



**Participant Direction During Difficult  
Budget Times:**  
A Toolkit for State Policymakers and Advocates

June 2010

## Background

States are struggling with extraordinary budget deficits. In some states, major budget shortfalls are leading to serious consideration of large cuts in programs and services, including participant direction. To respond to this reality, the National Resource Center for Participant-Directed Services (NRCPDS) has worked with state partners, advocates, and program participants to identify key budget concerns that put participant direction at risk. This Toolkit is intended to serve as a resource for informing decision-making during these difficult times.

### This Toolkit Includes Three Parts:

1. A **Budget Myths Chart** that highlights common myths, counter-arguments, and important facts to make your case. Just click on the fact for more information and access to helpful resources.
2. **Helpful Tools to Make Your Case** suggested by policymakers and advocates. This section includes links to personal stories, reports on involving program participants, and “op-ed” information.
3. A full listing of the **Important Facts to Know** for those who would rather review the list directly rather than review the chart.

Want to share your experiences fighting proposed budget cuts to participant-directed programs?

Contact the NRCPDS and let us know how you did it:  
[info@participantdirection.org](mailto:info@participantdirection.org)

## Budget Myths Chart

| Budget Myth   | Counter-Argument   | Important Facts to Make Your Case   |
|---|--|---|
| <p>Participant direction is growing too fast to be sustained in difficult economic times</p>  | <p>Participant direction (PD) is growing across the country, and with good reason. Not only is there a federal mandate to provide options for community-based long-term care, but PD can be a cost-efficient way to manage a finite budget while respecting each person's individual preferences.</p>                      | <ul style="list-style-type: none"> <li>✓ People want to live in their community. <a href="#">More</a></li> <li>✓ There are federal mandates to provide access to community-based options. <a href="#">More</a></li> <li>✓ Eliminating community options will increase costs. <a href="#">More</a></li> <li>✓ People want the option to direct their own long-term services and supports, and they have positive outcomes when given that option. <a href="#">More</a></li> <li>✓ Empowering people through participant-directed individual budgets is cost-efficient. <a href="#">More</a></li> <li>✓ PD can support people to work and volunteer, leading to additional benefits for the individual and community. <a href="#">More</a></li> </ul> |
| <p>Participant direction should be targeted to only those who are at immediate risk for nursing home admission. Others will find support elsewhere, and we can save money</p> | <p>PD is an appropriate option for people with many different levels of ability. It can allow people to live their lives as they prefer and strengthen the quality of the services they receive. It is also cost-efficient and can reduce caregiver burnout, which can have immediate and long-term cost implications.</p> | <ul style="list-style-type: none"> <li>✓ People want the option of directing their own long-term services and supports, and they have positive outcomes when given that option. <a href="#">More</a></li> <li>✓ Empowering people through participant-directed individual budgets is cost-efficient. <a href="#">More</a></li> <li>✓ PD can minimize caregiver burnout, thus decreasing the risk of nursing home admission down the road. <a href="#">More</a></li> </ul>   |

| Budget Myth   | Counter-Argument  | Important Facts to Make Your Case  |
|---|---|--|
| <p>We need to focus on economic growth and job development first and foremost</p> | <p>As with all home and community-based service options, PD creates new job opportunities, a key factor to economic growth. What makes PD unique is that it provides employment opportunities for individuals who may have otherwise never considered the profession until their friend or loved one needed assistance. PD can also benefit family caregivers who are at risk of financial losses or a loss of employment resulting from their caregiving. In addition to benefiting the job market, participant-directed individual budgets can actual enhance individuals' purchasing power by putting purchasing decisions in the hands of individuals to buy goods and services within their local community.</p> | <ul style="list-style-type: none"> <li>✓ PD creates new opportunities within local communities to employ people who may otherwise not be employed. <a href="#">More</a></li> <li>✓ PD can support people to work and volunteer, leading to additional benefits for the individual and the community. <a href="#">More</a></li> <li>✓ When people have the opportunity to direct their own budget, they can use that money to purchase goods and services within the local community. <a href="#">More</a></li> <li>✓ Participant direction can help ease financial burdens individuals face as caregivers. <a href="#">More</a></li> </ul> |
| <p>Fraud runs rampant in participant direction</p>                                | <p>Research indicates that fraud is no more of a concern for PD than it is for traditional agency services. In both cases, quality management systems are used to prevent fraud. PD is an efficient model in its own right: By directly linking services and supports to each person's needs and preferences, it promotes expedient service delivery.</p>   | <ul style="list-style-type: none"> <li>✓ Research indicates there is no increased risk of fraud within participant-directed programs. <a href="#">More</a></li> <li>✓ Quality management systems for participant-directed services are well-established. <a href="#">More</a></li> <li>✓ Financial management procedures for participant-directed services can monitor and address potential fraud. <a href="#">More</a></li> </ul>  |
| <p>Participant direction costs more</p>   | <p>Some people assume that putting individuals into the driver's seat to choose how they receive services and supports will lead to higher costs. With a well-designed PD program, providing high quality services can actually cost the same as traditional agency services and may even cost less due to lower administrative costs and less use of expensive Medicaid services.</p>  | <ul style="list-style-type: none"> <li>✓ Eliminating community options will increase costs. <a href="#">More</a></li> <li>✓ Empowering people through participant direction is cost-efficient. <a href="#">More</a></li> </ul>   |

