Personal Assistant Services:
A Review of Training Materials

BY

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Minnesota Governor's Planning Council on Developmental Disabilities.

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OVERVIEW

This report was produced for the Minnesota Governor's Planning Council on Developmental Disabilities. I reviewed a total of 8 documents or sets of documents to deal with the issue of Personal Assistant Services (PAS). The primary purpose of the review was to determine which (if any) of the materials were suitable for use by a specific target audience: families with children with intellectual impairments living at home and using PAS services.

In order to determine if the materials were suitable for this particular audience, I conducted a 2-part review. First, each manual was reviewed using the Criteria for Competency Based Training, produced by the Minnesota State Technical College Task Force for on Educational Opportunities for Developmental Disabilities Service Projects. These criteria are excellent, and offer an insightful critique into a training curricula.

Unfortunately, most of the materials being reviewed for this report scored so badly on this review, that I felt a need to re-review the materials with more modest standards that were specific to the question of applicability to our target audience (families with children with intellectual limitations in the home using PAS). To this end, I considered several aspects of each document. Specifically I asked:

What is the content focus?
Who is the target audience?
Is the information current and reflective of best practices?
Does the material specifically refer to
  parent/family issues
  intellectual impairment issues
  children's issues?
What are the strengths?
What are the weaknesses?
In terms of the specific questions I asked, there was little variety among the materials reviewed.

**CONTENT FOCUS & TARGET AUDIENCE:** Based on these reviews, I was able to sort the materials into three main categories:

- Materials to train people with disabilities (physical) to employ their own PAS workers.
- Materials to train PAS workers about their jobs.
- Materials to tell third parties about PAS issues, especially public policy issues.

**BEST PRACTICE:** Several of the materials used “People First” language, and referred to “personal assistants”. Many others used out-moded language of “attendants” and did not use people first language. Only a few of the materials focused on “New Way of Thinking” issues such as support rather than supplant natural supports, empowerment, and self-determination.

**REFERENCE TO TARGET AUDIENCE:** With one or two exceptions, the materials made no mention of people with mental retardation/intellectual impairments, special issues for families with children living at home, or children’s issues in any way.

**STRENGTHS:** Many of the materials were reasonably well produced, with helpful illustrations. Most were developed by or with people who use PAS services.

**WEAKNESSES:** Many of the materials were produced several years ago. Conceptually, the field has made great strides recently, and the “half-life” of this type of training information is quite limited.
CONCLUSIONS:

None of the materials reviewed were developed for the specific audience that had been targeted by the Council.

Several of the items reviewed did indeed have information and ideas that would be of use in a new document prepared specifically for the target audience, but there is no doubt that a new set of materials is warranted for the target population.

A new curriculum written specifically for use by parents/families with children living in the home would make an original contribution to the field. Special attention needs to be given to topics such as issues of a PAS worker in a family setting, accommodating the issues of "usual" parent/child stresses in adolescents, the questions of whose home it is, etc.
REVIEWS

OF

INDIVIDUAL MANUALS

AND

RELATED MATERIALS

Basic description: This 55 page manual contains a set of handouts for use by trainees. The text is printed in large crisp type with good use of white space.

What is the content focus? The content of the manual is divided into 4 modules: "Having control over my life", "How can personal services help me?" "Getting friends and family to help", and "Getting people to work for me. The modules have lesson plans, with clearly stated goals and objectives, making it the only manual in the set reviewed here with any orientation to competency based learning.

Who is the target audience? The target audience for the materials seems to be adults with physical disabilities who are involved in the independent living movement. The manual is set up for small group instruction, but a consumer with good literacy skills could master much of the content independently.

Does it reflect current and best practices? Best practice is reflected in the careful use of language, and the positive presumption of self-determination and independence.

Does the material specifically refer to:
- parent/family issues? No.
- intellectual impairment issues? No.
- children's issues? No.

What are the strengths? Good materials for training. Good competency based objectives.

What are the weaknesses? No information on children, families, or details on being an employer.
Center for Disability Rights, Inc. 1993. Early to bed/late to rise: An analysis of community-based personal assistance services in Monroe County and New York State. Author: Hilton, NY.

Basic description: A large volume of 199 pages produced in 1993, this is really one of a “white paper” on PAS issues rather than a training manual. Illustrations include very high quality photos of people with a variety of disabilities and crisp graphs and pie charts. The illustrations have reproduced quite well and augment the powerful information in the text.

What is the content focus? Content focuses on public policy issues in PAS, including, as the title implies, the fact that PAS agencies often end up determining a person’s daily schedule including when they get up and when they go to bed. Topics include information on funding streams and system development.

Who is the target audience? I think that the best audience for this material is advocates and policymakers (with and without disabilities) who are interested in systemic issues.

Does it reflect current and best practices? Yes. The content is quite progressive and includes quotes from a variety of people with disabilities. Content refers specifically to empowerment, self-advocacy, and related social movements.

Does the material specifically refer to
parent/family issues? Yes. In a public policy perspective.
intellectual impairment issues? No. Not directly.
children’s issues? No. The focus is on adults.

