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A Research Brief addresses  
attendant care services in  
Delaware.*

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# DELAWARE

R e s e a r c h B r i e f ■ I s s u e # 3

### *Letter from the editor:*

To live and participate fully in the community, people with disabilities may require assistance to live, work, and recreate as independently as possible. Attendant services facilitate access to employment, recreation, friends and family—a full life in the community. This edition of *delAware: A Research Brief* offers an overview of attendant care, the impact of the House Bill 30 legislation (HB 30), and highlights of the findings of the State Council for Persons with Disabilities/Center for Disabilities Studies research study on attendant services.

HB 30, legislation designed to improve access to personal attendant care in Delaware for persons with disabilities was signed into law by Governor Ruth Ann Minner on July 19, 2001. The passage of this legislation was the product of an intense two-year collaborative effort by a variety of individuals and groups in Delaware.

The study highlighted in this issue is a product of work done by the State Council for Persons with Disabilities, the Disabilities Law Program, the Developmental Disabilities Council, and the Center for Disabilities Studies. A series of five focus groups of consumers and attendants around the state were held to discuss experiences with attendant services. Consumers discussed what they would like to change about the system, what they need to successfully manage their attendants, and what they want and need from the attendant services program. Personal attendants were asked about their experiences and concerns including: working conditions, motivations, career incentives, and how legislation, policy, and practice impacts their ability to offer what consumers want. Using the feedback provided from the consumers and attendants, policy recommendations were developed that led to the HB 30 legislation. While the focus groups were held over four years ago, the information discussed continues to be relevant as attendant services programs in Delaware continue to grow and evolve.

The passage and implementation of HB 30 in Delaware has provided increased attendant services, a significant reduction in the number of people on the waiting list for services, greater collaboration between disabilities advocates and the State, improvements to the existing attendant care services program, and the opportunity to pursue federal Medicaid waivers for attendant services. Members of stakeholder groups have formed an advisory council to examine the issues around HB 30 and the attendant services programs in Delaware.

We hope that you will find this edition of *delAware: A Research Brief* both compelling and informative regarding the current status of attendant programs in Delaware.

Sincerely,



Tracy L. Mann

## Personal Attendant Care

### What are Attendant Care Services?

Attendant care assists people with disabilities who have limitations in performing essential daily activities at home and in the community. These services include assistance with:

- transferring to and from a bed, wheelchair, or vehicle
- using medical and nonmedical equipment
- assistive technology
- routine bodily functions
- health maintenance activities
- ancillary services such as cleaning, laundry, shopping, seasonal chores, transportation, companionship, facilitating communication, bill payment assistance, money management, decision-making, and planning

### A Quick Lesson in Terminology

Many titles are used to describe the personnel who assist persons with disabilities with the activities of daily life. The various titles can be confusing as to what duties any given worker can perform. The positions include:

#### Home Health Care Aides (HHCAs):

HHCAs are not nurses and are assigned to an individual with a disability based on a medical needs assessment. The hours and services of an HHCA are primarily controlled by the agencies that contract them to the consumer. Consumers report that they feel frustrated because they have little say in when and how HHCA services are provided.

#### Personal Assistants & Personal Care Attendants (PAs):

These titles are interchangeable. PAs are hired directly by the individual or their advocate and, like HHCAs, are not nurses. Working with personal assistants or personal care attendants can allow individuals with disabilities more freedom of service choice than HHCAs because PAs are hired directly by the consumer. The person hiring the PA has substantial control over hours worked and services provided; therefore, services meet specific individual support needs.

### Personal Attendant Care Challenges:

Some personal attendant care challenges arise for HHCAs and PAs because they are not nurses. The Nurse Practice Act, which regulates the performance of "invasive procedures" by non-nurses, can, at times, cause difficulty for HHCAs and PAs because of the limits it imposes on their roles. For example, one consumer reported that her HHCA could not help her with her earrings because, if the holes were blocked, her ear might bleed when the earrings were inserted. Because of the possibility of bleeding, putting on earrings is considered too invasive for an HHCA to perform. HHCAs tend to be the most restricted, while PAs have a little more freedom to provide a wider array of services to individuals.