## Helpful Tools to Make Your Case

### Personal Stories

Personal stories can help to make clear the impact of budget cuts on program participants. A sample of personal stories is provided below.

- Cash & Counseling participants- [cashandcounseling.org](http://cashandcounseling.org)
- A Day in the Life of Richard Decyleder- [Video](#)
- A blog site for personal stories hosted by the national disability rights grassroots community ADAPT- [Defending Our Freedom Blog](#)
- A short documentary of people in California gathered at the State Capitol to assert their human and civil rights and protest proposed budget cuts to services- [Video](#)

### Involvement Methods

Involving program participants in difficult discussions early on may help in the identification of solutions to budget cuts. Helpful reports are provided below.

- How to Involve Advocates and Reach Key Audiences- [Self-Direction Handbook, Appendix 1](#)
- More Can Be Done: Involvement of Older Consumers in the Design, Implementation and Oversight of Home and Community Based Services- [Report](#)
- When C-PIGS FLY: Meaningful Consumer Involvement in Systems Change- [Video & Report](#)

### Opinion Articles and Letters to the Editor

Opinion articles (also called “op-eds”) can be an effective way to communicate your message in state and local media outlets. They must be timely, concise (about 700 words) and focus on one point. In this case, the point would be about the value and cost-effectiveness of participant-directed programs.

You can also write letters to the editor in direct response to an article or editorial concerning participant direction. These letters should be written immediately (either the same day or next day) upon publication of the article. They should be about 100 to 200 words. [This letter](#), recently published in the Wall Street Journal, is an excellent example.

*NRCPPDS Members can [contact the NRCPPDS](#) for assistance writing opinion articles and letters.*

