaid benefits to supplement an employer’s health benefit plan that did cover non-traditional healthcare supports such as attendant care services and durable medical supplies. MBI removes the disincentives for people who refrain from work or “spend-down” their incomes to maintain their Medicaid benefits. More than 30 states have implemented a Medicaid Buy-In Program. The Commission’s Employment subcommittee has identified this initiative as their paramount priority. The Delaware General Assembly allocated $223,700 for the Medicaid Buy-In Program in June 2007.

Best practices for inclusive employment settings are governed by the following general principles:

- Individuals with disabilities are valuable human resources.
- Foster a community expectation that individuals with disabilities will participate in the labor force to the maximum extent possible.
- Anyone, regardless of disability, should have the opportunity to participate in the labor force and have the right to fair treatment in exercising this opportunity.
- Local labor market (employers) needs must be met.
- There must be a mutual benefit to the employee with a disability and the employer.
- Employment must be in typical, integrated workplace settings.
• All employment options must be available, from entry-level jobs to advanced positions.
• Individuals have the right to choose their employment and employer.
• Employers have the right to choose whom they hire.
• Individuals have the right to take reasonable risks in the employment they choose.

System, Service, and Support Principles will:
• work to maximize employment for individuals with disabilities;
• provide a high-quality workforce for employers;
• provide effective leadership at the state and local level;
• work for all job seekers;
• be responsive to the needs of employers and individuals with disabilities;
• effectively match potential qualified employees with employers;
• effectively track employment and earnings and demonstrate clear outcomes of success;
• be available to individuals, whenever they need it;
• be built on a stable funding base;
• not put the individual or the employer at risk; and
• emphasize communication and coordination among all the elements of the system.¹¹

See pages 4 and 14 of the insert for MBI and planned Employment subcommittee objectives and action steps.

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**Transportation**

**Goal 4: Ensure that reliable transportation services and choices are available.**

The level of independence a person has is largely determined by their ability to move around within a community. To stay connected and freely move within communities is one of the most difficult obstacles for individuals with disabilities and those aging-in-place. To avoid isolation within their home settings, individuals need a variety of mobility options available. Isolation has forced many individuals into institutions and nursing home environments. Appropriate mobility options are necessary for individuals with disabilities to remain safe and comfortable within the community.

The Delaware Transit Corporation continues to face daily challenges in providing transportation to increasing numbers of riders. Urban sprawl and traffic congestion have increased delays, road rage frustrations, and adjustments in travel time. The frustrations are mounting for riders and others who are impacted by the delays including employers, family members, friends, and other service providers. The Transportation subcommittee has

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**Ride Vouchers**

**Contributor: Rita Landgraf**

Some creative ideas in responding to transportation demands include examples from around the country. The Atlanta Regional Commission sells discounted vouchers to people who are at least 60 and cannot drive. These vouchers allow individuals to hire someone they know to drive them rather than depending on a formal government program. Another idea is provided by MIT AgeLab Director, Dr. Joe Coughlin, which involves the emergence of “car clubs”. Individuals who no longer drive may pool their resources to buy a car, then share it with a younger driver who serves as the chauffeur. This program could be especially attractive in college towns where many students have flexible schedules.

Some urban and suburban communities have set up fleets of small low-rise buses that travel on flexible schedules between residential areas and commercial settings. Individuals meeting the 55+ age criteria can walk from their new homes to centralized communal facilities and get a ride in a community van to more distant stores and entertainment sites. Another idea that is slowly gaining momentum is the creation of walkable communities specifically designed to avoid sprawl and foster easy mobility. These communities are not age-restrictive; one model exists in Rockville, Maryland. Parks and common areas are scattered throughout the community and a free shuttle bus takes people from their homes to the Washington Metro, commercial areas, and recreational facilities.¹²

All of these mentioned initiatives can target both individuals with disabilities and the aging population.
Outlined several priorities to address these issues and to improve the system within a five-year time-frame. Many of the recommendations focus on the expansion of the fixed-route paratransit system to offer transport options, as well as providing more accessible taxis and car/van pooling. There are many opportunities for creative collaboration, serving older and younger passengers to the benefit of all. A long-term commitment should be made to transform the current methods of transportation.

