



NATIONAL RESOURCE CENTER *for*
PARTICIPANT-DIRECTED SERVICES



Person-Centered and Participant-Directed Services and Supports Bibliography October 2015

1. Adams, N., & Grieder, D. (2014). *Treatment planning for person-centered care: Shared decision making for whole health*. London: Academic Press.

Guide on how to engage clients in building and enacting collaborative treatment plans that result in better outcomes. Suitable as a reference tool and a text for training programs, the book provides practical guidance on how to organize and conduct the recovery plan meeting, prepare and engage individuals in the treatment planning process, help with goal setting, use the plan in daily practice, and evaluate and improve the results. Case examples throughout help clarify information applied in practice, and sample documents illustrate assessment, objective planning, and program evaluation.

2. Agency for Healthcare Research and Quality. (2013). *Guide to Patient and Family Engagement in Hospital Quality and Safety*. Retrieved from www.ahrq.gov/professionals/systems/hospital/engagingfamilies/patfamilyengageguide/index.html

This guide is a tested, evidence-based resource that helps hospitals, patients, and their families partner together to improve quality and safety. The guide includes sections such as *Information to Help Hospitals Get Started* and four strategies: *Strategy 1: Working with Patients and Families as Advisors* shows how hospitals can work with patients and family members as advisors at the organizational level; *Strategy 2: Communicating to Improve Quality* helps improve communication among patients, family members, clinicians, and hospital staff from the point of admission; *Strategy 3: Nurse Bedside Shift Report* supports the safe handoff of care between nurses by involving the patient and family in the nurses' change of shift report; and *Strategy 4: IDEAL Discharge Planning* helps reduce preventable readmissions by engaging patients and family members in the transition from hospital to home. The guide addresses how to implement and evaluate each strategy and provides detailed guidance and customizable tools.

3. Applebaum, R., Schneider, B., Kunkel, S., & Davis, S. (2004, August 3) *A guide to quality in consumer directed services*. Retrieved from <http://nasuad.org/hcbs/article/guide-quality-consumer-directed-services>

This is a practical handbook on ensuring and improving the quality of services. It is based on a philosophy that the views of the major program stakeholders—consumers, families, program staff, regulators, funders—are the necessary starting point for the design of a quality system. This study was supported by the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE), as part of the National Cash and Counseling Demonstration and Evaluation.

4. **Boise, L., & White, D. (2004). The family's role in person-centered care: Practice considerations. *Journal of Psychosocial Nursing and Mental Health Services, 42(5), 12-20.***

Effective implementation of person-centered care requires a shared understanding and commitment to make it a reality by administrative personnel, direct care providers, and residents and their family members. Long-term care facilities must seek ways to engage residents' families in person-centered care through its training, policies, care planning, and documentation. Doing so may require revisions to policies and work practices, and ongoing leadership efforts to maintain this care framework within the realities of staff turnover and regulatory requirements. Developing protocols and procedures that facilitate family members' communication with staff and build consensus and shared values will result in a system that represents and honors the unique perspectives, values, and needs of each resident receiving care. It is important for facility leadership to set the tone for acknowledging the importance of family involvement in person-centered care by modeling acceptance of concerns and criticisms as valid and by acknowledging that direct care providers, residents, and their family members have a voice in care decisions. Such an approach has the greatest chance of success in promoting person-centered care and the shared values necessary to ensure its successful implementation.

5. **Briggs, L. A., Kirchhoff, K. T., Hammes, B. J., Song, M., & Colvin, E. R. (2004). Patient-centered advance care planning in special patient populations: A pilot study. *Journal of Professional Nursing, 20(1), 47-58.* doi:10.1016/j.profnurs.2003.12.001**

The purpose of this study was to assess the feasibility of a patient-centered advance care planning (PC-ACP) approach to patients with chronic illnesses and their surrogates with respect to promotion of shared decision-making outcomes—congruence between patient and surrogate, patient's decisional conflict, and knowledge of advance care planning. Greater satisfaction with the decision-making process and less decisional conflict were demonstrated in the treatment group. The PC-ACP interview can be effective in promoting shared decision-making between patients and their surrogates and in producing greater satisfaction with the process of decision-making and less decisional conflict.

