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Perceptions of Difference Between Aging and Disability Service Systems Consumers: Implications for Policy Initiatives to Rebalance Long-Term Care

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This study explores service professionals’ perceptions of how and why older adults and younger persons with disabilities are different consumers and clients within the long-term care service sector. Data are from 2004, early in the history of federal long-term care rebalancing initiatives, reflecting perceptions at that time. Findings suggest professionals working within aging, developmental disability, and physical disability service networks believe significant distinctions exist related to age of clients and nature of service required and how it is delivered. Overall need for greater professional and organizational capacity to support provision of service to both aging and disability populations is reported.

KEYWORDS aging with disability, long-term care, public policy

INTRODUCTION

“Trickle-Down” of the Long-Term Care Rebalancing Policy

The paradigm shift that is restructuring long-term care is nearly a decade old. In 2001, the New Freedom Initiative (NFI; Bush, 2001) mandated federal compliance with the Supreme Court’s ruling in Olmstead v. LC (1999) ordering equity in choice of location of service receipt between community and institutional settings. Since 2001, the federal government has pushed forward deinstitutionalization of long-term care, in large part by moving toward financial parity for home and community-based services (HCBS). The main
federal strategy has employed several sets of waiver and demonstration programs run by the Centers for Medicare and Medicaid Services (CMS) and the Administration on Aging (AOA; e.g., Nursing Home Diversion/Community Living Program, Money Follows the Person, and Aging and Disability Resource Center or ADRCs) to encourage states to restructure Medicaid programs and benefit options, implement single-entry points into long-term care services, support counseling of private pay consumers/clients about HCBS options at hospital discharge, and facilitate collaboration between local aging and disability service networks and the Veterans Administration (See Table 1 for a selected list of initiatives).

This somewhat quiet revolution in long-term care—generically known in the field as systems change—was already in progress in 2001, with about a two-decade history of slowly shifting policies in support of HCBS (Doty, 2010). NFI accelerated this shift, rebalancing programs exemplify this. The new 2010 Affordable Care Act expands existing efforts by establishing Medicare’s Independence at Home demonstration program, Medicaid’s Community First Choice Option, and the State Balancing Incentive Program. It also extends funding for the Money Follows the Person and ADRCs demonstrations. The new long-term care insurance program,

<table>
<thead>
<tr>
<th>Rebalancing initiative</th>
<th>Year introduced</th>
<th>Federal program authority</th>
<th>Target population</th>
<th>Current status as of 2010</th>
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</thead>
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<tr>
<td>Real Choice Systems Change Grants for Community Living</td>
<td>2001</td>
<td>Centers for Medicare &amp; Medicaid Services</td>
<td>Medicaid beneficiaries needing long-term care</td>
<td>352 grants awarded in 39 categories</td>
</tr>
<tr>
<td>Aging and Disability Resource Centers (ADRCs)</td>
<td>2003</td>
<td>Centers for Medicare &amp; Medicaid Services / Administration on Aging</td>
<td>Older adults, people with disabilities</td>
<td>54 states and territories awarded grants</td>
</tr>
<tr>
<td>Money follows the Person (MiCassa)</td>
<td>2005</td>
<td>Centers for Medicare &amp; Medicaid Services</td>
<td>Older adults, people with disabilities</td>
<td>29 states and Washington, DC awarded grants</td>
</tr>
<tr>
<td>Community Living Program (formerly Nursing Home Diversion Grants)</td>
<td>2007</td>
<td>Administration on Aging, Department of Veterans Affairs</td>
<td>Older adults, older veterans</td>
<td>28 states awarded grants</td>
</tr>
</tbody>
</table>

Note. Based on Centers for Medicare & Medicaid Services (2010) and the Administration on Aging (2010).
The Community Living Assistance Services and Supports Act (CLASS Act), equitably pays for HCBS and skilled nursing care—thus is balanced from its initiation (see H.R.3590 at www.thomas.gov for bill text and summary).

