Published in final edited form as:

Disabil Health J. 2014 January ; 7(1 0): S51–S59. doi:10.1016/j.dhjo.2013.08.002.

Bridging network divides: Building capacity to support aging with disability populations through research

Michelle Putnam, Ph.D, MGS

Simmons College, School of Social Work

Abstract

Federal and state efforts to rebalance long-term services and supports (LTSS) in favor of home and community-based over institutional settings has helped create structural bridges between the historically separated aging and disability LTSS networks by integrating and/or linking aging and disability systems. These changes present new opportunities to study bridging mechanisms and program related outcomes at national and local levels through federally sponsored LTSS initiatives termed Rebalancing programs. Rebalancing programs also offer opportunities to explore and understand the capacity of LTSS networks (age integrated or linked aging and disability systems) to serve aging with disability populations, persons who live with long-term chronic conditions or impairments such as multiple sclerosis, spinal cord injury, intellectual or developmental disabilities. To date, there is limited evidence-based LTSS program and practice knowledge about this heterogeneous population such as met and unmet need or interventions to support healthy aging. Efforts that center on bridging the larger fields of aging and disability in order to build new knowledge and engage in knowledge translation and translational research are critical for building capacity to support persons aging with disability in LTSS. Generating the investment in bridging aging and disability research across stakeholder group, including researchers and funders, is vital for these efforts.

Keywords

aging; disability; long term services and supports; public policy; bridging

© 2013 Elsevier Inc. All rights reserved.

Correspondence information: Michelle Putnam, Ph.D, Simmons College, School of Social Work, 300 The Fenway, Boston, MA 02115 michelle.putnam@simmons.edu Telephone: 617-521-3956, TTY: 617-521-2489.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Prior presentation: A similar version of this paper was presented orally at the meeting titled "Aging with disability: Demographic, social and policy considerations" organized by the Interagency Committee on Disability Research in Washington, D.C. on May 17-18, 2012.

BUILDING CAPACITY IN LTSS TO SUPPORT PERSONS AGING WITH DISABILITY THROUGH BRIDGING RESEARCH

Programs and policies that provide long-term services and supports (LTSS) to adults in the United States (U.S.) are usually segmented by age of the consumer (18-59 or 64, and age 60 or 65 and older) and nature of disability (e.g. developmental/intellectual, physical, and psychiatric), creating categorical service systems. This historical practice has created silos dividing aging and disability policies, programs, and consumers at federal, state, and local levels into distinct service recipient groups.¹ Categorical segmentation both helped generate and has been reinforced by distinct fields of scholarly research and professional training that respectively build knowledge for, and prepare practitioners to work within, specialized and divided aging and disability LTSS systems.² This silo system has produced age-based theories and conceptual frameworks, bifurcated scientific knowledge bases, parallel fields of professional practice, and system-specific ideologies, vocabularies, and cultures of service delivery that have been described in extensive detail.^{3,4} Elements such as program eligibility, organizational missions of service providers and professional training of their staff, and consumer-identification as either older or disabled all add to the synergy that sustains the silo system.²

But the landscape on which aging and disability silos are built is rapidly changing. Federally sponsored “Rebalancing” program initiatives are actively attempting to break down silos and build structural bridges across aging and disability LTSS networks, particularly targeting Medicaid and Older Americans Act (OAA) programs. Federal Rebalancing program initiatives aim to reduce institutional long-term care use and increase use of home and community-based services (HCBS)^{5,6}, and prioritize community living, a shared value between aging and disability fields of practice, policy, and scholarship. These initiatives contain mechanisms that mandate cross-network collaboration with the aim of reorganizing supports and services into more integrated and coordinated networks. As these bridges take shape, the potential for building new knowledge and supporting knowledge translation and translational research across the fields of aging and disability increases. The need for this type of knowledge bridging is substantial in order to support the needs of persons aging with long-term disability. The growing aging with long-term disability populations includes persons with onset of impairment and chronic conditions in early or mid-life such as multiple sclerosis, spinal cord injury, cerebral palsy, rheumatoid arthritis, traumatic brain injury, developmental or intellectual disability, and oral speech, auditory and sensory limitations.