6. **Center for Excellence in Assisted Living. (2010). *Person-centered care in assisted living: An informational guide.* Retrieved from <http://www.theceal.org/component/k2/item/644>**

This white paper presents a comprehensive framework about what is needed to support person-centered care (PCC) outcomes based on evidence-based practices obtained through a broad literature review. In addition, the paper draws on over 40 in-person and telephone interviews, and discussions with diverse PCC experts across the aging services network. The guide proposes a conceptual framework that can be tested and further refined through future research and aims to inform current discussions of PCC in assisted living settings.

7. **Claes, C., Van Hove, G., Vandeveldde, S., van Loon, J., & Schalock, R. L. (2010). Person-centered planning: Analysis of research and effectiveness. *Intellectual and Developmental Disabilities, 48(6), 432-453.***

Person-centered planning is a well-known and widely used approach to individual program planning in the field of intellectual and developmental disabilities. Its purpose is to develop collaborative supports focused on community presence, community participation, positive relationships, respect, and competence. Because there is little research on its effectiveness, our purpose here was to (a) review the current status of effectiveness research; (b) describe its effectiveness in terms of outcomes or results; and (c) discuss the effectiveness of person-centered planning in relation to evidence-based practices. Analyzed studies suggest that, overall, this planning has a positive, but moderate, impact on personal outcomes for this population. The body of evidence provided in this review is weak with regard to criteria for evidence-based research.

- 8. Crandall, L. G., White, D. L., Schuldheis, S., & Talerico, K. A. (2007). Initiating person-centered care practices in long-term care facilities. *Journal of Gerontological Nursing*, 33(11), 47-56.**

Person-centered care is a key concept guiding efforts to improve long-term care. Elements of person-centered care include personhood, knowing the person, maximizing choice and autonomy, comfort, nurturing relationships, and a supportive physical and organizational environment. The Oregon Health & Science University Hartford Center of Geriatric Nursing Excellence and the state agency that oversees health care for older adults worked in partnership with 9 long-term care facilities. Each developed and implemented person-centered care practices, including those focused on bathing, dining, or gardening. This article describes the processes used to develop and support these practices. Three exemplary facilities made significant practice changes, four made important but more moderate changes, and two made minimal progress. These facilities differed in terms of existing culture, management practices, staff involvement, and attention to sustainability.

- 9. Devenny, B., & Duffy, K. (2014). Person-centered reflective practice. *Nursing Standard*, 28(28), 37-43.**

Person-centered health and person-centered care have gained prominence across the UK following the publication of reports on public inquiries exploring failings in care. Self-awareness and participation in reflective practice are recognized as vital to supporting the person-centered agenda. This article presents an education framework for reflective practice, developed and used in one NHS board in Scotland, and based on the tenets of the clinical pastoral education movement. Providing an insight into the usefulness of a spiritual component in the reflective process, the framework provides an opportunity for nurses and other healthcare professionals to examine the spiritual dimensions of patient encounters, their own values and beliefs, and the effect these may have on their practice.

- 10. Doty, P., Mahoney, K. J., & Sciegaj, M. (2010). New state strategies to meet long-term care needs. *Health Affairs*, 29(1), 49-56.**

Compared to the employer-authority model with professionally managed, agency-delivered aide services, consumer-directed long-term care service programs give consumers more flexibility and receive positive responses in terms of unmet needs for home and community-based services and support. However, in an effort to expand these programs, including the federal Cash and Counseling demonstration and evaluation grants, major identified challenges have included costs, staffing and organizational issues, new infrastructure requirements, and resistance from stakeholders. Drawing from the original Cash and Counseling demonstration and evaluation implementation report and the Cash and Counseling replication report, however, the authors concluded that state program officials have identified successful strategies and learned important lessons that could lead policymakers in other states to successfully implement consumer directed service options.