State variation and aging and disability professionals as policy implementers. Although all states and territories are under the mandate to comply with the Olmstead (1999) ruling and NFI, some states have not won federal funds to support their rebalancing efforts. Additionally, each state and territory has designed its own response to creating equilibrium between institutional and HCBS, as there is no single federal model for achieving this goal. A recent study of state-based HCBS offerings by Rose, Ejaz, Noelker, and Castora-Binkley (2010) shows that although all 49 states in their sample were actively engaged in rebalancing efforts, a wide range of funding streams and programs were employed to support this work including Medicaid waivers, CMS funded-programs, state-funded programs, state Medicaid plans, and Older Americans Title III funds. Thus, state-to-state variance can be substantial.

In some cases, rebalancing initiatives such as ADRCs have led states to coordinate information and referral databases and share consumer/client information across home and community care agencies within the aging and disability networks. In other cases, states have consolidated long-term care units so that case workers/counselors serve both older and younger Medicaid beneficiaries needing HCBS under a Money Follows the Person grant or through consumer-directed programs. This is compared to workers specializing in service provision to just older adults or younger persons with disabilities. It is not unusual for states to have multiple, distinct rebalancing programs in place—particularly if they have received grant funds from the federal government for specific policy demonstration initiatives (Rose et al., 2010).

Most federal initiatives providing grant funds for rebalancing require at least some collaboration between organizations that serve older adults and younger/middle-aged adults with physical or developmental disabilities. Usually, this is at the administrative level with executives and program directors collaborating in both program development and operations. The intensity of these collaborations ranges from formal agreements using memorandums of understanding to colocating employees in the same unit or project. At this level of implementation, practice professionals (e.g. social workers, occupational therapists, licensed case workers) also carry out rebalancing efforts. And as noted by Kunkel and Nelson (2006), they, in fact, often

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1 This article uses the term consumer/client when referring to individual service users. In this article, this term does not include family care providers as the focus of the discussion is professional perceptions of older adults and younger/middle-aged adults with disabilities. Instead, family caregivers or care providers are directly referenced when the discussion relates to them. Use of joint terminology reflects disparate views of how HCBS populations are commonly referenced. Client is the term typically used within the aging services network. Consumer is the preferred term among most people with disabilities.
bear the greatest load of implementation, adjusting their daily work to incorporate systems change by altering their program designs, work processes, and activities. Thus, both professional administrators and practitioners are key mid-level policy actors in rebalancing initiatives. Direct care workers also carry out rebalancing efforts—as do consumers/clients and family caregivers who engage in service acquisition and provision. However for the purposes of this article, the focus will remain on this mezzo level as the first tier of trickle-down effects of top-down federal policy change.

Implementation “noise” and professional perceptions of consumer/clients needs. The collaboration requirement of rebalancing initiatives has introduced a good deal of noise into policy implementation. Historically, younger/middle-aged adults with disabilities and older adults have been viewed as distinct service populations with unique needs. The impact of this distinction on the formation and operation of aging and disability service networks has been discussed elsewhere (Campbell, 1997, Cohen, 2007, Putnam, 2007). Challenges this has produced for cross-network collaborations include variance in organizational mission, distinctive professional training, competition for program funding, and lack of investment in common goals (Putnam & Stoever, 2007).

Program evaluation of ADRCs (Lewin Group, 2006, 2009), Money Follows the Person (Denny-Brown & Lipson, 2009), and Real Choice Systems Change (Abt Associates, 2008) provide an indication of where this noise may come from. To achieve measurable success, federal authorities have been required to provide substantial professional training and organizational support to their grantees in areas such as working across aging and disability organizations, serving combined populations of older adults and younger/middle aged adults with disabilities, and understanding policy rules and regulations. This suggests that across states, administrative and practice professionals engaging in rebalancing activities enter these projects with different orientations to the work and, in some cases, limited experience working with an integrated HCBS population that includes both older adults and younger/middle-aged persons with disabilities.