The Transportation subcommittee believes people with disabilities should have expanded transportation options beyond public transportation. This group has identified a number of policies to improve the current system, including accessible driver’s education classes, vehicle ownership...
programs and repair services, and accessible road signage. Private citizens and corporations can also use their resources to provide transit services. These options include accessible car and van pooling and encouraging private taxi and car services to operate accessible vehicles. DART participates in a vehicle-sharing program with qualifying non-profit organizations to provide transportation to clients of those organizations. In fiscal year 2006, this program allowed Delaware non-profits to provide 300,000 trips to citizens, extending the reach of transportation services according to the DART representatives from the Transportation subcommittee.

See page 5 of the insert for planned Transportation subcommittee objectives and action steps.

Healthcare

Goal 5: Develop a comprehensive, flexible, consumer driven healthcare service system that would more effectively facilitate community living.

Goal 9: Effectively treat mental illness as a medical condition requiring the same quality of care as physical illness.

Goal 10: Expand infrastructure to accommodate medically, emotionally, and mentally fragile children transitioning to the adult service system.

Mental Health Parity

Contributor: AARP 2006 Policy Book

As referenced in Mental Health: A Report of the Surgeon General, mental health is fundamental to overall health. Mental illness can occur at any age, any income level, and can be as debilitating as any other major medical condition. However, insurance policies typically place restrictions on coverage for mental health services that do not apply to other services. “Even more than other areas of health and medicine, the mental health field is plagued by disparities in the availability of and access to its services,” observed US Surgeon General David Satcher in the preface to the report.

Spending for mental health has declined as a percentage of overall health spending. Moreover, the public sector, principally Medicaid and other state or local government sources, are paying for an increasing share of overall spending for mental health or substance
Innovative Healthcare Options

Contributor: Delaware Public Policy Institute

The following represents some options that states are exploring or implementing to address the need for healthcare reform and are inclusive of all populations. Some of these options are gaining attention within Delaware.

- A Single-Payer Government Run Healthcare System is exclusively funded by the government and similar to the Canadian healthcare system. In the United States a single-payer system might resemble Medicaid, Medicare or Veterans Affairs type coverage. The implementation of a single-payer system would require revenue enhancements to fund the government expansion.

- State subsidized insurance is supported by a public-private partnership model that establishes a health plan for small businesses. Either a state-designated board or a private insurer administers the plan, and the state subsidizes the premium for low-income workers, while small businesses also pay a share of the premium. Most programs create a standard benefit package that usually includes acute care, regular medical health checks and prescription coverage. Maine’s Dirigo Choice Health Plan and Massachusetts Commonwealth Plan are examples of state subsidized insurance.

- Insurance Purchasing Pools target individuals who lack access to both employer-sponsored insurance and government programs. Pools can provide an efficient source of health coverage for small employers and individuals needing to buy coverage on their own. Purchasing pools differ from state subsidies because they provide employers with a wider choice in plans and greater bargaining power due to multiple employer participation. At least eight states have some form of group purchasing arrangements in place.

- State Premium Assistance allows Medicaid to pay a portion of a low-income worker’s share of the employer-sponsored insurance premiums for those who are currently eligible for those programs. States must include this in a Medicaid State Plan Amendment. States set the income eligibility levels for premium assistance as well as the minimum benefit package. Five states now operate such a program.

- Employer health insurance mandates, also known as “pay or play” programs, mandate businesses to offer healthcare coverage to their employees or pay a penalty into a state fund to provide coverage.

- All individuals have a right to high-quality healthcare.

- All individuals should have a reasonable choice of healthcare providers.

- Financing of the healthcare system should be equitable, broadly-based, and affordable to all individuals.

- Methods of provider reimbursement should promote high-quality medical care, efficient service delivery, and compensate providers fairly.

- Healthcare spending should support the goals of more efficient planning, budgeting, and resource coordination.

- Health promotion and disease prevention efforts should be strengthened.
• Individuals share a responsibility for safeguarding their health by educating themselves and taking appropriate preventative measures to protect their health, safety, and well-being.