- 11. Doty, P., Mahoney, K. J., Simon-Rusinowitz, L., Sciegaj, M., Selkow, I., & Loughlin, D. M. (2012). How does Cash and Counseling affect the growth of participant-directed services? *Generations*, 36(1), 28-36.**

Elders benefit from tailoring services and supports to meet their specific needs, and paying known caregivers. There is reason to think the participant-directed services (PDS) movement will continue to grow. With our increasingly diverse older population, flexible long-term-care delivery is all the more necessary. Participant direction allows individuals of all ages with disabilities and their families to tailor services and supports to their unique needs and preferences. Budget authority PDS expand program participants' range of choice and control by providing a monetary allowance, or budget, that can be used to pay personal assistants and purchase other goods and services for meeting disability-related functional needs.

12. Doyle, P. J., & Rubinstein, R. L. (2013). Person-centered dementia care and the cultural matrix of othering. *The Gerontologist*. Advance online publication. doi:10.1093/geront/gnt081

Dementia and its treatment have primarily been viewed through the biomedical lens. Using participant observations and ethnographic interviews of 20 people with dementia and 25 staff members, this study examined how person-centered care (PCC) was defined and practiced by staff members at a dementia-specific, long-term care facility. The results indicated that the predominant culture of *othering*, such as staff members distancing themselves from the residents, was a major barrier for PCC to prevail in their daily care. The authors conclude that, although challenging, more training may be the primary avenue to reduce othering behaviors and integrate PCC into long-term care settings.

13. Fronstin, P., Sepúlveda, M. J., & Roebuck, M. C. (2013). Consumer-directed health plans reduce the long-term use of outpatient physician visits and prescription drugs. *Health Affairs*, 32, 1126-1134.

A fundamental mechanism of consumer-directed health plans (CDHPs) is that, by having employees directly exposed to the costs of their care, they become more cost- and health-conscious, which lowers care demand and controls premium growth, making CDHPs attractive to employers. Using data from two large employers with CDHPs implemented in 2007 and one without CDHP, this study explored effects of CDHPs on health care and preventive care use. The results were mixed relative to expectations – fewer physician office visits, prescriptions filled, and cancer screenings received while more emergency department visits for employers with CDHP. These results imply that, in order for CDHPs to work successfully and get employees to make cost-sensitive, informed decisions, policy makers and plan sponsors need to design ways to provide timely, accurate, and usable price and quality information.

14. Huang, X., & Rosenthal, M. B. (2014). Transforming specialty practice--the patient-centered medical neighborhood. *The New England Journal of Medicine*, 370(15), 1376-1379. doi:10.1056/NEJMp1315416

Many patient-centered medical home (PCMH) initiatives wrestle with building effective partnerships with specialty practices that aren't designed to support collaboration. One solution is the specialty analogue to the PCMH: the patient-centered specialty practice.

15. Kearney, L. K., Post, E. P., Zeiss, A., Goldstein, M. G., & Dundon, M. (2011). The role of mental and behavioral health in the application of the patient-centered medical home in the department of veterans affairs. *Translational Behavioral Medicine*, 1(4), 624-628. doi:10.1007/s13142-011-0093-4

The patient-centered medical home, which is termed the Patient Aligned Care Team (PACT) in the Department of Veterans Affairs (VA), is a transformational initiative with mental and behavioral health as integral components. Funding has been provided to VA medical facilities to assist with the transformation and process redesign of primary care into interdisciplinary teams focused on increased access, Veteran-centered care, and active incorporation of collaborative expertise from specialists within primary care. Primary care clinics are not simple machines that change by merely replacing parts or colocating additional resources. Rather, they are complex systems with a relationship infrastructure among members of the team that is critically important to the change process. Mental health professionals are integral, mandated members of the PACTs providing needed mental and behavioral health care to Veterans as an integrated component of primary care. They also work to catalyze a quality improvement process that encourages collaboration, innovation, and adoption of best practices that promote transformation based on patient-centered principles of care. The purpose of this article is to describe the evolution of VA primary care settings toward interdisciplinary teams that provide patient-centered care in collaboration with Primary Care–Mental Health Integration providers and Health Promotion Disease Prevention team members.