There is very modest evidence-based program and practice knowledge about LTSS and persons aging with disability. One effect of the silo system has been the reinforcement of specialized practice and research domains that typically focus on either older adults or younger people with disabilities, but not both. Although less age-based models of care and service delivery, such as person-centered care⁷, are being more widely implemented in HCBS programs, few practitioners working within those programs are likely to be trained in both the fields of aging and disability, resulting in limited expertise working across populations. Even for those who have this dual experience, the lack of research relating to

aging with disability and LSS remains problematic, particularly as LTSS professionals tend to think of older adults and younger persons aging with disability as qualitatively different consumers with differing aging-related needs.⁸ Fostering new knowledge development and knowledge translation can help to answer important global questions about providing LTSS to persons aging with disability such as: How does aging with long-term disability differ from aging into disability in later life? What types of LTSS do persons aging with disabilities need that are not currently found within existing aging or disability networks? How can existing LTSS and health and wellness interventions designed for younger adults with disabilities or older adults aging into disability be transferred to persons aging with disabilities? In what areas do new interventions need to be developed? What measures need to be included in administrative and programmatic data collection systems to better capture the disability status and LTSS needs, including assistive technologies, of individuals both aging with and aging into disability at different stages of the life course? What types and levels of professional training are needed to work with aging with disability populations and how might that differ from training and education already provided? and, Which HCBSs are best provided within disability services systems, aging service systems or some combination of both?

BACKGROUND FOR BRIDGING AGING AND DISABILITY RESEARCH IN LTSS

In simple terms, the practice of bridging brings the fields of aging and disability together by creating pathways across fields for sharing existing and developing new knowledge in areas of professional practice, policy, and research.⁹ A definition of bridging aging and disability was recently articulated by the authors of the Toronto Declaration on Bridging Knowledge, Policy and Practice in Aging and Disability:

Bridging encompasses a range of concepts, tasks, technologies and practices aimed at improving knowledge sharing and collaboration across stakeholders, organizations and fields of care and support for persons with disabilities, their families, and the aging population. Bridging tasks include activities of dissemination, coordination, assessment, empowerment, service delivery, management, financing and policy.¹⁰

Structural bridging efforts between aging and disability service systems date back several decades. In their recent review of bridging between aging and developmental disabilities networks, Factor, Heller, and Janicki³ cite several important markers of formal bridging efforts by state and federal administrators. A premier program example of bridging aging and disability is the Cash and Counseling demonstration (1998-2009), which evaluated participant-directed Medicaid HCBS.¹¹ Cash and Counseling was a high profile effort to test use of the disability model of consumer-direction with both older and younger clients. Supported by a private-public collaboration by the Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the United States Department of Health and Human Services (HHS), the Centers for Medicare & Medicaid Services (CMS), Cash and Counseling findings deemed consumer-direction to be a viable program option with successful outcomes.¹¹

Knowledge development and translation efforts have also been building slowly over time across fields of study. Examples include clinical research articulating physiological changes and related assistance needs based on duration of spinal cord injury¹² and accelerated aging¹³, assistive technology research focusing on maintaining function over several decades¹⁴, and research related to supporting individuals with intellectual disabilities and their families over the life course.¹⁵ The National Institute on Disability and Rehabilitation Research (NIDRR) has been a primary funder of this research, supporting Rehabilitation and Research Training Centers (RRTCs) and Rehabilitation Engineering Research Centers (RERCs) on aging with disability.¹⁶ The National Institutes of Health has also supported numerous studies on aging with disability through investigator-initiated research programs. While this funding has supported a growing body of research directly focusing on aging with disability, much of it is specific to individual diagnostic groups. Only a limited amount of scholarship focuses on LTSS need or use across aging with disability populations.

Recently, however, several national and international professional conferences have focused on developing agendas for moving forward work that bridges aging and disability LTSS systems and addresses gaps in program and practice knowledge in response to changing service systems and consumer and client needs.^{10, 17, 18, 19, 20} The bridging mechanisms found in Rebalancing efforts provide opportunities in the United States to engage in some of this work. A brief description of Rebalancing is provided below.

Rebalancing Directives: Legal Leverage for Bridging LTSS Systems

The 1999 Supreme Court ruling in the case of *Olmstead v L.C.*,²¹ known as the *Olmstead* decision, directed that people with disabilities (of all ages) must have access to community-based options for support and service receipt, within certain feasibility parameters. Importantly, President G.W. Bush facilitated implementation of this ruling through the 2001 New Freedom Initiative (NFI), mandating demonstrated compliance by entities receiving federal funds.²² This created a distinct legal lever, which has been used to move structural bridging of services forward through federal Rebalancing LTSS initiatives. However, this legal lever has had little effect on bridging or integrating aging and disability research in LTSS, a point addressed later in this paper.

