



Community Living Briefs

A publication of the Community Living Exchange Collaborative at ILRU

“Community Living Briefs” is a resource for Real Choice Systems Change grantees and their stakeholders, which provides practical tools and strategies to facilitate the full integration of people with disabilities into the mainstream community.

Framework for Building State Level Personal Assistance Services Infrastructure

by Melissa Wittman and Lee Bezanson

Personal assistance services (or “PAS”) are the hands-on support that people with disabilities use to participate more fully in community living. These services are related to personal care that people would do for themselves if not for a disability—such as bathing or showering, eating, dressing, getting in or out of bed or a chair, using the toilet, housekeeping, and shopping; within the social service world, including the Medicaid Home and Community-based waivers, these personal care services are known as Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs). Personal support services allow individuals who use them to live independently, pursue a career, attend school and be active citizens in their communities.

Each state offers a variety of personal assistance services for people with disabilities. Services are funded through a combination of Medicaid, Medicare, state- or locally-funded programs and privately paid arrangements. The delivery of, eligibility for, access to, and coverage of these services illustrate a complex infrastructure of disparate programs and services. However, states currently have access to a number of federal grants available to reduce this complexity and to develop services resulting in greater community inclusion. These grants include the Medicaid Infrastructure Grants (MIG); Benefits Planning, Assistance & Outreach (BPAO); Community-integrated Personal Assistance Services (CPAS); Real Choice (RC); and Direct Service Worker (DSW) grants. The collective work of these

resources reveals the magnitude of the challenge states face in developing a policy vision that is comprehensive enough to make high quality personal assistance services available to the extent needed and in the setting best suited to consumer choice and individual preference.

States also have access to the experiences and promising practices of their policy colleagues across the country through a number of technical assistance networks such as the National Consortium for Health Systems Development (NCHSD). This network of Medicaid Infrastructure Grantees has developed a tool to help identify the key elements of a comprehensive system for personal assistance supports—and provide a structure to begin addressing the numerous issues raised by each element.

This tool, called the PAS Framework, is designed to encourage broad dialogue—resulting in a more comprehensive approach to improving existing services, a decrease in the service gaps for people wishing to live and work in the community, continuing identification of relevant policy barriers to full community inclusion and an increase in consumer-directed supports. The PAS Framework can help policymakers identify critical issues for consideration as they partner with the community to implement a vision for the future. Some uses for the tool include:

- Conducting a self-evaluation for measuring personal assistance strategies and accomplishments
- Setting personal assistance service policy goals and benchmarks
- Analyzing service gaps across programs and agencies



- Planning a more comprehensive needs analysis
- Ensuring inclusiveness in the policymaking processes for system analysis and development
- Identifying performance monitoring and evaluation needs

The Community Living Exchange Collaborative at ILRU, a technical assistance provider to the Real Choice Systems Change grants, has partnered with NCHSD to work collaboratively on some of the more challenging policy issues facing grantees. In support of this collaboration, the Exchange is pleased to present the PAS Framework. We hope this tool will facilitate the work of all the grantees.



Framework for Building State Level Personal Assistance Services Infrastructure

Elements: Specific issue areas related to the provision of a comprehensive PAS system of supports for workers

Goals: Stakeholder-identified statements about desired service provisions

Questions to Consider: Targeted questions to inform whether goals are being met

Element	Goal*	Questions to Consider
ACCESS: What services exist?		
Location of Service Provision (State Plan)	Services are available inside and outside the home in any community setting.	<ul style="list-style-type: none"> • Are there limitations to the settings in which services are offered? • Are services available inside the home only? • Are services available at the worksite?
Location of Service Provision (Home- & Community-based Waivers)	Services are available throughout the state, both inside and outside the home in any setting.	<ul style="list-style-type: none"> • Are services available statewide? • What geographical limitations are there to the availability of services? • Are there limitations to the settings in which services are offered? • Are services available at the worksite?
Cost-sharing Mechanisms	Premiums, co-pays, and other cost-sharing obligations are affordable and equitable.	<ul style="list-style-type: none"> • Are cost sharing obligations a barrier to obtaining services? • Have program staffs conducted a fiscal impact analysis of the impact of cost sharing obligations? • Do program personnel and other decision makers understand the fiscal impact of the existing structure and proposed changes?