## Important Facts to Know

- ✓ **People want to live in their community.** People with disabilities and those who are elderly overwhelmingly prefer home and community-based services to living in a nursing home. In an alarming [1997 study](#), patients were asked their willingness to live in a nursing home and 26% of patients were “very unwilling” and 30% would “rather die.” In a [2007 Kaiser survey](#), 81 percent preferred a community setting.
- ✓ **There are federal mandates to provide access to community-based options.** The [Olmstead vs. L.C. & E.W.](#) Supreme Court Decision recognizes that community support should be provided in lieu of facility care when appropriate. In addition, advocacy efforts have led to passage of the Americans with Disabilities Act, the Deficit Reduction Act, the Reauthorization of the Older Americans Act, and more recently Community First Choice and the CLASS Plan in the Patient Protection and Affordable Care Act. Each calls for community access, and several recognize participant direction as a viable method for providing that access. Faced with budget cuts, some states are making decisions to significantly reduce or even eliminate community-based programs, including participant direction. These decisions are being argued to violate federal law, resulting in costly law suits ([Testimony](#)). In a [May 2010 letter](#) to State Medicaid Directors, the Centers for Medicare and Medicaid Services encouraged states to address the ADA and the Olmstead decision while providing tools to assist them to do so.
- ✓ **Eliminating community options will increase costs.** The population of people with disabilities is growing and people with chronic conditions are living longer ([Urban Institute Report](#)). Targeting Medicaid home and community-based services that are considered “optional” for budget cuts is a shortsighted approach that will actually cost more money as people enter nursing homes, according to an [AARP report](#). [Data from 1995 to 2005](#) also points to lower overall long-term care costs in states that have “well established non-institutional programs” than those that do not. While some may think that those living in nursing homes have higher needs than those in the community, this is not totally true: People in nursing homes need assistance with an average of 3.9 activities of daily living compared to an average of 3.5 for those receiving home and community-based services ([Testimony](#)). Also, existing housing barriers and waiting lists for community-based services make it extremely difficult for people to leave nursing homes once they are admitted ([KFF Report](#)). [Wiener & Anderson](#) (2009) provide concrete suggestions on how to make more efficient use of home and community-based services to assure the best “bang for the buck,” and one of their recommendations is to implement participant direction.
- ✓ **People want the option of directing their own long-term services and supports and they have positive outcomes when given that option.** In a 1997 survey, AARP found that 76 percent of people 50 and older would prefer to manage their home care services rather than receive agency services, and a [2002 AARP survey](#) found that only 15 percent desired services managed by an agency. Research has indicated that people who direct their own services report less unmet need, higher satisfaction, and higher quality of services when they have this option ([ASPE Report](#), [Health Affairs Article](#), [Gerontologist Article](#) and [Chapter 10 of Costs and Outcomes](#)). The Federal government’s support for participant direction is evident in numerous initiatives, such as Real Choice Systems Change Grants, the Independence Plus Initiative, 1915j Cash & Counseling option under the Deficit Reduction Act, and the more recent Community First Choice component of the Patient Protection and Affordable Care Act. Support for participant direction is also apparent given models that exist in other countries ([AARP Report](#)).

- ✓ **Empowering people through participant direction is cost-efficient.** Providing individuals with control over a budget can allow for well-informed decisions on how to use scarce resources given personal circumstances and needs. Fixed individual budgets with lower administrative costs can also provide predictability to administrators challenged by financial uncertainty ([PMPC Report](#) and [University of Minnesota Research](#)). Costs may increase in the short run, but for good reason: People with previous unmet needs get the services they require ([Health Services Research](#) and [Chapter 10 of Costs and Outcomes](#)). Even so, longitudinal data from Arkansas' Cash & Counseling program documents that participant direction can significantly decrease long-term care and general health care costs as people avoid accessing high cost services, such as hospitals, nursing homes, and home health. By the third year of implementation, Arkansas' Cash & Counseling program (known as IndependentChoices) led to an 18 percent reduction in nursing facility use. [Follow-up cost evaluations](#) have shown that IndependentChoices reduced overall Medicaid program costs while producing more than five million dollars in savings in the first ten years of implementation. Research findings on cost implications of Michigan's individual budget program had similar findings. When adjusted for inflation, participants' costs decreased by 16 percent ([Chapter 10 of Costs and Outcomes](#)). Important lessons learned on how to address short run cost concerns can be found [here](#).
- ✓ **Participant direction can support people to work and volunteer, leading to additional benefits for the individual and the community.** Allowing individuals to directly hire their workers can provide them with the support needed to seek employment or volunteer opportunities ([PAS Report](#)). Not only can increased access to employment lead to financial independence for individuals, it can benefit businesses by creating a larger and less costly worker pool and benefit government through increased taxable earnings and reduced dependency on public programs ([Cornell Report](#) and [Volunteering in America](#)). Volunteering can lead to skill development and positive health outcomes as a result of increased physical, cognitive, and social activity ([University of Minnesota Report](#) and [Johns Hopkins Research](#)). Technology-based individual budget purchases may have indirect benefits as well, such as opportunities for virtually volunteering ([RJK Center](#)).
- ✓ **Participant direction can minimize caregiver burnout, thus decreasing the risk of nursing home admission down the road.** Caregivers spend an average of 20.4 hours a week providing care (almost 40 hours a week when they live with the person). Fifty-three percent of caregivers find caregiving to be highly or moderately stressful ([National Alliance for Caregiving](#)). Caregivers are the largest providers of community-based supports, playing a critical role in containing health and long-term care costs by providing complex support and delaying or reducing nursing home and hospital care ([AARP](#)). Caregivers who are paid have less physical, emotional, and financial strain than those who are not paid ([Cash & Counseling Final Report](#)). Reducing caregiver strain, especially physical strain, can reduce the risk of nursing home entry ([ASPE Report](#), [AARP Report](#), [AARP Report](#)).
- ✓ **Participant direction creates new opportunities within local communities to employ people who may otherwise not be employed.** There is already a significant direct worker shortage and projections indicate a need for an additional 1 million new positions by 2016 ([Direct Care Clearinghouse](#)). Economists recognize job creation at the local level is pivotal to economic recovery ([Brookings](#)). Cutting funding for participant-directed workers will only exacerbate this problem. Not only can increased access to employment lead to financial independence for individuals, it can benefit businesses by creating a larger and less costly worker pool and benefit government through increased taxable earnings and reduced dependency on public programs ([Cornell Report](#) and [Volunteering in America Research](#)). Employed individuals also pay into Medicare and Social Security, assisting with long-term viability for social programs.
- ✓ **When people have the opportunity to direct their own budget, they can use that money to purchase goods and services within the local community.** Not only does participant direction permit people to hire workers who otherwise might not become direct care workers, but access to and control over an individual budget also encourages the flow of money to the local community for the purchase of goods and other services. Research shows that an individual budget authority in Rhode Island led approximately one-third of individuals to purchase goods (e.g., a microwave or a washer machine) and two-thirds or more of