CMS, in collaboration with the Administration on Aging (AoA), took leadership to implement the *Olmstead* decision within federal LTSS policies through Medicaid and the OAA programs. At that time, LTSS policies were heavily biased toward funding institutional care and the national OAA network of Area Agencies on Aging (AAA's) was challenged to help consumers negotiate the fragmented HCBS marketplace through its information and referral systems. Since 2001, CMS and AoA have continuously offered competitively awarded grants to states in support of initiatives that reduce institutional care use, increase use of HCBS, and improve access to and coordination of HCBS options for older adults and persons with disabilities including those who individuals with public insurance and those paying privately for services. As a part of rebalancing, many states have combined their units on aging and disability into a single government agency.²³ Following this pattern, on April 16, 2012 the United States Department of Health and Human Services announced the reorganization of the AoA, the Office of Disability, and the Administration

on Intellectual and Developmental Disabilities (AIDD) under the umbrella of the Administration for Community Living (ACL)²⁴ with the goal of “increasing access to community supports and full participation, while focusing attention and resources on the unique needs of older Americans and people with disabilities.”²⁵ ACL now is comprised of four units, AoA, AIDD, the Center for Disability and Aging Policy, and a Center for Management and Budget.²⁶

Figure 1 presents a summary timeline of selected LTSS rebalancing programs administered by CMS and AoA. Prior to the NFI, States could obtain Medicaid HCBS waivers through Section 1915(c) of the Social Security Act; thus some states had already initiated the movement towards rebalancing.²⁷ Grantees receiving Rebalancing funds include state and local government agencies as well as quasi- and non-governmental organizations. Funding for Rebalancing initiatives is modest given their overall aims of promoting significant change in the national LTSS system. For example, the total grant outlay for the Aging and Disability Resource Center program since its inception was only \$111 million dollars between 2003 and 2010.²⁸

State Medicaid agencies arguably form the core of the LTSS network funding paying for the majority of publicly funded institutional care and long-term HCBS.²⁹ ACL administers a broad set of LTSS and health promotion programs through titled legislation including the Older Americans Act and the Developmental Disabilities Assistance and Bill of Rights Act of 2000, providing modest funding for these efforts through its extensive national network of over 1000 local state, tribal, and native entities supporting programs for both younger and older adults.³⁰ Nearly 400 Centers for Independent Living, most entitled and funded in part through the U.S. Department of Education, provide additional consumer support services intended to facilitate community living.³¹ Private for and not-for-profit LTSS service and support providers are also constituents of the LTSS network.

Critiques of Rebalancing programs include: concerns about inequitable distribution of program funds, imbalances in power and leadership among aging and disability program partners, and token inclusion and minimal outreach to disability partners by primary grantees.^{3,32} Program evaluations substantiate the need for grantees to improve in these areas.[33] AoA and CMS continue to formally require cross-network collaboration in program guidelines and provide technical assistance to grantees to support it.³⁴ Despite the challenges, Rebalancing programs represent the most concentrated and widespread federal effort to bridge aging and disability LTSS systems to date and they serve as promising pathways to develop knowledge and capacity to meet the needs of aging with disability populations.

EXAMPLES OF BRIDGING ACTIVITIES IN REBALANCING LTSS PROGRAMS

Brief descriptions of two Rebalancing programs and the structural bridging activities they engage in are provided below. Following that is a discussion about the potential to build professional capacity by using these Rebalancing programs as vehicles for research that builds new knowledge and supports knowledge translation efforts. Opportunities to investigate the effectiveness of structural bridging mechanisms themselves are also identified.

Aging and Disability Resource Centers (ADRCs)

ADRC demonstration program grants were first awarded in 2003 and have been authorized through 2016 by the Patient Protection & Affordable Care Act (ACA).³⁵ The ADRC program is principally administered by AoA, but is a collaborative effort with CMS. ADRCs are charged with streamlining access to LTSS for older adults (60 and older) and adults with disabilities (ages 18-59).³⁶ As of 2012, all 50 states and 4 territories are operating or planning ADRCs, 22 have state-wide coverage based on self-reported assessments and across states a total of 416 individual program sites are identified.³⁷ AoA continues to link existing and new programs to ADRCs, seeking to establish them as central nodes in the LTSS network. The two models for ADRCs are: *single-entry point*, where consumers funnel into the LTSS network through a single portal; and the *no wrong door* approach, where consumers enter the network through any public or private organization linked into the ADRC. ADRCs streamline access to LTSS through better coordination of organizational infrastructure, strengthening information technology systems, improving service coordination and tracking, and employing universal intake or shared needs assessment protocols.³⁶ Several states were recently funded to pilot Evidence-Based Care Transitions programs intended to strengthen the role of ADRCs in facilitating consumer decision-making along “critical pathways” of care using evidence-based transition models (e.g. movement from hospital or nursing homes to HCBS³⁸).