Reflections by leaders of Medicaid’s Cash & Counseling demonstration program (a precursor to NFI HCBS initiatives and aimed at testing consumer-directed HCBS models), suggested that the actions of individual administrators and practice professionals who championed the Cash & Counseling program helped lower resistance to shifting in service delivery models (Doty, Mahoney & Sciegaj, 2010). This champion model seems to indicate that shifting beliefs and perceptions of individual professionals play an important role in moving forward systems change.

Investigating contributions of professional perceptions to implementation noise. There is minimal scientific investigation on the perceptions and beliefs of administrative and practice professionals working within aging and disability networks regarding the diverse needs of older adults and
younger/middle-aged adults with disabilities. Rebalancing program regulations require collaboration among aging and disability partners, foci of national grantees, conferences, and events, and technical assistance materials and supports designed to help facilitate partnerships between aging and disability organizations. Collaboration plans between aging and disability partners are evaluated in several pilot award applications, including ADRCs (Administration on Aging, 2009). Additionally, program officials invest substantial technical resources in supporting cross-network collaborations once a grant award is made (www.adrc-tae.org).

Variance in perceptions may affect how professionals carry out rebalancing efforts—e.g., whether they direct an older client to consumer-directed services or suggest a middle-aged adult with multiple sclerosis move into a nursing home—thus perceptions affect the success of policy implementation efforts that depend heavily on mid-level actors. As a means of helping to build an evidence base in this area, I report findings from a 2002–2004 study that examined practice professionals’ perceptions of similarities and differences in service needs between older adult and disability client populations as part of a larger study on cross-network collaborations. Data are previously unpublished, from one state, and collected towards the beginning of rebalancing efforts. However, they can serve as a reference point for understanding how professionals thought and felt about older and younger long-term care service system consumers/clients as systems change began.

METHODS

Sample Procedures and Study Participants

Professionals working with aging, developmental disability, and physical disability service networks in a mid-western state were the sampling framework. Three formal community partners (one from each network) helped identify key informants with experience working on collaborative activities across aging and disability service networks. Snowball sampling was also employed as sample members recommended peers to interview. Prospective participants were recruited by telephone; only one declined participation. Free admission to a statewide preconference workshop on aging and disability was offered as an incentive for participation in the study.

Fifty-seven professionals were interviewed. Each service network was represented in equal proportion. Two-thirds of participants worked in local organizations, one-third at the state level. Participants were affiliates with a wide range of long-term care services including home health care, rehabilitation, nutrition, elder abuse, health promotion, veterans assistance, skilled nursing, assistive technology, social and leisure, adult day, independent living, caregiving, dementia-related, financial planning, home modification, and employment assistance. Participants held professional posts ranging from policy analysts, administrators, clinical practitioners, and consumer...
advocates. Years of experience working within their current service networks ranged from one to over 20 years; all participants had worked for over 5 years in aging or disability service networks. Professional background and training was highly varied. Some participants held degrees related to their current posts, others transferred into current positions from other fields. Most participants had worked in multiple professional roles at different organizations both within their current service network and outside of that network.

At the time of this study (2002–2004), the state this sample is drawn from had in place Medicaid’s 1115 and 1915(c) waiver permitting HCBS options, as well as several state-level disability programs that including various independent living components. However, Medicaid wait lists for HCBS were long, with only several hundred slots available to beneficiaries and funding for independent living services limited. The state was not a recipient of other rebalancing funds (e.g., Money Follows the Person, ADRCs) awarded at that time. Additionally, there were few state efforts to link aging and disability organizations and state budget reductions emphasized controlling all long-term care costs as a means of fiscal restraint. In sum, at the time the New Freedom Initiative was issued in 2001, the conditions of this state were similar to that of other states that were just beginning to address long-term care rebalancing issues.

Interview Procedures and Data

Fifty-five face-to-face and two telephone interviews were conducted at either the participant’s or researcher’s offices using IRB-approved procedures from November 2002 to January 2004. Interviews were tape recorded and transcribed verbatim for analysis. The interview protocol included 30 semistructured questions with three specific to this data analysis: (a) What do service network professionals perceive to be similar and/or different support and service needs between older adults, persons with physical disability, and persons with intellectual disabilities/developmental disabilities? (b) Do professionals and their organizations work with nontraditional consumer groups? Why? Why not? (c) What implications do similarities or difference have for working across aging and disability service networks? Participants were added to the study until repetition in the data was seen within all three service network subsample groups, indicating data saturation. Interviewers compared field notes and transcripts to make this determination.