NOTE: Light blue shading indicates elements and goals based on full eligibility for Medicaid Infrastructure Grant (MIG) funding.

*These are examples of possible goals—actual goals would be determined by each state.

Element	Goal*	Questions to Consider
ACCESS: What services exist?		
Program Entry	Entry points to access services are clear to consumers and other stakeholders.	<ul style="list-style-type: none"> • Do program staffs understand where, how and to whom PAS services are offered within the state? • Are consumers aware of entry points for services? • Are consumers provided information about services available to support employment?
Community Living & Inclusion	State policies and procedures support individuals to live, work and play in their communities and maximize their use of the communities' natural supports	<ul style="list-style-type: none"> • Has the state embraced the broader community through education and outreach on disability issues? • Does the state maximize use of informal and natural supports available in local communities? • Has the state conducted education and outreach to eliminate old stereotypes, including medical model stereotypes, about individuals with disabilities?

Element	Goal*	Questions to Consider
ELIGIBILITY: Who qualifies for services and how is the determination made?		
Population Served (State Plan)	Services are provided to all individuals without regard to type or level of disability.	<ul style="list-style-type: none"> • What limitations are there to the populations served? • Are services only provided to individuals with certain disabilities? • Are services only provided to individuals requiring a certain level of care?
Eligibility Categories Covered (Waivers)	Medicaid Buy-In enrollees are automatically financially eligible for waiver services.	<ul style="list-style-type: none"> • Do all waivers include the Medicaid Buy-In as a covered eligibility category (if the state has a Medicaid Buy-In)? • Is cost-sharing under waiver programs a barrier for Buy-In enrollees?
Functional Assessment	Functional assessments use objective, need-based criteria to identify PAS needs and intensity of services	<ul style="list-style-type: none"> • Does the assessment take into account work-related needs? • Do limitations on the amount of services authorized based on ADL/IADL or Level of Care needs interfere with consumers' employment goals? • Does the assessment gather information useful in assessing different types of disabilities, including psychiatric disabilities?

Element	Goal*	Questions to Consider
ELIGIBILITY: Who qualifies for services and how is the determination made?		
Functional Assessment (continued)	Functional assessments use objective, need-based criteria to identify PAS needs and intensity of services	<ul style="list-style-type: none"> • Is physician or nurse authorization required? • Is the consumer, or his/her representative when desired, involved in the assessment and service planning process? • Is the same agency or provider that conducts the assessment also responsible for providing services (raising conflict of interest issues)? • Are there any barriers to the appeals process for consumers who want to challenge assessment results?
Program Entry	The eligibility process maximizes consumers' access to services through the appropriate program.	<ul style="list-style-type: none"> • Are eligibility criteria coordinated across different programs in different administrative homes (VR, DHS, Medicaid, etc.)? • Is there a simplified application process for PAS across agencies/programs?

Element	Goal*	Questions to Consider
ADEQUACY: Is the service available in ways that support workers' employment goals?		
Hours of Service Available (State Plan)	Services are available (without caps) for 40 hours/week or more.	<ul style="list-style-type: none"> • How many hours per month are services offered? • How many hours per week are services offered?
Hours of Service Available (Waivers)	Services are available for 40 hours/week or more.	<ul style="list-style-type: none"> • How many hours per month are services offered? • How many hours per week are services offered?
Sufficiency (Waivers)	Waivers have adequate funding.	<ul style="list-style-type: none"> • Are waiver services available to individuals who need them? • Are eligible consumers on waiting lists?
Consumer Control	Consumers exercise the level of control they desire over their own services.	<ul style="list-style-type: none"> • Do consumers have the option of controlling their services? • Do programs maximize the number of consumers directing their own services? • Is technical assistance available to consumers as needed in hiring, managing, and training their assistants?