Mechanisms for bridging aging and disability LTSS networks are formalized within the ADRC program design. ADRCs are required to have operational partnerships between aging and disability entities.³⁹ The most frequently reported partnerships are between Area Agencies on Aging, Centers for Independent Living and State Units on Aging or state Medicaid units.³³ ADRCs link partners through formal memorandums, contracts, and in many states legislation codifying the ADRC program and its collaboration requirements. Examples of structural bridging tools include integrated information technology systems, universal information and referral databases, standardized information and referral protocols, and co-located professional staff.³⁷ AoA provides extensive technical assistance to ADRC grantees to develop, implement, and sustain their programs through the online Technical Assistance Exchange (TAE) led by the Lewin Group.⁴⁰ Initial challenges to the ADRC program included difficulty in maintaining partnerships, staff turnover and leadership changes, addressing management information difficulties, and development of fully operational ADRC programs⁴¹, however more recent evaluations do not comment extensively on these issues. Help in breaking down the silos that segment aging and disability networks appears to be an area of ongoing technical assistance need.³ Findings based on state's self-reported assessment tool data suggest that overall ADRCs are making positive progress towards the goals³³, but progress varies significantly across states.^{42,43} An evaluation of the overall value of adding an ADRC to local and state LTSS networks is currently being led by Impaq International, LLC with results due in 2014.

Money Follows the Person (MFP)

Money Follows the Person Rebalancing Demonstration Program grants were first awarded to states in 2007 to help identify and transition eligible Medicaid beneficiaries from institutional to community-based care.⁴⁴ The program provides additional HCBS funds for

transitioned persons for one year. MFP has its legislative roots in several state-based initiatives.^{45,46,47} At the federal level, disability rights activists have championed the Medicaid Community Attendant Services Act (MiCASA) first introduced in House of Representatives in 1997⁴⁸ and most recently introduced as the 2009 Community Choice Act. The Community Choice Act permits Medicaid beneficiaries choice regarding where LTSS are provided and essentially makes permanent the options provided through the MFP program. Administered by CMS, 43 states and the District of Columbia currently have MFP programs.⁴⁹ The 2010 MFP Annual Evaluation report completed by Irvin et al.⁴⁴ at Mathematica, found that more than 12,000 people nationally have transitioned to community-based care through MFP. More than two-thirds of these individuals were younger than age 65. This is reported as about one-third of the aggregated number initially proposed by state grantees, who post-funding, readjusted program participation targets based on difficulties in program implementation.⁴⁴ Program outcomes indicated that about 85% of transitioned persons remained in the community for over one year. Improvement of quality of life outcomes for program participants is noted to be important as over one-third of transitioned individuals report barriers to community integration and feelings of low mood, which may suggest the need for additional supports.⁴⁴ MFP has been reauthorized by the ACA through 2016.

A central bridging component of MFP is expected collaboration between state aging and disability units and other stakeholder groups to facilitate successful transitions. Many MFP grantees work with ADRCs to help coordinate transitions. Known implementation challenges for MFP include: finding eligible participants, locating affordable and accessible housing to transition to, securing adequate services in the community, having skilled and dedicated program staff, ability to fund one-time moving costs, and state reductions in Medicaid benefit funding.^{44,50} To help grantees address these challenges, CMS funds both a MFP technical assistance program⁵¹ and a Balancing Incentive Program technical assistance center.⁵² Grantees can also find support through the U.S. Department of Housing and Urban Development's Technical Assistance Collaborative Resource Center on Supportive Housing.⁵³

Capitalizing on Rebalancing Opportunities to Study Bridging and Build Capacity

Within Rebalancing initiatives there is potential to engage in two types of LTSS research that can support bridging – research on capacity to meet the needs of persons aging with disability (knowledge development and translation) and research on the effectiveness of structural bridging mechanisms in dismantling aging and disability silos and creating more coordinated LTSS networks for persons with disabilities of all ages. Table 1 presents examples of what this might look like for three different bridging activities within the ADRC program.

In the first example, a needs assessment is typically one of the first protocols completed when a consumer (or proxy) contacts an ADRC. Most ADRCs have developed electronic shared or universal assessment protocols so that information on individual needs and program eligibilities is readily transferrable across local and state-level organizations participating in the ADRC. This eliminates the need for each service provider to repeat the

assessment and to facilitate a more accurate and accessible record of the consumer's current participation in LTSS programs. One example of knowledge building and transfer opportunities identified in Table 1 focuses on using a shared or universal protocol as a way to capture additional data about persons aging with disability that may be relevant for identifying unique or unmet need. This data could help identify areas where knowledge translation of successful interventions designed for older adults, for example physical exercise programs, might be translated into evidence-based interventions for older adults aging long-term with conditions like multiple sclerosis or Down's Syndrome. Thus the content of the shared or universal protocol could help build capacity in meeting the LTSS needs of persons aging with disability. The protocol also provides an opportunity to study structural bridging by investigating the implementation of the universal protocol and evaluating its effectiveness at integrating or linking aging and disability service systems and LTSS providers.

