# A Checklist for Evaluating
# Personal Assistance Services (PAS) Policies and Programs

With individualized support…

…people with disabilities can pursue their own life choices concerning…

Assistive Technologies

Transportation

personal relationships

**Personal Assistance**

occupation

education

Housing

involvement in civic life

Good Health Care

Planning & Problem Solving

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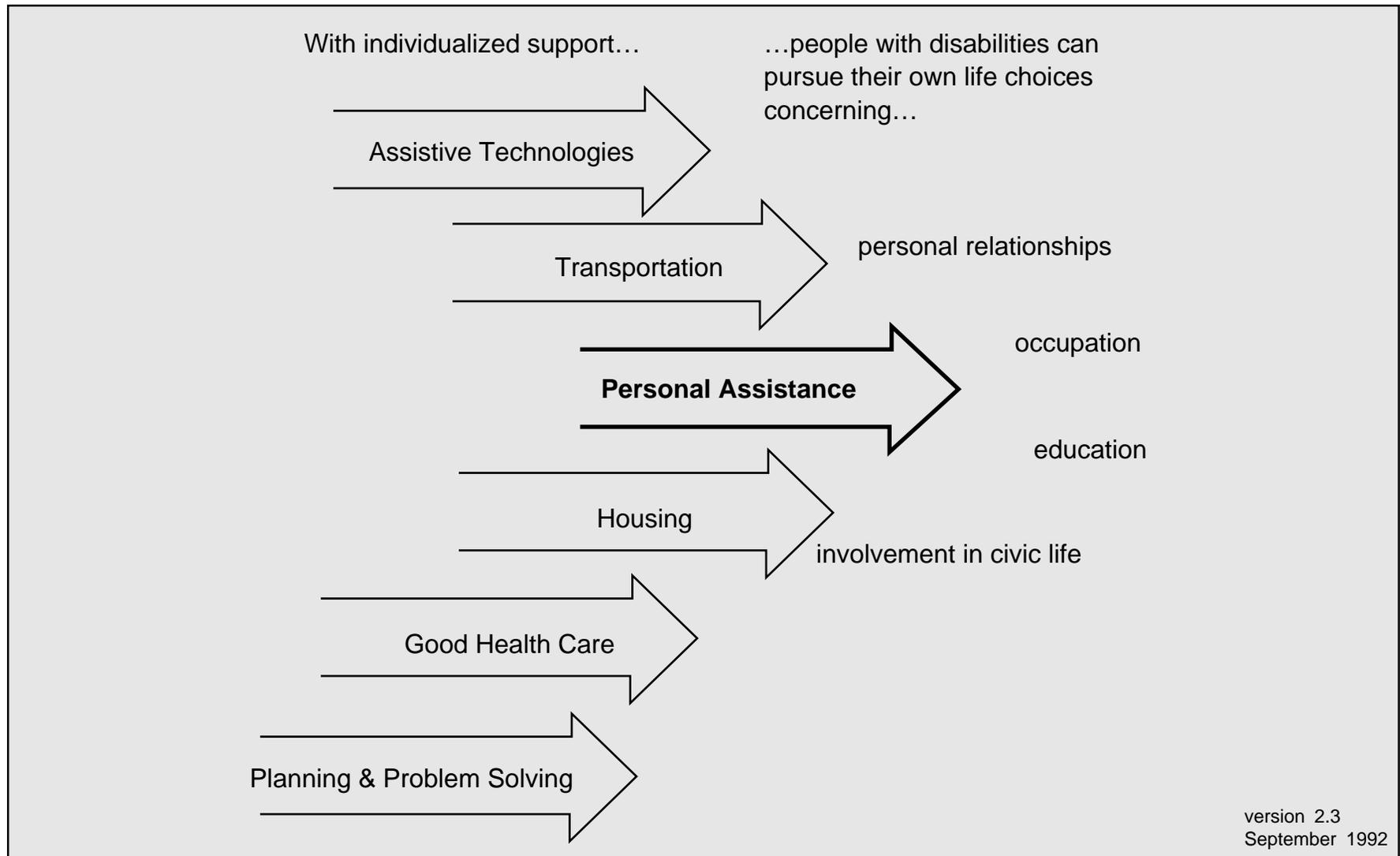
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About the consultants:

**Tony Cordova** directs Able/Disabled, an advocacy group in Augusta, GA. An active member of ADAPT, Tony directs his own system of personal assistance.

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**Gabrielle Nesbitt** is Secretary of Georgia Options, an innovative supported living agency in Athens. GA. Gabrielle has just moved into her own apartment with support from Georgia Options.

**Fred Pinson** is President of the Board of DeKalb Citizen Advocacy and a member of the Georgia State Special Education Advisory Committee. He lives in a nursing home in Snellville, GA because, despite his and his advocates' continuing efforts, he is unable to get the personal assistance services he needs.