• Acute, chronic, and long-term care services should be coordinated and integrated to ensure a continuum of care throughout an individual’s lifetime.\textsuperscript{16}

Transition planning is essential for individuals with disabilities who exit the Children, Youth and their Families system and/or the education system. Whether the transition occurs at age 18 or 21, the planning and coordination far too often does not occur until the transition is imminent. This transition population needs to be addressed as a component of the work of the Commission. Coordinated efforts must be made to include the Department of Health and Social Services, Department of Services for Children, Youth and Their Families and the Department of Education in addressing and enhancing a seamless, wrap-around transition into the adult service delivery system.

In order to expand home- and community-based services, states should design budgets and policies to eliminate institutional bias, expand access to home and community, and allow consumers to choose the setting in which they receive services. In the areas of family support and caregiving, states should establish policies to pay relatives and friends who care for people with long-term support needs as part of a care plan. Programs and policies must protect consumers, avoid the erosion of the family care networks, guard against fraud and abuse, and avoid disincentives for unpaid caregiving.

Delawareans face a major challenge in healthcare and long-term service and supports as the population ages and individuals are living longer. The nation lacks a comprehensive system that serves the needs of millions of older individuals and individuals with disabilities. Long-term support services encompass a broad range of services and supports needed by individuals of all ages who have physical or mental impairments and have lost or never acquired the ability to function independent of the supports. Surveys indicate that most individuals who need long-term support services strongly prefer to remain in their homes, receiving assistance from family or friends or from paid direct service professionals. However, because of the high cost of services, lack of private affordable financing options, and limited public funding, people often do not have access to the service options they prefer.\textsuperscript{17}

Implementation of any comprehensive public program should be phased in to ensure orderly development of the new system. Expansion of services

\textbf{Family Support Services}

\textbf{Contributor: AARP 2006 Policy Book}

Families and individuals need comprehensive supports that allow them to direct their own care and help families and friends bear the financial and emotional responsibilities of caregiving. Some states provide individuals with opportunities to manage their own long-term services. Federal and state programs that assist caregivers are limited, even though unpaid family and friends provide the bulk of long-term services. In 2004, an estimated 44.4 million caregivers age 18 and older, 21% of the adult population, provided unpaid care to an adult family member or friend. Through Medicaid and state-funded home and community-based services programs, some states provide respite care for caregivers, while others allow payments to relative and friends who care for people with long-term support needs. Some states give families who care for individuals with disabilities and/or older relatives limited support either through Medicaid, state funding, or tax policies. These programs include respite, cash allowances, tax incentives, family leave policies, worker’s compensation, and healthcare benefits. While the above policies provide incentives for family caregiving, the Supplemental Security Income program reduces benefits for beneficiaries who live with their families, creating a disincentive for family caregiving. Services for caregivers are extremely insufficient.\textsuperscript{18}
should be accompanied by the development of infrastructure, inclusive of healthcare and direct services workers, case managers, and other needed personnel that will permit the delivery of a comprehensive range of home- and community-based services.

See pages 7 and 15 of the insert for planned Healthcare subcommittee objectives and action steps.

Workforce Development

**Goal 6: Ensure fiscal and human resources necessary to develop and retain a professional workforce.**

A Direct Support Professional (DSP) provides support services to individuals with disabilities to assist with activities of daily living within the community settings. A large proportion of home care services do not require utilizing a medical approach, rather services are highly personal in nature (e.g., bathing, dressing, toileting, and grooming). Other activities supported by DSPs may include supports to facilitate independent living such as budgeting, shopping, and transporting to various individual and/or community activities.

Industry guiding principles to increase the availability of qualified long-term services and supports personnel include:

- Ensuring that Medicaid and other public reimbursement for providers’ labor costs are sufficient to offer wages and benefits to attract and retain the workforce.
- State wages and salaries being commensurate with others in the region.
- Creating legislative mechanisms to increase compensation for Direct Support Professionals. These mechanisms should include adequate accountability procedures, such as audits, to ensure the reimbursement increases designated for staffing costs are actually used for that purpose.
- Supporting research to identify effective ways of addressing staffing shortages.
- Encouraging schools to include in their curricula long-term support services related specializations, such as home health, supportive housing, and home care in their curricula for Direct Support Professionals.
- Encouraging the state to establish training requirements for all individuals who provide personal care in home and community settings and are paid through public funds. The training should include a core curriculum covering the needs of individuals who require long-term services and supports and should be inclusive of classroom instruction and practicum experience.
- Training and continuing education services that focus on how to maximize the quality of care while supporting the independence, autonomy, dignity, and privacy of individuals with disabilities.