In the second example, shared databases that hold information generated by both the universal needs assessment protocol and other information that might include service receipt, program participation, and possible outcome information such as health status could be used to assess variability in LTSS service use between persons aging with and aging into disability. This type of information might inform knowledge translation efforts by identifying LTSS that are surprisingly more effective for persons aging with than aging into disability. For example adoption and use of assistive devices may be greater among certain groups of persons aging with disability, like those with spinal cord injury than older adults aging into disability. Outcome data might show lower depression scores for this group compared to their aging into disability counterparts with comparable functional limitations because the assistive technology permits the spinal cord injured group to more actively engage in their desired daily activities. This is speculative, but it is the type of information that could potentially come from a shared database that could inform professionals where to best focus knowledge translation efforts. In terms of investigating structural bridging, assessing the use and capacity of a shared database to produce relevant program participation information, including met and unmet need would yield knowledge about the utility of employing a shared database a bridging mechanism.

GENERATING INVESTMENT IN BRIDGING RESEARCH

Building program and professional capacity to serve persons aging with disability and their families in LTSS and to conduct bridging research should be a high priority for practitioners, policy makers and scholars working in aging and disability fields. Population trends are such that regardless of whether service systems are prepared or not, they will begin to see more people aging with disability contacting them for assistance. If we fail to create strong structural bridges between aging and disability networks, people aging with disability may become lost in the LTSS system, which even as it becomes better coordinated is dauntingly complex. If we fail to develop effective practices for working with people aging with disabilities, these consumers needs may not be adequately or effectively met within our LTSS systems and practice professionals will be left to do the best they can with the skills and program offerings they have available which may not be enough to address growing concerns about health disparities⁵⁴ or ongoing training needs to work with aging with

disability populations^{5,54}. Publications such as this special issue provide an opportunity for aging and disability researchers to form new collaborations and to join together in advocating for more funding opportunities in cross-network LTSS research.

As Washko, Campbell, and Tilly⁵⁵ indicate, federal leadership to both support bridging aging and disability and to move research on aging with disability to practice, is important for building capacity to meet the needs of persons aging with disability. Part of this, however, requires gaining buy-in from researchers and professional practice stakeholders as well as persons with disabilities of all ages, including older adults, and their representative advocacy groups to the idea that bridging aging and disability is a good investment. Obtaining broad-based support for bridging research will require addressing healthy skepticisms held by stakeholders in 1) the ability to create integrated aging and disability LTSS networks that serve younger persons with disabilities, persons aging with disability, and older adults aging into disability equally well; 2) the permanency, meaningfulness, and equity of the structural bridges built through Rebalancing in terms of their ability to be sustained after Rebalancing funding ends, support an ideology of community living shared by both aging and disability fields, and allot both disability and aging organizations equal leadership roles and operational resources; and 3) the capacity of LTSS professionals to have adequate knowledge and training to work with a broad range of consumers including persons aging with long-term disability and their families. These are not small challenges.

Much of the work in the past to encourage bridging has come through advocacy efforts related to political support of LTSS programs and their funding.⁵⁶ Much less emphasis has been placed on building a body of research-based evidence about what works in terms of structural bridging and/or that produces the new knowledge and knowledge translation required to support professional practice in bridged LTSS systems. This lack of focus on bridging research might be attributable in some part to the historical LTSS silo system, which often failed to highlight similarities between aging and disability populations. It is likely also related to a strategic disentangling of stereotypes in both the fields of aging and disability – distinguishing old age from disability and disability from being disengaged – aimed at creating more positive images of aging and the experience of disability in younger life.

Now, however, the fields of aging and disability are beginning to find ideological converges in their interest in community living, a basic belief that people prefer being connected to their normative roles, social networks, and communities rather than being segregated in institutional settings. The shared outcome goal of successful community living may be an important platform that helps support research related to bridging aging and disability in LTSS and shapes a strong trajectory for bridging research. Outcome measures that investigate benefits related to community living are part of the overall evaluation of Rebalancing programs⁵⁷ and help assess the true value of services to individuals and families. They also inform the benefit portion of a cost-benefit equation highly relevant at all government levels in the current fiscal climate. To the extent that investment in bridging work is increased, particularly in the area of research, the silos segmenting aging and disability could be replaced by a more flexible LTSS systems and professional practices that foster innovation and build capacity while working towards this common goal.

Acknowledgments

Financial disclosure: Support for development of this paper was provided by the National Institute on Aging grant no. P30 AG012846 to the University of Michigan and P30 AG034464 to Syracuse University.