Data Analysis

Interview data were coded thematically according to constant-comparative procedures (Krueger & Casey, 2008; Ryan & Bernard, 2000; Spencer, Ritchie,
& O'Connor, 2003) using Nu*dist 6.0 software program (QSR International, 2002). The coding team included the investigator and two graduate student research assistants (RAs). The RAs were trained by the investigator in qualitative interviewing and coding and underwent supervised pilot coding exercise prior to analyzing study data. The data analysis process went through several steps. First, the investigator identified a set of codes from the data, adding and refining codes over the course of analyzing the entire set of transcripts. This yielded the initial coding framework. Second, one RA applied this coding framework to a clean set of transcripts also adding and refining codes during the process of analysis. Third, to obtain coding reliability and validity, both sets of coded transcripts were compared and disagreements were discussed until coder agreement was reached. From this, a final coding structure was determined. Fourth, to validate its application, the second RA coded clean copies of all transcripts using the finalized codes. The comparison and discussion process was then repeated among all three researchers for a final assessment of coder equivalency or intercoder concordance (reliability; Padgett, 2008). Then, a thematic audit was conducted by charting code usage across transcripts to examine consistency in the application of codes by coders. No significant discrepancies were found.

FINDINGS

Participants identified three major themes related to consumer similarities and differences that may have bearing on implementation of rebalancing initiatives: the need for differences in service and program aims based on life stage, the variance in nature and delivery of service related to age and disability type, and the lack of professional and organizational capacity to support multiple consumer populations. These themes are described below with exemplary quotes.

Theme 1: The Need for Differences in Service and Program Aims Based on Life Stage

Life stage was identified by study participants as an important difference between older adults and younger/middle-aged adult consumer/client populations. Many participants cited the distinction between individuals in the work-phase and those in a retirement-stage of life. For the most part, the aims of services for younger persons with disability were described as promoting employment and maintaining independence in the community. In comparison, the aims of programs for older adults were also generally seen as fostering independence, however the goal was framed in terms of aging in place or engaging in retirement activities. As an example:
I think there is also the idea that . . . the needs of people with disabilities are the same as senior citizens. Well, we know that's not true for younger people . . . the whole philosophy of independent living is that we want people to get out in the community to work; to have an independent life. Well, for a senior citizen, they are working harder to be able to stay in that home and maintain their independence that way. (Physical disability network professional)

Participants’ emphasis of life stage distinction may be influenced, in part, by historical program criteria or driven by existing policy funding requirements. More than one professional spoke about disability program eligibility requirements that consumers/clients demonstrate improvement of capabilities or attempts to seek employment in order to receive support services. This is not a requirement for older adults using services funded through the Older Americans Act (OAA), but OAA programs also do not provide paid support for personal attendants to help consumers seek or engage in employment activities. An implicit assumption about normative roles and levels of community engagement seemed to resonate across participant comments, surfacing in a second area - family roles and responsibilities.

Many informants indicated that younger people with disabilities had a wider-range of individual and family concerns than older adults—particularly related to spousal/martial and parent/child relationships and financial concerns. One participant described her sense of the anxiety younger/middle-aged adults with disabilities face:

Well, the big thing is, will they keep their jobs? And how are they going to raise their families? Will they be able to play ball with them in 5 years? The financial question is a big one, and the main thing is the medical insurance. If they don’t get the medical insurance, they won’t be able to afford the drugs, which generally run around $800 a month, once you’re advanced. So that’s scary. And will their marriage survive? (Physical disability network professional)

Very few comments surfaced regarding family relations or household issues relating to older adults. This may reflect the larger safety net and social insurance supports available to persons over age 65 (e.g., Medicare, Social Security retirement insurance) and/or beliefs that older adults may have already passed through critical phases of family relations and responsibilities.