16. Kirkendall, A. M., Waldrop, D., & Moone, R. P. (2012). Caring for people with intellectual disabilities and life-limiting illness: Merging person-centered planning and patient-centered,

family-focused care. *Journal of Social Work in End-of-Life & Palliative Care*, 8(2), 135-150. doi:10.1080/15524256.2012.685440

The number of older people with intellectual disabilities (IDs) is increasing in parallel to the lengthening life expectancy of the overall population. Little is known about the needs of older people with IDs who are at life's end. Service providers who offer direct care to people with IDs have begun to develop partnerships with hospice and palliative care specialists to provide focused care that is more specialized for their clients or residents who are approaching the end of life. However, community-based programs utilize different philosophies of care that focus on the daily management of people with IDs compared to programs that focus on care at the end of life. Merging these two approaches to care in community-based residences or community-based programs for people with IDs brings challenges for both types of programs. This article compares person-centered planning and patient-focused, family-centered care and proposes means for merging the two seemingly disparate approaches to care. Adapted from the source document.

17. Koren, M. J. (2010). Person-centered care for nursing home residents: The culture-change movement. *Health Affairs*, 29(2), 312-317.

Based on three decades of advocacy work by consumers, policy makers, and providers, the "culture change" movement (an effort to transform nursing homes from impersonal health care institutions into true person-centered long-term care homes) has brought a fundamental shift in the principal thinking of nursing homes. Awareness of the movement has grown. However, operationalizing the culture change and its maintenance remains challenging. Based on the provision of high-quality, individualized nursing home care to meet residents' needs and maximize self-determination and wellbeing, the author recommends that policy makers encourage culture change and maximize its benefits through regulation, reimbursement, and public reporting, especially before the baby-boom generation needs long-term care.

18. Kwak, J., & Polivka, L. (2014). The future of long-term care and the Aging Network. *Generations*, 38(2), 67-73.

Our long-term-care (LTC) system should be an asset in our efforts to build strong local and regional communities for everyone, regardless of age or disability. To achieve this goal, we need to have a serious national conversation and debate about LTC policy. Such debate should include a careful review of the role and history of the aging network in the development of community-based LTC services and supports. This article describes and assesses the existing, mostly aging network-administered home- and community-based LTC system and its capacity to provide cost-effective services that promote quality of life and community integration. The concluding section focuses on the need for more rigorous evaluations that compare cost-effectiveness between the network and HMO-managed long-term services and supports (LTSS) alternatives, and for a vigorous, comprehensive discussion about the future of LTSS.

19. Landers, M. G., & McCarthy, G. M. (2007). Person-centered nursing practice with older people in Ireland. *Nursing Science Quarterly*, 20(1), 78-84. doi:10.1177/0894318406296811

This column presents an analysis of McCormack's conceptual framework for person-centered practice with older people as a theoretical basis for the delivery of care of older adults in an Irish context. The evaluative process is guided by the framework proposed by Fawcett (2000) for the analysis and evaluation of conceptual models of nursing. The historical evolution, philosophical claims, and an overview of the content of the model are addressed. The following criteria are then applied: logical congruence, the generation of the theory, the credibility of the model, and the contribution of the model to the discipline of nursing.

20. Mahoney, K. (2011). Person-centered planning and participant decision-making. *Health and Social Work*, 36(3), 233-234.

This article assesses the growing trend and need for the participant-directed model in long-term care. A large majority of surveyed seniors (75%) indicate that they would prefer managing themselves when it

comes to ADLs in later life. With the initiation of the Affordable Care Act (ACA), both acute and long-term care are being renovated in the area of participant-directed care. Within the ACA, section 2402(a) indicates that the Secretary of the Department of Health and Human Services must develop a framework to support participant-directed care in all programs across the department. At the moment, all states have at least one program offering employer authority, and 41 states have at least one program with the budget authority option. This trend is expected to continue to expand. The article emphasizes that this is not a one-size-fits-all approach, and participant direction allows for each individual and their family to create a system that meets their unique needs and preferences. In order to make the change from professional/medical to empowerment/person-centered, training will be required for support brokers, care managers, and their supervisors. Without training, participant direction will never become the norm in regards to long-term care.

21. Mahoney, K. J., Simon-Rusinowitz L., Loughlin, D. M., Desmond, S. M., & Squillace, M. R. (2004). Determining personal care consumers' preferences for a consumer-directed cash and counseling option: Survey results from Arkansas, Florida, New Jersey, and New York elders and adults with physical disabilities. *Health Services Research* 39(3), 643-663.