Pat Puckett is founder of Creative Pathways in Atlanta, GA. An activist for the rights of people with disabilities and a member of ADAPT, Pat specializes in assisting people with disabilities to develop their own systems of assistance and to advocate for effective public policies.

**Judith Snow** is Senior Associate of The Centre for Integrated Education and Community in Toronto, ON. Judith advocates for effective personal assistance services in her home province and throughout the world. With the support of a circle of her friends, Judith directs her own system of personal assistance, the first individually funded system in Canada.

**Robert Williams** is a poet who works as Policy Associate  for United Cerebral Palsy of America in Washington, DC. With help from his friends and neighbors, he organizes his own system of assistance.

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# Introduction

Effective Personal Assistance Services (PAS) form the foundation for a decent and dignified life for people with significant disabilities and their families and friends. The less effective a community's PAS are, the greater the number of people who will be forced out of their own homes into nursing facilities and other institutions. The less effective a community's PAS, the more people will have to curtail their lives to fit the conditions imposed by available assistance. PAS allow people with disabilities to contribute to other people and to their communities. This reduces the perception that people with disabilities are a burden to society and that services to them are wasteful. It also allows them to enrich the diversity of their communities by their distinctive contributions.

This checklist grew out of a study with eleven people with significant disabilities who live in Georgia. Together with them, we described the way current policies and programs affect their lives (Lyle O'Brien, 1992). The ten point checklist, used by Simi Litvak, Hale Zukas, and Judith Heumann (1987) to assess the extent to which PAS programs fit the values of the independent living movement, was particularly helpful in making sense of the fragmented, under-funded, and ineffective programs now available. As we talked with more people who rely on PAS, and as we read the growing number of statements that refine disabled people's demand for effective assistance (summarized in WID, 1991 and CCD, 1992), the number of dimensions of PAS quality increased.

Effective personal assistance services have three essential qualities. They are…

✓ **Available** to all those who need them on the basis of functional need

✓ **Comprehensive** enough to offer a genuine alternative to living in a nursing facility or other institution

✓ **Controllable** by the people who use them so that they can be tailored to fit individual circumstances

PAS are the key component of individualized supports for people with significant disabilities, but, as the diagram on the cover suggests, they are only one component. PAS effectiveness depends on the quality of the other types of necessary assistance including physically and socially accessible community environments, decent and affordable housing, effective and affordable transportation, good health care, assistive technologies, and good help with the personal planning and problem solving necessary to establish and maintain an individual support system.

Because none of these elements of individualized support is widely available, people with disabilities and their allies need to continue to organize and work for policy changes. We hope that this checklist will help people working for change to describe what's missing in currently available programs and to communicate what is necessary if people with significant disabilities are to take their rightful place as full citizens.

A Note on Terms

• Many people refer to personal assistance services as *attendant care*.

• *People with significant disabilities* is a broad term which includes all people who need personal assistance regardless of the reason for their disability. People can come to need PAS in childhood and as a result of aging. People may need PAS because of physical or cognitive or sensory disability.

• A *system of personal assistance* refers to the whole array of paid for and unpaid assistance a person needs to live safely and with dignity as a full citizen.

• We choose to refer to people with significant disabilities as *participants* in PAS programs; many people prefer to say *consumer.* But under most current programs, people are not consumers in any meaningful sense: they don't have control of the money, they don't have a choice among competing providers, and they are kept from necessary information.

• You can use the checklist to evaluate either PAS policies or PAS programs. *Policies* are the laws, rules, regulations, and budgets that provide the resources for PAS. *Programs* are the particular ways people decide to provide PAS, whether through state agencies, centers for independent living, other agencies, cooperatives of people with disabilities, or direct cash benefits.

References

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World Institute on Disability (1991). *Personal assistance services: A guide to policy and action.* Oakland, CA: Author.

## Availability

| Criteria | ✓ Policy Allows | ✓ Program Provides | If no ✓, describe current reality |
|---|---|---|---|
| ✓ PAS are available to people … <br><br> … of all ages. | | | |
| …on the basis of functional need (not restricted to people with a particular disability label). | | | |
| …of all incomes <br><br> …costs of PAS are shared by people with incomes over 300% of the poverty level | | | |
| …no participant pays more for PAS than 2% of net income after deduction of disability related expenses | | | |
| …no resource test is applied to PAS participants' non-income assets | | | |

| Criteria | ✓ Policy Allows | ✓ Program Provides | If no ✓, describe current reality |
|---|---|---|---|
| ✓ PAS do not create disincentives… <br><br> …to participant's employment. | | | |
| …to participant's eligibility for other statutory benefits and services (payments to participants are not treated as disposable personal income). | | | |
| …to participant's marriage and child rearing. | | | |
| ✓ PAS encourage and supplement the support that is available to participants from family, friends, neighbors, and other community members. | | | |
| ✓ PAS funding comes through a long-term, stable source. | | | |
| ✓ PAS funding provides fair pay and benefits for assistants. | | | |

# Comprehensiveness

PAS provide or enable people to assist participants to perform the tasks they would do for themselves if they were not disabled. More than one person can be involved in providing assistance.