References

1. Cohen, E. Social, economic, and political realities of cross-network partnerships and coalitions.. In: Putnam, M., editor. Aging and disability: Crossing network lines. Springer Publishing Company; New York: 2007. p. 91-134.
2. Putnam, M. Moving from separate to crossing aging and disability service networks.. In: Putnam, M., editor. Aging and disability: Crossing network lines. Springer Publishing; New York: 2007. p. 5-17.
3. Factor, A.; Heller, T.; Janicki, M. [2012 Oct 24] Bridging the aging and developmental disability service networks: Challenges and best practices [Internet]. Mar. 2012 Available from: <http://www.rtcadd.org/resources/Resources/Publications/Policy/Service/Briefs-&-Reports/Bridging-Report.pdf>
4. Putnam M. Issues in the further integration of aging and disability services. Public Policy & Aging Report. 2004; 14(1):19–23.
5. Medicaid program: State plan home and community-based services, 5-year period for waivers, Provider payment reassignment, and Setting requirements for Community First Choice (Proposed rule). Federal Register. 77(86):26362–26406.
6. Centers for Medicare & Medicaid Services. [2012 Oct 24] Balancing long-term services & supports [Internet]. No date. Available from: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Balancing-Long-Term-Services-and-Supports.html>
7. Shugarman L. The SCAN Foundations framework for advancing integrated person-centered care. Health Aff. 2012; 31(12):2821–2825.
8. Putnam M. Perceptions of difference between aging and disability service systems consumers: Implications for policy initiatives to rebalance long-term care. J Gerontol Soc Work. 2011; 54(3): 325–342. [PubMed: 21462062]
9. Salvador-Carulla, L. Bridging knowledge and practice between aging and disability.. Paper presented at: Jointly Sponsored Meeting of the Administration on Aging and the National Institute of Disability and Rehabilitation Research; Washington, D.C.. 2012 Apr;
10. Bickenbach J, Bigby C, Salvador-Carulla L, Heller T, Leonardi M, LeRoy B, Medez J, Putnam M, Spindel A. The Toronto declaration on bridging knowledge, policy and practice in aging and disability. Int J Integr Care. Nov 16.2012 12
11. Brown, R.; Carlson, BL.; Dale, S.; Foster, L.; Phillips, B.; Schore, J. [2012 Oct 24] Cash & Counseling: Improving the lives of Medicaid beneficiaries who need personal care or home and community-based services, final report [Internet]. Aug. 2007 Available from: <http://www.mathematica-mpr.com/publications/pdfs/CCpersonalcare.pdf>
12. Jensen MP, Molton IR, Groah SL, et al. Secondary health conditions in individuals aging with SCI: Terminology, concepts, and analytic approaches. Spinal Cord. 2011; 50(5):373–378. [PubMed: 22143678]
13. Groah SL, Charlifue S, Tate D, et al. Spinal cord injury and aging: Challenges and recommendations for future research. PM R. 2012; 91(1):80–93.
14. Wilson DJ, Mitchell JM, Kemp BJ, et al. Effects of assistive technology on functional decline in people aging with a disability. Assist. Technol. 2009; 21(4):208–217. [PubMed: 20066887]
15. Innes A, McCabe L, Watchman K. Caring for older people with an intellectual disability: A systematic review. Maturitas. 2012; 72(4):286–295. [PubMed: 22687365]
16. Office of Special Education & Rehabilitative Services. [2012 Oct 24] NIDRR, legislation and policy [Internet]. 2011. Available from: <http://www2.ed.gov/about/offices/list/osers/nidrr/policy.html>