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2 The terms many, few, often, and other quantifications of frequency of code/theme occurrence are used in this article in lieu of providing actual counts. This is in alignment with study methods that emphasize gathering breadth of data (understandings) to describe the issue, rather than assessing rank or frequency of identification of issue components. This approach aligns well with the nonrandomized, key-informant sampling model.
Age-Based Interests

Many informants indicated they believed that older and younger adults were interested in doing different types of activities based on their age and life stage. Some informant’s responses seemed to contain stereotypical views of older adults and people with disabilities:

I think what they [younger people] are going to be having an interest in doing is probably going be different than what a 70-year-old woman’s interested in doing. . . . We go to ball games, go to the [theater]. . . . We’re going—instead of playing bingo or playing cards . . . painting.
(Developmental disability network professional)

Others thought more broadly about how consumer/client group might participant in joint activities: “It may start out with something as simple as a game of cards, because that is something that they [older people with developmental disabilities] can be on even footing with them [older adults without developmental disabilities]” (Developmental disability network professional). However, at least one informant suggested a finer distinction that should be made within the older population to represent what she saw as their heterogeneity of interests.

Theme 2: Variance in Nature and Delivery of Service Related to Age and Disability Type

Professionals across all three service networks consistently voiced a belief that service needs of older and younger/middle-aged adults differed in quantitative and qualitative ways. Differences were emphasized to the extent that similarities were rarely spoken about. Specific differences were identified in the areas of information and referral, the breadth or spectrum of support required by professionals, and how supports and services are delivered to clients/consumers.

For information and referral, participants stressed a distinction in the level of experience and capabilities of consumer/clients. Persons aging with disability and their family care providers were considered more adept at seeking information and obtaining supports due to prior experience and duration in these roles compared to older adults and their family members who may be new to long-term care service systems and require more guidance. One participant referenced this:

If you list off two or three things, the [older adult] caregiver is like “Oh my gosh I had no idea.” . . . Whereas with a caregiver for a DD client . . . they typically kind of already know what is going on, and it is more of ‘well this is what I want’ to see happen for my child. (Aging network professional)
However, at least one participant noted that substantially more assistance may be required to help persons aging with development or intellectual disabilities apply for new services:

Hunting down records and stuff on people with disabilities . . . you know, “I need a copy of your social security card and I need a copy of your birth certificate,” . . . because she [the person with DD] has been moved through different systems . . . not all of her paperwork is with her, . . . that’s going to take a little greater effort on, like a social service person’s part to help out. (Developmental disability network professional)

This would be particularly true for individuals with parents who had served as long-term supports but are now deceased or no longer able to perform this role.

Likewise, participants discussed variation in amount or spectrum of support provided to consumers/clients based on disability type and intellectual capabilities. For example, one participant described a sense of the different items a professional must consider when assisting with exercise activities:

People with physical disabilities may really only need to do a physical workout, but they do understand what’s going on. People with developmental disabilities, you’ve got language concerns, you’ve got cognitive concerns, you’ve got actual motor functioning concerns. It’s a much broader range that has to be dealt with. (Developmental disability network professional)

Layered into these issues are different models of service delivery—which study participants described as a distinction between training individuals to help themselves through education and supervision (e.g., learning to cook, more typical for younger people with physical disabilities) and assisting a person in doing an activity or doing it for him/her (providing home delivered meals, assisting with feeding—more typical for older adults). The following statement typifies the way participants discussed this:

Most of the ones [clients with disabilities] that are in our program are fairly independent, or have hypo-severe problems and so they are able to, you know, take care of most of their own needs, so they might need a little supervision here or there, or a little bit of assistance, but some of our seniors need a little bit because they are frail, they need more of an assist. (Aging network professional).
Some participants noted that distinctions in how services are provided to younger/middle-aged and older adults are related to program design and outside of an administrative or practice professional’s control:

The main difference that I can see is that if the person has a physical disability, they may need that service performed for them. . . . Whereas, someone with a developmental disability maybe physically able to bathe themselves but they need training, encouragement and prompting. . . . We do draw a distinction between [them] . . . the service that we put out has to be that hands on service. We [aging service provider] cannot have authorized someone to do personal care just to come and say okay it is time to take a bath, you need to go do that and we will monitor you or whatever, they actually need to be doing the hands on giving a bath service. That is some of the difference that I see between the physically disabled and developmentally disabled. (Aging network professional)

On the occasions that informants did mention similarities in service and delivery needs between older and younger/middle-aged adults, references were made within a global context of understanding the landscape of HCBS but minimized as a basis for shared interests across consumers/clients: “The basic needs we try to fulfill are nutrition, housing, safe housing, medical, of course someone with developmental disability needs all those things too. . . . So there are those similarities, but that is about it.” (Aging network professional)

Theme 3: Lack of Professional and Organizational Capacity to Support Multiple Consumer Populations

Across all three networks, participants suggested that there were factors related to professional and organizational capacity that limited their ability to work with multiple client populations. Overwhelmingly, participants spoke about the absence of training, education, and knowledge among professional administrators and practitioners about how to serve consumers/clients they were less familiar with. For aging organizations, this was usually younger/middle-aged adults with physical or developmental/intellectual disabilities or older individuals aging with disabilities. For disability organizations, the range was wider. For example, this could be persons with impairments/disabilities unfamiliar to them (e.g., an organization for the deaf working with a person with developmental disabilities) or an older adult who had not previously experienced disability.

Most participants tended to present professional and organizational capacity together—defining organizational capacity as having both professionals and programs ready to meet the needs of a broad-based consumer/client population. Some participants expressed concerns related to lack of capacity and what it meant, for particularly for persons aging with disabilities who transition from disability to aging service systems:
I don’t see as much of it happening as there should be [training on how to work with persons aging with developmental disabilities]. . . . I can speak about some of the clients that come in here. . . . What you might have is really elderly parents [with] an adult child who is 60 with a disability . . . wondering how are we going to continue to manage to take care of this person [child] after we are gone. . . . I don’t know where they go from there though. I can only tell you that I know those concerns come through here. But are there places to help the elderly and the disabled elderly population? I don’t know. I don’t think I can give you a real good answer.” (Aging network professional)

Oh, I don’t think we’re ready [aging service providers]. I mean, I think we certainly could handle it, but nobody’s really done any training or obtained information on how you serve that population [people with developmental disabilities] or what the needs and characteristics of that population are and what their service network is. You know, nobody’s done it.” (Aging network professional)

Other participants were not convinced that there was need for specialized training. They felt their organizations already had the capacity to serve a broader consumer/client population:

Dementia is still dementia. There are lots of providers I think, and nursing home providers for example, who do not think that they have the capacity to serve people with developmental disabilities well, but I am not so sure about that. I think that dementia is dementia and so there are associated behaviors and psychiatric issues that may result that really are not so different. (Aging network professional)

Beyond knowledge and skills, many participants expressed concern regarding the financial capacity of organizations to take on broader consumer/client populations (e.g., aging network services folding in younger/middle-aged disability populations, disability network services assisting older adults. Often this related to cost variances in service delivery models that consumers might expect to follow them into a new system:

We did not spend a lot per person [last year]. . . . Within the developmental disability community [providers] spent a lot of dollars per person. . . . I love the model the developmental disability community has as a person-centered plan and it brings a lot of resources around a given individual situation . . . I learned some things from that in terms of trying to involve a broader arena to help the given senior citizen in terms of coping with their situation. But it is also very, very expensive. (Aging network professional)

In the cases of persons aging with disabilities, participants linked fiscal concerns to restrictions in program funding that made it difficult (if
not impossible) to keep individuals consumers/clients enrolled in programs over the long term. For example, as noted earlier, state rehabilitation program funds for personal attendants are usually provided only to individuals seeking employment thus older individuals (with or without disabilities) not seeking work would not be eligible:

Oftentimes you’ve [got] to show that somebody can “improve.” In a lot of cases people with physical disabilities aren’t going to improve. We’re dealing with maintenance issues. . . . You are always supposedly gearing them towards employment when the societal norm in our population you start in your 60s, you’re thinking about retirement. (Physical disability network professional)

Participants wondered where the supplemental funding to support these individuals would come from. Policy change was often mentioned as a solution for improving organizational capacity to meet the HCBS needs of both older adults and younger/middle-aged persons with disabilities.