| Criteria | ✓ Policy Allows | ✓ Program Provides | If no ✓, describe current reality |
|---|---|---|---|
| ✓ PAS are negotiated based on individual need, preferences, and circumstances. | | | |
| ✓ The program does not limit the type of tasks that assistants can agree to perform in response to an individual plan. Participants can get the **assistance needed with…**<br><br>…**personal routines** such as getting up, changing position, and going to bed; bathing and personal hygiene;  getting dressed;  eating; using the toilet and carrying out bladder and bowel care; exercising; carrying out ordinary health care routines, including taking medications and injections and ostomy care; and operating and routine maintenance of breathing equipment. | | | |
| …**household routines** such as shopping, planning and cooking meals, doing laundry, doing housecleaning, doing yard work, performing simple household maintenance and repairs, doing daily or routine maintenance of adaptive equipment, and offering hospitality to friends and visitors | | | |

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| Criteria | ✓ Policy Allows | ✓ Program Provides | If no ✓, describe current reality |
|---|---|---|---|
| **…travel** including activities such as escort and mobility assistance, help with using public transit, driving and routine vehicle maintenance | | | |
| **…communication**, including activities like reading, interpreting, writing, and use of communication or telecommunication equipment | | | |
| **…cognitive assistance** with daily planning and scheduling; orientation and routine decision making; maintaining safety; managing money; making sense of everyday situations which are difficult for the person to understand; and routine problem solving | | | |
| **…**assisting parents with disabilities to **raise their children** including feeding, diapering, lifting, and dressing young children, transporting children, and carrying out parental responsibilities such as arranging medical appointments and participating in school activities. | | | |
| **…assuring security** by such activities as monitoring and responding to alarm or alert systems and periodic personal or phone contact | | | |

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| …Comprehensiveness<br>**Criteria** | **✓ Policy Allows** | **✓ Program Provides** | **If no ✓, describe current reality** |
|---|---|---|---|
| ✓ The program provides **emergency back-up** assistants to substitute for assistants who are unable to fulfill their duties. | | | |
| ✓ The program does not limit the location in which participants can get necessary assistance. Assistance is available both in the participant's home and outside the participant's home. As needed, assistants can help the person…<br><br>…at work<br><br>…at school<br><br>…to participate in community life<br><br>…to travel | | | |
| ✓ The program offers as much assistance as the participant needs, at the times the participant needs assistance…<br><br>…Assistance is available up to 24 hours a day, 168 hours a week as needed. | | | |
| …Assistance is available 7 days a week at whatever time of day or night the participant requires it. | | | |
| …The amount of assistance available can increase (or decrease) as the participant's needs change. | | | |

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# Control

The best way to insure that supports are individualized is provide the person who uses PAS with the option to control his or her own PAS for him or herself. A program which makes it easy for a participant to take complete charge of hiring, training, scheduling, supervising, and firing assistants has more options for dealing with situations in which a participant either does not want to assume these responsibilities or apparently cannot assume them.

| Criteria | ✓ Policy Allows | ✓ Program Provides | If no ✓, describe current reality |
|---|---|---|---|
| ✓ Participants have the option of deciding how much direct control they want to exercise over their PAS… …Participant can receive cash or voucher to hire and supervise assistants | | | |
| …Participants can hire a business agent or use an agency as fiscal agent and employer of assistants with the option to control hiring, training, scheduling, supervision, and firing of assistants and budgeting, payroll, and reporting for their personal assistance system. | | | |
| …Participant can use assistants employed, trained, and supervised by an agency. | | | |
| ✓ No medical supervision is required. | | | |

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| …Control… Criteria | ✓ Policy Allows | ✓ Program Provides | If no ✓, describe current reality |
|---|---|---|---|
| ✓ Assistants can perform the same health care routines for participants that the participant would be able to perform for him or herself if the participant were not disabled. This includes administering medications and routine injections, managing a catheter or ostomy, and routine operation of breathing equipment. Participants do not have to engage different agencies or funding sources in order to meet domestic, personal, and routine health care needs. | | | |
| ✓ Participants can choose to provide all training for their assistants. No other training or certification is required by the agency when a participant decides to train his or her own assistants. | | | |
| ✓ Family members can be hired as assistants. | | | |
| ✓ The program provides participants with access to effective ways to learn how to employ, train, and super-vise assistants how to perform daily routines, and how to budget for, schedule, and manage their personal assis-tance system. | | | |
| ✓ The program provides access to an effective way to mediate conflicts and disputes between participants and assistants. Either a participant or an assistant can request this assistance. | | | |

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| Criteria | ✓ Policy Allows | ✓ Program Provides | If no ✓, describe current reality |
|---|---|---|---|
| ✓ The program provides participants with an effective way to exchange information on the performance of assistants. | | | |

Summary of program strengths (**+**) and weaknesses (**-**)

Summary of policy strengths (**+**) and weaknesses (**-**)