*Photographer Lily Bandak of Newark, pictured here with Jeff, who assists her with professional and household projects. Lily has used Personal Care Attendants for over eight years and feels that her life is greatly improved by having choices and access to the community.*

## Attendant Care in Delaware

### Personal Attendant Services

Personal attendant services, established by the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), are offered through a collaboration of Easter Seals of Delaware and Maryland's Eastern Shore. Two programs currently provide attendant services for people in Delaware: the state funded (pre-HB 30) program and the HB 30 program. The state funded program is currently budgeted at \$900,000 per year and serves 34 people. The HB 30 program has increased the number and breadth of services with funding of \$430,000 and provides personal attendant services for an additional 30 people. The only distinction between the two programs is that funding for HB 30 comes from the Tobacco Settlement Funds, and those enrolled in the HB 30 program must be Medicaid eligible in order to continue receiving services once a waiver is implemented in Delaware. Both the state funded and HB 30 programs are run concurrently by Easter Seals as a single personal attendant services program.

■ **Eligibility:** A person must be a Delaware resident over the age of 18 who has an anatomical or physiological need that is anticipated to last 12 months or more. The need must substantially affect that person's ability to live independently and carry out daily activities. These needs cannot be remedied through assistive technology nor home modification.

■ **Length of services:** Up to 30 hours per week.

■ **Priority:** People completing their education, people becoming or remaining employed; people with environmental, social, and/or financial constraints (especially those with constraints in all three areas); and people who choose to live independently and more cost-effectively with attendant services rather than in congregate care facilities.



*Jamie Wolfe and Theda Ellis facilitated the attendant care research study highlighted in this edition of delAware: A Research Brief.*

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### Channels of Communication

There was substantial attention given to the issue of communication among participants in the attendant care system.

*Consumers want to:*

- communicate more clearly with their attendants.

*Attendants want to:*

- be enabled to communicate more clearly with employment agencies.

*Both consumers and attendants want:*

- clearer communication between the agencies and persons receiving services.

In the focus group discussions consumers express that they want to be responsible recipients of care, and providers expressed that they want to meet the needs of their clients as best they can. A range of stumbling blocks often occurs. For example:

- foreign language barriers between people in the system.
- a lack of positive feedback, so that neither consumers nor providers feel they are being treated with appropriate respect.
- a need for more information to help attendants and consumers know if they are functioning well at their jobs.

### Empowerment

In conclusion, the focus group participants voiced their desire to become more empowered to navigate and mediate the process of attendant care provision.

*Consumers want:*

- more autonomy.
- opportunities to learn to articulate their needs more clearly.
- increased ability to hire staff with skills and characteristics that fit their personal needs.

*Both consumers and attendants think there is a system wide need for:*

- better overall understanding of the attendant care systems.
- improved flow of information among involved parties.
- more knowledge about whom attendants and consumers should contact when problems arise.

## Implications & Recommendations for Future Investigation

Findings indicate the need for further investigation to support the development of future legislation. The system of service delivery of quality care needs to be changed in many ways.

***Training for personal attendants must be improved significantly.***

Improving the quality of training would do more than simply provide attendants with better job skills. Better training will also improve communication by increasing the personal attendant's awareness of what is valued most by consumers, employers, and their fellow attendants.

***There must be a sufficient back-up service delivery system for use during emergencies.***

Attendant care is necessary for the persons who use them; they are not an optional luxury.

***There should be greater quality control at every level of the system and more positive incentives for attendants.***

When an attendant feels devalued and disrespected, the resulting climate can easily promote poor attitudes, neglect, and problems between staff and consumers.

***An appeals process with mediators must be established to ensure consumers get their needs heard and met.***

A process to address problems related to quality, neglect, or abuse must be in place that is widely accessible and ensures the safety of consumers.

***The system must become more consumer-driven.***

Consumers consistently expressed interest in acquiring the skills to more actively manage the services they receive. These skills range from hiring and paying their attendants, to being assertive and clear when giving directions, and knowing how to approach local service agencies to obtain the care they need.

***Empowerment must be an overarching goal.***

***Laws and policy must be reviewed, so that advocates can understand current policy better and advocate for change.***

Clarification of which services are "medical," and therefore outside of the scope of personal care attendants' duties, is needed. At this time, varied interpretations of Delaware's Nurse Practice Act have led to many disparities in definitions. For effective change to occur, the nature of the job responsibilities must be determined and agreed upon by all service providers.