17. [2012 Oct 24] Festival of International Conferences on Caregiving, Disability, Aging and Technology [Internet]. 2011. Available from: <http://www.ficcdat.ca/main.cfm?cid=1559>
18. [2012 Oct 24] European Association of Service Providers for Persons with Disabilities. The Graz declaration [Internet]. Jun. 2006 Available from: <http://www.easpd.eu/LinkClick.aspx?fileticket=eDUBIDI0HSU%3D&tabid=3531>
19. [2012 Oct 24] European Association of Service Providers for Persons with Disabilities. The Linz declaration [Internet]. Jan. 2012 Available from: <http://www.easpd.eu/Portals/easpd/Conference%20Linz/EASPD%20Linz%20Declaration%202011.pdf>
20. Salvador-Carulla, L.; Balot, J.; Weber, G.; Zelderloo, L.; Parent, AS.; McDaid, D.; Solans, J.; Knapp, M.; Mestheneos, L.; Wolfmayr, F. [2012 Oct 24] The declaration on bridging knowledge in long-term care and support.. Int J Integr Care [serial on the Internet]. Mar. 2010 participants at the conference; 10. Available from: <http://www.ijic.org/index.php/ijic/article/viewArticle/521/1035>
21. 1999. Olmstead v. L.C., 527 U.S. 581
22. 2001. Executive Order No. 13217, 3 C.F.R. Sect. 13217
23. National Association of States United for Aging and Disabilities. [2012 Oct 24] State aging and disability agencies in times of change: State of the states survey 2011 [Internet]. 2012. Available from: http://www.nasuad.org/documentation/nasuad_materials/NASUAD%20States%20Survey%202011.pdf
24. Statement of organization, functions, and delegations of authority, Administration for Community Living, 77 C.F.R. Sect. 23250. 2012.
25. [2012 Oct 24] Department of Health & Human Resources. Introducing the Administration for Community Living [Internet]. No date. Available from: <http://www.hhs.gov/acl/index.html>
26. [May 2013 May 5] Administration for Community Living organizational chart [Internet]. No date. Available from: <http://dhhs.gov/acl/organization.html>
27. Centers for Medicare & Medicaid Services. [2012 Oct 24] 1915(c) Home & community-based waivers [Internet]. No date. Available from: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Home-and-Community-Based-1915-c-Waivers.html>
28. O'Shaughnessy, C. [2012 Oct 24] Aging and Disability Resource Centers (ADRCs): Federal and state efforts to guide consumers through the long-term services and supports maze [Internet]. 2010. Available from: http://www.nhpf.org/library/background-papers/BP81_ADRCs_11-19-10.pdf
29. Kaiser Commission on Medicaid Facts. Medicaid and long term care services and supports [Internet]. Jun. 2012 Available from: <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/2186-09.pdf>
30. Statement of organization, functions, and delegations of authority; Administration for Community Living (Notice). Federal Register. Apr 18; 2012 77(75):23250–23260. 2012.
31. Centers for Independent Living [Internet]. 2013. Available from: <http://www2.ed.gov/programs/cil/index.html>
32. National Council on Independent Living. [2012 Oct 24] NCIL/ADRC luncheon transcript [Internet]. Jul. 2007 Available from: <http://www.ncil.org/conference/ADRCtranscript.html#trans>
33. Blakeway, C. Aging and disability resource centers: “Just the facts”.. Paper presented at: National Aging and Disability I&R Symposium; Dearborn, Michigan. 2011 June;
34. Administration on Aging. [2012 Oct 24] Aging and disability resource centers: Empowering individuals to navigate their health and long term support options [Internet]. 2009. Available from: http://www.aoa.gov/AoA_programs/HCLTC/ADRC/docs/2009/ADRC_PA2009.pdf
35. Affordable Care Act – Aging and Disability Resource Center (Program information). Catalog of Federal Domestic Assistance No. 93.517 [Internet]. N.D. Available from: <https://www.cfda.gov/?s=program&mode=form&tab=step1&id=2c3e30bf1e7fd3abe145ec88156a7be0>
36. Administration on Aging. [2012 Oct 24] Aging and disability resource centers: Facts [Internet]. No date. Available from: http://www.aoa.gov/Press_Room/Products_Materials/fact/pdf/ADRC.pdf
37. The Lewin Group. [2012 Oct 24] Aging and Disability Resource Center Semi-Annual Report Outcomes [Internet]. 2011. Available from: www.adrc-tae.org/tiki-download_file.php?fileId=31754