Through structured telephone survey interviews and post-survey focus groups with 2,140 Medicaid consumers, this study assessed the participants' interest in a consumer-directed cash option for personal care and other services, in lieu of agency-delivered services. Principal findings indicated that cash option interest was positively associated with experience hiring and supervising workers, more severe levels of disability, having a live-in caregiver, living in Florida, and minority status. Age of the client was also a significant factor.

22. Maslow, K., Fazio, S., Ortigara, A., Kuhn, D., & Zeisel, J. (2013). From concept to practice: Training in person-centered care for people with dementia. *Generations*, 37(3), 100-107.

This article describes the central concepts of person-centered care for people with dementia and discuss implications for practice with individuals in different stages of dementia and in a wide array of care settings. It is essential to share these ideas throughout your organization and practice community in order to provide better, more appropriate care for people with dementia. This concluding article suggests ways the articles herein can be used for training that will result in greater understanding and wider implementation of person-centered care for people with dementia. To bring current knowledge and best practices in person-centered care into settings and practices across the continuum, the delivery of training must be appropriate for learners. Care providers are adults: they deserve training that is based on adult learning principles. Each provider comes to the caregiving role with unique experiences and beliefs about the needs of people with dementia, and any training should acknowledge these.

23. Markwick, A. (2013). Person-centered planning and the recovery approach. *Learning Disability Practice*, 16(7), 31-34.

Comparisons of recovery-oriented and person-centered approaches to the care of people with learning disabilities reveal that the two complementary processes enable clients to have some control in their lives. However, both approaches require thoughtful, creative work rather than homogeneous, quick-fix solutions. This article explains why person-centered planning and recovery approaches should be bespoke and flexible, rather than mechanistic, processes that require sophisticated practice.

24. National Ageing Research Institute. (2006). *What is person-centered health care? A literature review*. Retrieved from http://www.mednwh.unimelb.edu.au/pchc/pchc_literature.html

This review was conducted for the Best Practice in Person-Centered Care for Older Victorians Project (2004-2007). A key principle of this policy is "involving older people and carers." The review questions included: 1) What is person-centered health care?, 2) What models of person-centered health care are currently being used?, 3) What evidence is there of the effectiveness of these models?, 4) What are the documented barriers and enablers for providing a service that is person-centered?, 5) What tools are currently being used to

assess the extent or adequacy of person-centered practice in health care?, and 6) What are the concerns of clients and carers in relation to health care? Findings noted the limited literature on direct client, carer, or family perspectives on person-centered health care; limited empirical evidence about the effectiveness of these approaches; and the barriers and opportunities for person-centered health care.

25. National Council on Aging. *The Myths and Realities of Consumer-Directed Services for Older Persons*. Retrieved from www.hcbs.org/moreInfo.php/doc/1629

This publication summarizes and synthesizes some of the most important things that research and demonstration programs have learned about consumer direction. The paper provides leaders and practitioners with a common framework of understanding for our next challenge: To build upon current knowledge and to make “consumer direction” an integral part of the options available for all older persons who may need long-term care. Read the 12 common consumer direction myths and then learn the reality.

26. National Resource Center for Participant-Directed Services. *A Guide to Quality in Consumer Directed Services*. Retrieved from www.cashandcounseling.org/resources/20060111-143548

This is a practical handbook on ensuring and improving the quality of services. It is based on a philosophy that the views of the major program stakeholders—consumers, families, program staff, regulators, funders—are the necessary starting point for the design of a quality system. This study was supported by the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE) as part of the National Cash and Counseling Demonstration and Evaluation.

27. National Resource Center for Participant-Directed Services. (2012). *Participant direction training resource guide for options counselors*. Retrieved from <http://nrcpds.adobeconnect.com/p48gtxbfr0t/>

This training resource guide was developed as part of the Administration for Community Living’s Long-Term Services and Supports Workforce Competency Project. Created for options counselors, the guide lists training resources linked to 14 participant direction competencies.

28. National Resource Center for Participant-Directed Services. (2012). *Person-centered training resource guide for options counselors*. Retrieved from <http://nrcpds.adobeconnect.com/p48tlbhmohu/>

This training resource guide was developed as part the Administration for Community Living’s Long-Term Services and Supports Workforce Competency Project. Created for options counselors, the guide lists training resources linked to seven person-centered competencies.