Efforts must promote changes in the work environment to encourage employee recruitment and retention. This could include adequate staffing recommendation, providing increased salaries and health benefits, providing specialized staff, encouraging employee participation in decisions on individuals’ with disabilities support needs, offering ongoing education on best practices and providing programs, career ladders and lattices, and educational incentives to facilitate career advancement. For example, a ‘career lattice,’ would allow for professional/career advancement beyond a certificate and should include specializations in health, mental health, recreation, socialization, and employment.

Finally, the creation and promotion of a professional association would allow DSPs to advocate for themselves while improving worker morale and allows a vehicle for formal collaboration, continuing education, peer support, and formal networking.

See page 9 of the insert for planned Workforce Development subcommittee objectives and action steps.
Assessment Care Planning

Goal 7: Develop common assessment domains for eligibility and care planning.

The Supreme Court’s Olmstead Decision ensures that individuals with disabilities in long-term care facilities and institutions and those at risk are assessed in a fair and timely manner to determine how community living would be possible without limiting options solely to what is currently available within the community. All individuals with disabilities residing in institutional settings will need to participate in an assessment to identify their community support needs and services.

The Supreme Court further highlighted that:

- institutional placement of individuals who can benefit from community settings perpetuates “unwarranted assumptions” that persons so isolated are incapable or unworthy of participating in community life; and

Workforce Training

Contributor: Renee Bean

The Commission’s Workforce Development subcommittee includes representatives from provider agencies, state divisions, the University of Delaware, and others with firsthand experience who provide professional direct support to persons with disabilities. These experts have identified challenges to retaining and recruiting a qualified workforce, including the turnover rate for first-year direct support workers in Delaware, which is currently around 67 percent. Workers report that one of the challenges to staying in direct support is the lack of training to equip them to perform effectively, coupled with the lack of unqualified, unreliable colleagues. Persons with disabilities who rely on these employees to assist them in daily activities bear the burden of an unreliable workforce that includes workers who do not know how to communicate with persons with disabilities, often do not show up for work, and are not knowledgeable about person-centered and community-based services and supports.

In response to a demand from both the workforce and persons with disabilities, the Workforce Development subcommittee proposed a plan to implement a more effective training in community-based service delivery. The system should serve individuals with disabilities based on their needs, not their diagnosis; however, training has not evolved from an institutional, medical model. In the next five years, the Commission aims to offer a statewide training program focused on value-based skills to enhance the quality of services and self-determination of persons with disabilities. The curriculum will utilize core competencies and technical skills to increase the knowledge, skills, and abilities of consumers, staff, and service provider agencies about their mutual and respective needs. The values include teamwork, inclusion, mutual respect, and personal autonomy, based on the nationally recognized Community Support Skills Standards, developed by the Human Services Research Institute in 1996. These standards also include training in participant empowerment, communication, assessment, community and service networking, facilitation of services, community living skills and supports, education, training and self-development, advocacy, vocational, educational and career support, crisis intervention, organization participation, and documentation.

The Workforce Development subcommittee, through a contract between the Commission and the Center for Disabilities Studies, will direct the development of a curriculum that can be introduced, piloted, and implemented across Delaware’s Health and Social Services Departments serving individuals with disabilities. This training will serve to enhance the quality of care and service and could serve as the foundation for a professional credential for frontline Direct Support Professionals. The curricula have the potential to support the state and its contracted provider agencies, their staff, and guarantee people with disabilities a qualified workforce, improve workforce recruitment and retention rates, establish a basis for negotiation for wages and benefit parity for all direct service staff, and establish a professional credential/certification for the direct support professional.
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.20