participants with similar authority in Arkansas, Florida, and New Jersey to spend money on flexible purchases beyond hiring workers ([NRCPDS Issue Brief](#)).

- ✓ **Participant direction can help ease financial burdens individuals face as caregivers.** The estimated economic value of unpaid caregivers was \$375 billion in 2007, an estimated increase of \$25 billion from 2006 ([AARP Report](#)). According to a [report from Georgetown University](#), caregiver responsibilities have led to approximately 17 percent of caregivers working fewer hours, 16 percent taking time off without pay, and 8 percent quitting their jobs, all of which have huge implications given this troubled economy. Caregiver health problems resulted in an 8 percent increase in health care costs for caregivers' employers and even more when caregivers were "blue collar" and male employees ([MetLife Study](#)). Through participant direction, individuals can pay caregivers who, as a result of their caregiving, have lost work or financial income. Individuals may also choose to pay workers to provide assistance while their primary caregiver is working, alleviating some of the primary caregiver's conflicting responsibilities. Caregivers who became paid workers had less financial strain than those who were not paid ([Cash & Counseling Final Report](#)).
- ✓ **Research indicates there is no increased risk of fraud within participant directed programs.** Cases of fraud within participant direction have been rare ([Cash & Counseling Brief](#)). Within the Cash & Counseling Demonstration, only 1 of 37 New Jersey counselors interviewed reported *any* incidents of financial exploitation, and that counselor reported only a single incident ([Cash & Counseling Final Report](#)). Even so, it is important to recognize that fraud is possible regardless of the model of service delivery, and because of this, quality management systems must include mechanisms to monitor and address fraud. It is also important to recognize that quality mechanisms within any participant direction program need to be built on the founding principles of participant direction ([Rutgers Discussion Paper](#)).
- ✓ **Quality management systems for participant-directed services are well established.** The National Resource Center for Participant-Directed Services has made a Self-Direction Handbook available free of charge to policymakers to assist them in creating and improving participant direction programs. [Chapter 8](#) of this Handbook provides an in-depth review of a strong quality management system. The Scripps Gerontology Center at Miami University has also developed a useful [Guide to Quality in Consumer Directed Services](#). Additional efforts to "redefine" quality as states move from facility and agency-driven care to participant-driven services can be found in the work of the [Center for Self-Determination](#) and of the [Rutgers Center for State Health Policy](#).
- ✓ **Financial management procedures for participant-directed services can monitor and address potential fraud.** The National Resource Center for Participant-Directed Services has produced a [Financial Management Services Toolkit](#) that provides guidance on financial management procedures for tracking expenditures for both the fiscal/employer agent and agency with choice models. This Toolkit lists financial management requirements, regardless of model, as well as various approaches to meet the requirements and the pros and cons of each approach.



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The National Resource Center for Participant-Directed Services provides research-based technical assistance on all aspects of designing, implementing, managing and evaluating participant-directed programs.