29. Polivka, L. (2000). *The ethical and empirical basis for consumer-directed care for the frail elderly*. *Contemporary Gerontology*. 7(2), 50-52.

In recent years, concern for long-term care systems has increased as the baby boomer generation becomes more involved with parents and grandparents during their aging process. Due to this heightened involvement, long-term care is expected to be a highly visible public issue in the future. Currently, there is an overall dissatisfaction with long-term care services. Critics of the system plead for a qualitative change: switching the focus from providers to consumers. This focus on consumers and autonomy for these consumers falls under the umbrella of consumer-directed care. The article states that consumer-directed care is the most flexible of long-term care approaches, and is appropriate for both frail older persons and younger disabled persons. In order to mesh with the funding programs already in place, the cash for counseling method is the recommended consumer-directed care approach. Consumers would choose their compensation strategy, and would receive counseling involving a needs assessment, consumer information,

advice, and housing options. In order to incorporate consumer-directed care, a change in the way agencies provide case management is required. Consumers must regain control through the use of empowerment.

30. Putnam, M. (2011). Perceptions of difference between aging and disability service systems consumers: Implications for policy initiatives to rebalance long-term care. *Journal of Gerontological Social Work*, 54(3), 325-342.

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.

31. Reed, M. E., Graetz, I., Fung, V., Newhouse, J. P., & John Hsu, J. (2012). In consumer-directed health plans, a majority of patients were unaware of free or low-cost preventive care. *Health Affairs*, 31(12), 2641-2648.

This article reported the results of interviews and surveys of 456 people whose consumer-directed health plan has high deductibles but exempts routine physicals and preventive medical tests from their deductible. The authors examined knowledge of preventive care cost-sharing exemptions, whether beneficiaries avoided preventive care due to cost concerns, how well beneficiaries understood preventive care deductible exemptions, and whether they reported avoiding or delaying preventive care due to cost. The results showed that the majority of beneficiaries did not understand the details of preventive care cost-sharing exemptions, and this fact appeared to create barriers to seek preventive care. The authors concluded that education and consumer decision support are necessary in order to increase beneficiaries' awareness of the benefit features and remove the cost barrier for preventive care.

32. Robert Wood Johnson Foundation. (2013). Cash & counseling. Program report, Grant ID# CAS. Retrieved from www.rwjf.org/content/dam/farm/reports/program_results_reports/2013/rwjf406468

The Cash & Counseling program provides consumers the choice of managing a budget to pay for their goods and services based on their functional assistance needs and pays for counseling services on how to manage their services. This program introduced directed personal assistance services for Medicaid recipients with disabilities, including older people, in 15 states. It was a joint venture between RWJF and the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Service, and ran from 1996 to 2009. Three states in the demonstration phase and 12 in the replication phase participated. Both demonstration and replication phases showed positive results such as reduced unmet needs of Medicaid consumers, positive health outcomes, and improved quality of life for participants and their caregivers.

33. Sanders, C. (2010). Resource guide: Integrating participant direction in the aging network: Tools and strategies for culture change. National Resource Center for Participant-Directed Services (NRCPS). Retrieved from http://web.bc.edu/libtools/downloadfile.php?filename=1308247508_Resource_Guide.pdf

This guide includes lists of resources on published articles and books on culture change, culture change tools, and additional culture change resources as well as summaries of each article and book, and brief explanations on how to use culture change tools. Additional resources include videos and clips on culture change, and names of leading organizations and agencies.

- 34. Sanders, C. (2010). *Resource guide: Person-centered planning for consumer-directed care*. National Resource Center for Participant-Directed Services (NRCPS). Retrieved from http://web.bc.edu/libtools/downloadfile.php?filename=1308247708_Resource_Guide.pdf**

This resource guide was compiled with the purpose of infusing participant-directed options into all home- and community-based services and providing information on national leadership, technical assistance, education, and research to improve the lives of individuals of all ages with disabilities. The information includes a bibliography on person-centered planning; a list of online resources, such as *Developing and Implementing Self-Direction Programs and Policies: A Handbook*, *the Myths and Realities of Consumer-Directed Services for Older Persons*, *A Guide to Quality in Consumer Directed Services*, *Independent Choices Procedure Manual*, etc.; a list of articles and assessment tools relevant to consumer-directed care, the cash and counseling program, and personal care assessment; evaluation results of the National Participant Network Cash & Counseling; and some helpful websites.