Element	Goal*	Questions to Consider
ADEQUACY: Is the service available in ways that support workers' employment goals?		
Consumer Control (continued)	Consumers exercise the level of control they desire over their own services.	<ul style="list-style-type: none"> • Are state training or certification requirements consistent with consumers' needs and choices? • Have liability issues been addressed?
Personal Assistance Workforce	An adequate, qualified workforce of personal assistants is available and accessible.	<ul style="list-style-type: none"> • Are there enough personal assistants in the workforce to meet consumers' needs? • Do personal assistants have access to health care/benefits they need? • Are personal assistants able to provide services at the workplace (logistics)? • Do state training or certification requirements prevent qualified workers from entering the field? • Are mechanisms in place, such as registries, to facilitate consumers' access to qualified assistants? • Are family members eligible to be paid assistants? • Do reimbursement rates support adequate pay for assistants? • Are pay rates comparable to those offered in other states? • Is premium pay available for "off hours"?
Affordable & Available Workers Compensation	Workers Compensation is readily available and affordable for consumer employers; the state's approach to workers' compensation for direct service workers does not jeopardize the consumer employer.	<ul style="list-style-type: none"> • Do the state workers compensation laws explicitly address direct service workers hired by consumer? • Do any of the state's workers compensation laws or policies jeopardize the consumer by creating new risks (i.e. risk to maintaining homeowners insurance)? • Has the state reviewed Best Practices nationwide and evaluated the need for modifications to its workers compensation laws and policies? • Is workers compensation readily available and affordable? • Do consumers have good information about workers compensation requirements and the process to access insurance?

Element	Goal*	Questions to Consider
ADEQUACY: Is the service available in ways that support workers' employment goals?		
Employer Responsibilities	Employers comply with reasonable accommodation responsibilities.	<ul style="list-style-type: none"> • Are employers aware of reasonable accommodation guidelines? • Are employers in compliance with reasonable accommodation guidelines? • Has the state developed information explaining publicly funded services versus those defined by reasonable accommodation?
Disability Group	Services are appropriate to meet the needs of people with different disabilities.	<ul style="list-style-type: none"> • Has the state identified different service configurations for different eligibility groups? • Do available programs and services reflect different needs of eligibility groups?
Program Services	Consumers receive the type and amount of services they need to meet their employment goals.	<ul style="list-style-type: none"> • Do the services provided meet the needs of workers with disabilities, including issues like transportation? • Are available hours sufficient to meet the consumer's work-related needs?
Collateral Impacts	State policies maximize earnings and assets consumers may retain when they return to work	<ul style="list-style-type: none"> • Are the state's disregard policies as generous as permissible in support of individuals with disabilities who choose to work? • Has the state made a thorough analysis of the impact of work on other program benefits individuals may be receiving, including Section 8 housing, food stamps, etc.?

Element	Goal*	Questions to Consider
POLICY DEVELOPMENT: What is the process for developing policy?		
Inclusive Process	Policy decisions are made with input from people with disabilities and their representatives.	<ul style="list-style-type: none"> • Does the program facilitate consumer and other key stakeholder involvement in the policymaking process? • Are program staffs able to identify key issues of concern and challenges related to services for workers with disabilities? • Does the program employ people with disabilities as advisors, consultants, program designers and trainers?

Element	Goal*	Questions to Consider
POLICY DEVELOPMENT: What is the process for developing policy?		
Inclusive Process (continued)	Policy decisions are made with input from people with disabilities and their representatives.	<ul style="list-style-type: none"> • Is preference given to people with disabilities and organizations of people with disabilities in awarding grants and contracts? • Does the program conduct on-going meetings with people with disabilities and consumer groups? • Are people with disabilities involved with program design, delivery, and continuous improvement?
Developing Partnerships	The program actively partners with other agencies and organizations to meet PAS goals.	<ul style="list-style-type: none"> • Have program staffs built relationships between agencies and organizations relevant to PAS issues for workers with disabilities? (e.g. Medicaid, VR, Independent Living Centers, Olmstead initiatives, Real Choice projects, New Freedom initiatives, etc.) • Do agencies and organizations work together to coordinate and maximize PAS resources?