Nursing homes continue to provide services to a larger number of individuals who are aging or have disabilities, even when many of the individuals living in nursing facilities would prefer to receive services in community-based living arrangements. This statement is supported by data from Delaware’s Minimum Data Set (MDS) which indicates that 19.9% (756 of 3,846) of individuals living in nursing facilities indicate a preference to live in the community in the 2006 Second Quarter’s MDS questionnaire. The MDS is data collected on individuals in Delaware’s Medicaid- and Medicare-certified long-term care settings. Additionally, data from surveys of Delaware’s AARP membership indicates very few individuals (4%) would want to receive long-term care services in a nursing facility.21

Currently, Delaware disability agencies and advocacy groups engage in various information dissemination and outreach activities regarding community-based long-term care options and services. However, there is no single process reaching all targeted long-term care groups. The need to address this important gap from both a transition and diversion perspective is a goal of the Assessment, Discharge Planning, and MFP subcommittees.

The Assessment subcommittee was allocated funding and was successful in the development of a five-year comprehensive plan to support and finance incremental steps to develop comprehensive, cross-disability, cross-agency assessments which would facilitate a coordinated effort in care planning. In addition, this information will be aggregated to identify trends to aid in the planning for future services, supports, and areas of concentration such as access to housing, transportation, and employment. One integrated planning format should be adopted and utilized for all services and supports while allowing and promoting person-centered goals and interests. Provision for measurable plan outcomes is recommended and should be made for tracking against the individual plan. The tracking should have a capability for aggregation of quality assurance measures. Collectively, the recommendations identified in the Assessment Plan, the MFP proposal, and the Discharge Exemplary Practices are designed to encourage and facilitate plans of care that will improve oversight, outcomes assessment, and resource utilization across all state-administered programs serving the population.

The development of protocols to aid in common assessment domains should be established. A tool identifying support needs with an emphasis on housing needs, integration, preferences, and risk of homelessness should be a priority, along with an information technology platform necessary to support this assessment tool. These efforts highlight the need for reliable data collection and management. By recording individuals’ needs for supports and services in the community, housing agencies will be better able to serve clients and project future needs.

See page 11 of the insert for planned Assessment subcommittee objectives and action steps.

Strategic Plan: Beyond Ten Priorities

This report marks an initial five-year Comprehensive Administrative and Legislative Plan with identified priorities, goals, objectives, action steps and fiscal notes. Commission members have adopted this plan with the intention of accomplishing goals in increments. While the Commission has prioritized a five-year agenda, subcommittees continue to meet to review and set priorities in conjunction with the Commission’s work and priorities. The Commission members’ resources and influence extend beyond the top ten priorities to continued work in subcommittee areas.

As the plan evolves, the Commission, through its subcommittee structure, is charged with
continuous updating of the plan, monitoring progress toward achieving the goals and objectives of the plan, and adapting to unforeseen issues. Harnessing the knowledge and expertise of subcommittee members, as well as receiving ongoing input from members of the public, subcommittee plans will be updated on an ongoing basis in the next five years. Subcommittees Chairs and Staff are responsible for updating Commission members of changes to the plan at Commission meetings and will be posted on the Commission’s website at www.udel.edu/eds/ccba.
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**Text Terms**

**MFP** — Money Follows the Person  
**PAS** — Personal Attendant Services  
**ADA** — Americans with Disabilities Act

**Template Acronyms**

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End Notes

1 A Call to Action: Building a Community-Based Plan for Delaware (2003). Commission on Community-Base Alternatives for Individuals with Disabilities.


5 A Call to Action: Building a Community-Based Plan for Delaware (2003). Commission on Community-Base Alternatives for Individuals with Disabilities.


7 Finding a Way Home: Delaware’s Proposal to Implement MFP — A Money Follows the Person Demonstration Project submitted by the State of Delaware (November 1, 2006, updated - April 19, 2007). Governor’s Commission on Community-Based Alternatives for People with Disabilities, Department of Health and Social Services and Division of Medicaid and Medical Assistance.


13 Available online at www.dartfirststate.com


21 Finding a Way Home: Delaware’s Proposal to Implement MFP — A Money Follows the Person Demonstration Project submitted by the State of Delaware (November 1, 2006, updated - April 19, 2007). Governor’s Commission on Community-Based Alternatives for People with Disabilities, Department of Health and Social Services and Division of Medicaid and Medical Assistance.
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