STUDY LIMITATIONS

As noted previously, these data are from 2002–2004 and capture perceptions of that time. Assumptions should not be made that professional beliefs remain stagnant, particularly as HCBS rebalancing grants have become widespread and new federal initiatives continue to come forward. Additionally, the 57 participants in this study represent only a small proportion of professionals working in the aging and disability service networks in the study state. Existing professional relationships between participants or prior experiences in attempting to work collaboratively may have influenced their responses. It is also possible that order of interview questions contributed to participants’ focus on the differences between older adults and younger/middle-aged adults with disabilities. The question about differences was asked prior to the parallel question on similarities.

Strengths of this study include the diversity of the respondent pool and the in-depth data about the capacity of multiple networks in one region to meet aging and disability population needs in a changing policy environment.

DISCUSSION

Consumer/Client Difference as the Benchmark

As HCBS rebalancing initiatives began, administrative and practice professionals in this 2002–2004 study emphasized that the needs of older adults and younger/middle-aged people with disabilities were distinct. Participants
also indicated that they did not have the expertise to work with multiple consumer/client populations. Moving beyond their respective fields of expertise (aging, developmental/intellectual disability, or disability) would require additional training and organizational supports. At the time, there seemed to be little rationale for broadening programming to include both older and younger adults.

HCBS options are not, in and of themselves, age- or disability-specific. One of the challenges of rebalancing initiatives, however, is that they are overlaid onto age and disability service systems. This is reflected in this study’s findings. For example, participants’ emphasis on life stage as an indicator of consumer/client needs suggests professional investment in age-segmented policies and programs. Their assessment that providing supports and services to clients/consumers can be quite different based on age and disability type follows this line as well.

This assessment is not intended to minimize participants’ professional judgments—they provided case examples derived from professional experience and generally seemed to be offering their best professional assessments. Instead, it offers a window into implementation challenges. These findings are consistent with patterns of categorical eligibility for aging and disability services, as well as with larger socio-cultural norms regarding age-based roles and behaviors (Cohen, 2007). This might raise the question of whether the policy regulations drive professional perceptions or vice versa. Policy and program distinctions have influenced the development of professional expertise and set parameters for client populations and program aims. All of these factors feed back into the refinement of existing and development of new programs and policies for target populations. Thus, study participants’ perceptions about older adults and younger/middle-aged adults with disabilities (cognitive and noncognitive) have substantial merit.

The implementation challenges of HCBS rebalancing may lie in their expectations of (or you could say, the demands they place on) professional administrators and practitioners who might start from a similar position as participants in this study. Rebalancing initiatives ask professionals to suspend their assumptions about what clients/consumers need or want based on age and disability type alone, and to offer a broad range of HCBS options for consumers to choose from. Moreover, some rebalancing initiatives ask professionals to work either with multiple consumer/client populations or collaborate across aging and disability service networks. Thus the ask could be viewed as a request to remove a defining trait from a program’s mission or a professional’s practice. In this case, implementation noise may stem from lack of experience in an other form of service delivery or working with an other group of consumers/clients. This may be a sticking point for professionals. Or, it could be concerns related to loss of organizational and/or professional identity.
Although concerns about loss of identity were not identified by study participants, lack of professional and organizational capacity to provide adequate and appropriate services to multiple consumers/client populations was. Most participants believed that there was a need for additional training and resources if they and their organizations were going to be asked to serve multiple consumer/client populations. This included developing expertise in the area of aging with disability.