Element	Goal*	Questions to Consider
PERFORMANCE MONITORING/EVALUATION: What is in place to assess the need for, availability & quality of services?		
Performance Monitoring System	Program administrators have a plan for gathering, analyzing and reporting information to monitor the availability and use of PAS.	<ul style="list-style-type: none"> • Has a comprehensive monitoring plan been developed? • Have appropriate performance indicators been identified? • Do the PAS performance benchmarks encompass all the dimensions of service provision, including access, availability, quality, and site of service? • Are processes in place to provide ongoing feedback to policy decision makers about access, availability and quality? • Do people with disabilities and other stakeholders participate in all aspects of the performance monitoring system?

Element	Goal*	Questions to Consider
PERFORMANCE MONITORING/EVALUATION: What is in place to assess the need for, availability & quality of services?		
Data & Data Systems	Program administrators have access to needed data to conduct an on-going assessment of the performance of PAS.	<ul style="list-style-type: none"> • Do available information systems have indicators that can measure and monitor work-related needs and service utilization in the workplace? • Are data available to monitor access, availability and quality of personal assistance services? • Is data capacity adequate? • Are data sharing agreements in place to meet performance monitoring goals? • Are data collection methods adequate and appropriate to assess consumer experience and satisfaction with PAS?
Consumer Satisfaction	Consumer feedback and satisfaction are an integral part of the performance monitoring system.	<ul style="list-style-type: none"> • Are processes in place to collect consumer experience and satisfaction with PAS services? • Are data collection methods appropriate for monitoring consumer satisfaction with PAS over time? • Are efforts to obtain consumer feedback about PAS reaching all consumers in the target population? • Are consumer appeals regarding service denials monitored on an on-going basis?

About the Authors

Melissa Wittman is the Project Director for the National Consortium for Health Systems Development (NCHSD), a partnership of state health policy makers, consumers, legislators and other interested stakeholders working together on policy issues related to supporting competitive employment opportunities for persons with disabilities. In collaboration with the Medicaid Infrastructure Grant projects across the country, NCHSD functions as a national forum for learning,

dissemination and technical assistance in the area of work incentives initiatives. NCHSD was established in March 2001.

Prior to directing the Consortium, Ms. Wittman provided policy analysis for Wisconsin's work incentives project. She has technical experience with state and federal work incentives regulations and legislation, developing federal waivers and designing Medicaid buy-in programs. Her past and present work also includes strategic planning, policy development and program implementation.

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Lee Bezanson is Associate Research Professor at the Boston College Graduate School of Social Work, the Director of the Community Living Exchange Collaborative: A National Technical Assistance Program Clearinghouse, and a member of the management team for the Exchange at ILRU. She provides technical assistance to state and Independent Living Center Systems Change Grants for Community Living grantees with a focus on consumer-directed initiatives and model community approaches to systemic change in the

delivery of supports to individuals with disabilities and chronic illnesses.

Ms. Bezanson is a co-author of the three-part series, “Making Accessibility Real: A Guide for Planning Meetings, Conferences and Gatherings.” Ms. Bezanson was formerly the National Project Director of the HCBS Resource Network and served as Co-chair of the HCBS Resource Network Board. Ms. Bezanson is a former Medicaid Director for the State of New Hampshire.



Community Living Exchange Collaborative at ILRU

On September 28, 2001, the Centers for Medicare and Medicaid Services (CMS) awarded two grants for the implementation of the National Technical Assistance Exchange for Community Living, one to Independent Living Research Utilization (ILRU), a program of The Institute for Rehabilitation and Research, the other to the Center for State Health Policy (CSHP) at Rutgers University. The goal of the grants is to provide, in collaboration, a program of technical assistance for

grantees implementing programs under the CMS National Community Living Initiative. The views expressed in this publication do not necessarily represent the position of the funder.

Community Living Exchange Collaborative at ILRU directs its support toward systemic changes to enable children and adults of any age who have a disability or long-term illness to live as fully integrated as possible in the community, to exercise meaningful choices about any and all aspects of their lives, and to obtain quality services consistent with their preferences.



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