***Information about attendant care must be centralized so that families and consumers have a better way to access it as the need arises.***

People should be able to access a resource clearinghouse to find out what funding and services are available, as well as information on training for consumers, families, and persons interested in becoming attendants themselves.

*deAware: A Research Brief* is sponsored by the University of Delaware's Center for Disabilities Studies, a University Center for Excellence in Developmental Disabilities Education, Research, and Service, as part of our dissemination efforts to educate people in the community about people with disabilities. Comments may be made to:

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Rosemary Barbati and her assistant Tramaine, get ready to attend college courses. "If it weren't for her," Rosemary says, "I wouldn't be able to go to school."

## Attendant Care & Delaware Law: House Bill 30

House Bill 30 (HB 30) amends Titles 16, 24, and 29 of the Delaware Code relating to community-based attendant care services introduced by Representative Pamela Maier on January 18, 2001. Previously, these services were not mandated by law and could have been discontinued at any time. However, as of January 15, 2002, HB 30 has enacted attendant care services as a permanent part of Delaware's health care system.

The HB 30 attendant services program receives \$430,000 per year and provides services for 30 people. These personal attendant services are administered by Easter Seals in conjunction with the system in place before the passing of HB 30. By providing community-based attendant services, HB 30 aims to "reduce barriers to participation in vocational, educational, social, and other community based activities." This increase in flexibility and access should eventually hold true for a wider range of consumers.

In addition, HB 30 requires the screening of potential attendants through a comprehensive interview process and criminal background checks, as well as checking registries for any history of abuse, neglect, mistreatment, and financial exploitation of clients.

## Attendant Care Research Study Focus Group Questions

The focus groups were guided by the following questions.

### Questions Asked of Consumers:

1. What kind of personal attendant care do you need to live independently and happily as part of the community?
2. What is the greatest barrier that prevents you from getting the services you need?
3. What training do you need to use an attendant effectively?

### Questions Asked of Personal Attendants:

1. What is your major concern or issue as a personal attendant?
2. What incentives do you need to make personal attendant work a career?
3. What duties would you be willing to do that you cannot do now under various rules of the insurer, the agency for whom you work, the Nurse Practice Act, or others?

## Focus Group Findings

### Employment Systems

For the most part, consumers and providers of personal care clearly expressed overlapping concerns. The largest number of issues raised by both groups centered on problems within the employment system. In addition, some consumers stressed the need for overall changes in the way service delivery is approached. While these responses were not always specific about how far-reaching and comprehensive the changes should be, other responses seemed to begin the process of discussion around the issues.

#### Examples of needed system changes:

**Flexible policies**—current inflexibility keeps things from working as well as they could.

**Better training**—could help service delivery occur more smoothly.

**Benefits**—attractive employee benefit packages would encourage attendants to be invested in offering higher quality care, instead of the current practice that keeps workers at part-time status to avoid offering benefits. Part-time status forces attendants to work 60-80 hours a week to survive financially.

**Career advancement**—possibilities for long-term career path success would help a great deal.

**Reformed management practices**—all focus group participants expressed concern and urged reform.

**Formal backup system**—needed by consumers to avoid loss of help when the unexpected occurs.

**Increased Accountability**—more attention to quality control from

employers, and more employer accountability for their consumers' experiences.

**Regular performance monitoring**—attendants support systematic performance monitoring to improve the quality of services.

### Monetary Concerns

**Consumer concerns:** Lack of money may be the greatest barrier to getting services needed.

#### Consumer concerns include:

- the need for more financial support from both personal health insurance or public funding sources for personal attendant care.

- the feeling that they do not get all of the hours of personal care they want and need.

- general problems with the high cost of living for persons with disabilities.

- policies that require people with paid employment to pay directly for attendant care, which can cost up to \$600 per month.

**Attendant and consumer concerns:** The pay scale for attendants has a lot of implications for quality of care, including:

- discouraging experienced individuals from applying for these kind of jobs.

- leaving only limited funding for attendant training.

- increasing the chance that attendants may leave their jobs quickly and may not necessarily be motivated to act in a trustworthy way.

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