38. Administration on Aging. [2012 Oct 24] Aging & disability resource centers evidence-based care transitions [Internet]. 2011. Available from: http://www.aoa.gov/AoA_programs/HCLTC/ADRC_CareTransitions/index.aspx
39. Administration for Community Living, Centers for Medicare & Medicaid Services, Veterans Health Administration. Aging and disability resource center program: Funding opportunity and grant application instructions [Internet]. May.2012 31:1–166.
40. The Lewin Group. [2012 Oct 24] The Technical Assistance Exchange [Internet]. Dec. 2011 Available from www.adrc-tae.org/tiki-index.php?page=AboutTAE
41. The Lewin Group. [2012 Oct 24] The Aging and Disability Resource Center (ADRC) Demonstration Grant Initiative: Interim Outcomes Report [Internet]. Nov. 2006 Available from: www.adrc-tae.org/documents/InterimReport.pdf
42. The Lewin Group. [2012 Oct 24] Summary analysis of ADRC state-level narrative reporting: Quality assurance and continuous improvement [Internet]. 2011. Available from: www.adrc-tae.org/tiki-download_file.php?fileId=31210
43. Ruiz S, Urdapilleta O, Clark-Shirley LJ, Howard J, Poey J. Indicators of a balanced long-term service and support system: Examining the impact on individuals aging with a lifelong disability. J Gerontol Soc Work. 2012; 55(2):126–145. [PubMed: 22324330]
44. Irvin, C.; Lipson, D.; Simon, S.; Wenzlow, A.; Ballou, J. [2012 Oct 24] Money Follows the Person, 2009: Annual evaluation report, final report [Internet]. Sep. 2010 Available from: http://www.mathematica-mpr.com/publications/pdfs/health/MFP_2009_Annual.pdf
45. Wisconsin Department of Health Services. [2013 May 5] Community Options Program: Program start-up and funding history [Internet]. N.D. Available from: http://www.dhs.wisconsin.gov/LTC_COP/bkgcom.htm
46. Kaiser Commission on Medicaid and the Uninsured. Roads to community living: A closer look at Washington state's Money Follows the Person demonstration [Internet]. Feb. 2013 Available from <http://kaiserfamilyfoundation.files.wordpress.com/2013/02/8413.pdf>
47. Niesz, H. [2013 May 5] Texas “Money Follows the Person” program [Internet]. Dec. 2006 Available from: <http://www.cga.ct.gov/2006/rpt/2006-R-0709.htm>
48. Glazier R. The “re-invention” of personal assistance services. Disabil Stud Q. 2001; 21(2)
49. Centers for Medicare & Medicaid Services. [2012 Oct 24] Money follows the person (MFP) [Internet]. No date. Available from: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html>
50. Lipson, D.; Valenzano, CS.; Williams, SR. [2012 Oct 24] What determines progress in state MFP transition programs? [Internet]. Oct. 2011 Available from: <http://www.mathematica-mpr.com/publications/PDFs/health/MFPfieldrpt8.pdf>
51. Money Follows the Person. [2012 Oct 24] Technical assistance [Internet]. No date. Available from: www.mfp-tac.com
52. [2012 Oct 24] Balancing Incentive Program [Internet]. 2011. Available from: <http://www.balancingincentiveprogram.org/>
53. [2012 Oct 24] Technical Assistance Collaborative (TAC) Resource Center on Supportive Housing. [Internet]. No date. Available from: <http://811resourcecenter.tacinc.org/about>
54. Robinson L, Dauenhauer J, Bishop K, Baxter J. Growing health disparities for persons who are aging with intellectual and developmental disabilities: The social work linchpin. J Gerontol Soc Work. 2012; 55(2):175–190. [PubMed: 22324333]
55. Washko M, Campbell M, Tilly J. Accelerating the translation of research into practice in long term services and supports: A critical need for federal infrastructure at the nexus of aging and disability. J Gerontol Soc Work. 2012; 55(2):112–125. [PubMed: 22324329]
56. Kane, R. Coalitions between aging and disability interests: A potential vehicle to promote community care for older people.. In: Putnam, M., editor. Aging and disability: Crossing network lines. Springer Publishing; New York: 2007. p. 135-160.
57. Urdapilleta, O.; Clark-Shirley, L.; Gall, E.; Moore, T.; Walker, D.; Flanagan, S.; Lutzky, S. [2012 Oct 24] National Balancing Indicator contractor: Project overview and findings [Internet]. Oct.

2010 Available from: http://nationalbalancingindicators.com/index.php?option=com_content&view=article&id=63&Itemid=94

Figure 1.
Timeless of Selected Reblancing/Balancing Programs

Table 1

Examples of Using Bridging Activities within the ADRC program for LTSS Capacity Building and Evaluation of Bridging Mechanisms

Examples of mandated bridging activities required of all ADRCs	Potential ways to build new knowledge & translate existing knowledge or forward translational research using mandated ADRC bridging activities	Potential structural bridging mechanisms of the ADRC to evaluate in relation to efficacy of mechanism and program outcomes
1) Shared or universal needs assessment (e.g. single need assessment protocol used across all organizations participating in the ADRC)	<ul style="list-style-type: none">• Build new knowledge:<ul style="list-style-type: none">○ Collect data to identify aging with disability population (e.g. duration of disability, medical diagnosis, age of impairment onset).○ Collect data on met and unmet needs unique to aging with disability populations (e.g. prior use of informal and formal LTSS, guardian transition planning for persons aging with intellectual disabilities).• Knowledge translation/translational research:<ul style="list-style-type: none">○ Identify best practices for meeting LTSS needs within traditional older adult population and translate intervention to specific aging with disability population(s) and vice versa.	<ul style="list-style-type: none">• Implementation of the universal needs assessment: (e.g. the creation, adoption & use of a universal protocol across networks, organizations, and practitioners).• Evaluation of the universal needs assessment protocol: E.g. What is gained or lost by using a single protocol? How effective is a single protocol in meeting the program and practice needs of organizations participating in the ADRC?
2) Coordination of consumer/client information across ADRC participating organizations (e.g. Single shared consumer databases and/or linked information technology infrastructure permitting access across data bases)	<ul style="list-style-type: none">• Build new knowledge:<ul style="list-style-type: none">○ Use shared databases to assess variance in type and amount of LTSS used by persons aging compared to persons aging into disability.○ Used shared databases to assess variance in health and wellness outcomes between persons aging with and persons aging into disability based on LTSS receipt.• Knowledge translation/translational research:<ul style="list-style-type: none">○ Identify successful LTSS interventions for traditional older adult population and translate intervention to specific aging with disability population(s) and vice versa.	<ul style="list-style-type: none">• Assessment of the capacity of shared databases to identify met & unmet need.• Assessment of ADRC participating organizations to participate in linked IT systems.• Differential use of shared database systems between aging and disability organizations participating in the ADRC.