What are the strengths? High quality information in a pleasing format. Strong social issues orientation.

What are the weaknesses? Short on “how-to” information, not support staff oriented.

Basic description: This is a massive volume of over 300 pages, bound with a “lay-flat” spiral binding that does make it easier to use. The book is divided into 5 modules with index tabs.

What is the content focus? The 5 modules include: the ethical approaches towards working with persons with disabilities; an overview of developmental disabilities and family needs; positive programming for the entire person (PEP; strategies for increasing positive behaviors; and developing an action plan that works in your community.

Who is the target audience? The book is designed to be a manual to train people to work as PAS employees.

Does it reflect current and best practices? Yes. The authors use people first language, stress current concepts of assistant services, support, and self-determination.

Does the material specifically refer to
- parent/family issues? Yes. One module discusses family issues.
- mental retardation? Yes. There is a discussion of the special needs of people with mental retardation.
- children’s issues? Somewhat, in relation to families.

What are the strengths? The book offers a great deal of information all in one place. It is well organized, and relatively easy to use.

What are the weaknesses? There is more detail than many PAS workers will need about all kinds of disabilities. Also, the amount of information all in one place comes at a price - literally. At $37.50, it requires a substantial financial commitment.

Basic description: This volume consists of about 40 pages of text with about a dozen pages of appendices. Illustrations include some very odd cartoons that many people may find offensive. In one panel, a man is carrying a placard that reads: God is Dead. A man in a wheelchair says - “No I’m not!”

What is the content focus? The content focuses on preparing individuals who use PAS supports to take an active role in hiring and supervising their staff. The 10 sections include information on developing a job description for your PAS, how to train them, and how to terminate a PAS relationship.

Who is the target audience? The target audience seems to be people with physical disabilities, with little or no intellectual disabilities. To use the material as written, the consumer will need to have good reading skills, and be able to learn independently.

Does it reflect current and best practices? PAS workers are referred to as “attendants”. In an effort to describe types of assistants (attendants), and consumers, the authors use a number of stereotype characters that some may find offensive. “Attendant character types” include “the mother”, “the drug abuser”, and “the talker”. “Disability character types” (not people) include “The maryter”, “the guilt-maker” and “the scatter-brain”.

Does the material specifically refer to
- parent/family issues? No.
- intellectual impairment issues? No.
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What are the strengths? Some good worksheets on how to figure pay.

What are the weaknesses? There is a small amount of Nebraska specific information that will not apply in other states. Mostly, the material is just dated, and uninspiring.

Basic description: This manual is composed of 30 pages of text with several appendices, and is produced by the Research and Training Center that has produced a number of other materials regarding PAS supports, including one other set of materials reviewed in this report.

What is the content focus? The content focuses on a highly specialized topic, as the title implies: how to create and manage a pool for assistants to be managed by consumers themselves.

Who is the target audience? The target audience is people with physical disabilities who are interested in creating and managing a PAS pool.

Does it reflect current and best practices? The manual does reflect best practices in its language and in the fact that it focuses on a consumer-directed approach to services.

Does the material specifically refer to parent/family issues? No.
   intellectual impairment issues? No.
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What are the strengths? The manual is well written and highly detailed.

What are the weaknesses? The target audience is really quite limited.

Basic description: The main text is 30 pages of rather small type with no illustrations. In addition there are 72 pages of appendices that include reproductions of relevant IRS forms and several state and county (Wisconsin) specific data collection forms.

What is the content focus? The content focuses entirely on the employer/employee relationship. Special topics include the IRS "common law" test for who qualifies as an employer and the obligations of an employer.

Who is the target audience? The target audience is people with physical disabilities who want to be the employers of their Personal Assistants.

Does it reflect current and best practices? Yes, especially in the focus on consumer as employer.

Does the material specifically refer to
  parent/family issues? No.
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What are the strengths? Great detail on the specific topic of employing your own PAS.

What are the weaknesses? Strict focus on employment of your PAS as opposed to directing and controlling your PAS without necessarily being the employer of records. Lack of attention to intellectual disability and home and family issues.
Basic description: This is actually a 4-part package: A Consumer Guide, an Agency Guide, an Appendix, and a Videotape.

What is the content focus? The content of the materials all focus around the issues of recruiting, screening, hiring, supervising, and firing your own PAS worker. The videotape begins with a statement that several of the skills described in the manuals are difficult to master, so the video offers several visual examples of people interviewing, hiring, and supervising their PAS workers.

Who is the target audience?: The target audience for the manuals seems to be people with physical impairments who want to be employers of their PAS workers.

Does it reflect current and best practices? The manuals do reflect the best practice issues of self-determination and consumer-driven services.

Does the material specifically refer to
- parent/family issues? No.
- intellectual impairment issues? No.
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What are the strengths? Strengths include an easy to use video that provides good examples for consumers.

What are the weaknesses? Weaknesses include the fact that the training component is quite weak.
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Independent Living Center: Lincoln, Nebraska.

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