At the time of this study (2002–2004), it was generally unclear whether federal rebalancing initiatives would seek to combine consumer/client populations under a unified program umbrella or organizations would be permitted to remain segregated by age and disability eligibility criteria. This may have influenced participants’ responses or heightened their concerns about needing additional supports. The collaborative model has been rolled out by most federal rebalancing initiatives—requiring grant applicants to collaborate with both aging and disability organizational partners in the program designs and leadership plans. This approach permits organizations and professionals to retain their identities, but asks them to build bridges across and within aging and disability long-term care service networks. Thus, some new knowledge might be useful, or even required, but there is less burden to expand professional competency to serve multiple populations. Some states—like the one in which this study took place—have consolidated aging and disability departments into a single HCBS unit. Further research could explore the effects adoption one model over the other for professionals and consumers.

Lessons for On-Going Implementation Efforts

Much to their credit, federal leaders of rebalancing initiatives have paid close attention to the need for professional and organizational technical assistance from the time this work began. ADRC’s have developed a strong model of technical support for grantees (see www.ardc-tae.org). It builds on lessons learned by Medicaid’s Cash and Counseling program which, during its demonstration phase, offered significant support to test sites. Cash and Counseling leaders continue to provide broad support for states and local entities adopting consumer-direction models through the National Resource Center for Participant-Directed Services (see www.CashandCounseling.org and www.participantdirection.org).

Technical supports offered in the ADRC model range from templates for memos of understanding between organizations, to curricula for staff trainings, guides to building consumer advisory boards, and white papers summarizing best practices in program development. Additionally, there are Webinars, regular conference call trainings, and opportunities for one-on-one organizational consultations. Although these efforts are certainly comprehensive, research findings and current demonstration evaluation
data suggest that developing professionals’ competency to work with multiple populations and building organizational bridges across aging and disability networks remain significant challenges for federal grantees (Abt Associates, 2008; Denny-Brown & Lipson, 2009; Lewin Group, 2006, 2009). Future research should investigate the contribution of technical assistance to successful program implementation.

Additionally, although finding and targeting ideological champions to sell rebalancing efforts to their peers, as suggested by Doty et al. (2010) is one strategy to improve policy implementation, it may be more fruitful to undertake more targeted research to ascertain where professionals are stuck in the implementation process and how to most effectively and efficiently move forward in ways that foster professional investment in rebalancing. Experts at the National Center for Participant-Directed Services have identified primary inhibitors to expanding participant-directed services at the state and local levels as lack of understanding and knowledge, lack of participation by those implementing change in developing the change, and absence of leadership buy-in (Gerhard, Sanders, & Sciegaj, 2010). A similar type of investigation into other rebalancing initiatives could provide direction and suggest where new or more intensive technical assistance could be provided to grantees and the professionals working with in the fields of aging, disability, and HCBS in general. Findings from this study can offer baseline knowledge for this work.

CONCLUSION: IMPLICATIONS FOR POLICY IMPLEMENTATION

Efforts to implement rebalancing policies have come with sizable fiscal incentives to support structural transitioning of systems—up to 1.75 billion dollars in federal grants for Money Follows the Person (Wenzlow & Lipson, 2009) and 11.3 million dollars in 2009 alone for ADRCs (Administration on Aging, 2009). It is not clear that permanent federal funding will be offered to support these revised structures or programs. Even the new ACA’s HCBS options function mostly as incentives for change—the Community First Choice Option has a 5-year sunset clause, State Balancing Initiative, ADRCs, and Money Follows the Person are extended only for a few years each. Thus, states and localities will likely need to assume greater responsibility for sustaining and evaluating implementation efforts. The federally based CLASS Act, with its focus on HCBC, could positively contribute to climate change supporting these efforts. As thoughtful as federal officials have been in rolling out and implementing these programs, however, technical assistance alone cannot ensure the widespread investment necessary for sustained systems change. Given the findings of this study, it seems prudent to more deeply explore and address the professional needs and concerns of administrative and practice professionals working in the aging and disability
networks. These local-level implementers will largely determine the success of these policies. In this effort, one would be well-served to remember that rebalancing policies carry forward the aims of the Americans with Disabilities Act and for persons with disabilities (younger and older), success in rebalancing long-term care relevancies an important aspect of efforts to protect their civil rights.

REFERENCES