- 35. Scheeres, D. J. (2012). *Patient-centered healthcare in practice*. Norcross: Institute of Industrial Engineers.**

Upcoming changes to patient access and healthcare provider choice as a result of the Patient Protection and Affordable Care Act soon will shift new consumers into the marketplace and increase competition for patients. But be forewarned. This is a new breed of healthcare consumer with the ability to affect the financial viability of your healthcare organization. They will not be mollified into accepting the status quo. Organizations need to create a healthcare experience a patient is willing to write home about. Organizations that stay proactive in this evolving environment will reap the benefits of their patient-centered efforts.

- 36. Sciegaj, M., Capitman, J., & Kyriacou, C. (2004). Consumer-directed community care: Race/ethnicity and individual differences in preferences for control. *The Gerontologist*, 44(4), 489-499.**

This study used a cross-sectional research design to assess level of control desired by elders in different areas of community long-term-care service delivery and preference for consumer direction. Study findings indicated significant differences between and within race/ethnic groups for preferences for levels of consumer-directed care and suggested that consumer direction occurs along a continuum, with elders desiring control over some service areas but not others, and the importance of recognizing heterogeneity within racial/ethnic groups regarding consumer-directed care.

- 37. Shay, K., Hyduke, B., & Burris, J. F. (2013). Strategic plan for geriatrics and extended care in the Veterans Health Administration: Background, plan, and progress to date. *Journal of the American Geriatrics Society*, 61(4), 632-638. doi:10.1111/jgs.12165**

The leaders of Geriatrics and Extended Care (GEC) in the Veterans Health Administration (VHA) undertook a strategic planning process that led to approval in 2009 of a multidisciplinary, evidence-guided strategic plan. This article reviews the four goals contained in that plan and describes VHA's progress in addressing them. The goals included transforming the healthcare system to a veteran-centric approach, achieving universal access to a panel of services, ensuring that the Veterans Affairs (VA) healthcare workforce was adequately prepared to manage the needs of the growing elderly veteran population, and integrating continuous improvement into all care enhancements. There has been substantial progress in addressing all four goals. All VHA health care has undergone an extensive transformation to patient-centered care, has enriched the services it can offer caregivers of dependent veterans, and has instituted models to better integrate VA and non-VA cares and services. A range of successful models of geriatric care described in the professional literature has been adapted to VA environments to gauge suitability for broader implementation. An executive-level task force developed a three-pronged approach for enhancing the VA's geriatric workforce. The VHA's performance measurement approaches increasingly include incentives to enhance the quality of management of vulnerable elderly adults in primary care. The GEC strategic plan was intended to serve as a

road map for keeping VHA aligned with an ambitious but important long-term vision for GEC services. Although no discrete set of resources was appropriated for fulfillment of the plan's recommendations, this initial report reflects substantial progress in addressing most of its goals.

38. Shen, C., Smyer, M. A., Mahoney, K. J., Loughlin, D. M., Simon-Rusinowitz, L., & Mahoney, E. K. (2008). Does mental illness affect consumer direction of community-based care? Lessons from the Arkansas Cash and Counseling Program. *The Gerontologist*, 48(1), 93-104.

Previous Cash and Counseling Demonstration and Evaluation (CCDE) research concluded with mixed results: some suggests consumer-direct care positively affects consumers' satisfaction and outlook on life while some argues that it is not appropriate for people with intellectual disabilities or mental health diagnoses. Using the Arkansas CCDE baseline and 9-month follow-up data, this study examined how Cash and Counseling affects consumers with mental health diagnoses in meeting their personal care needs and their well-being. The results indicate that the Cash & Counseling system is a valuable alternative.

39. Simon-Rusinowitz, L., Loughlin, D. M., Ruben, K., Garcia, G. M., & Mahoney, K. (2010). The benefits of consumer-directed services for elders and their caregivers in the cash and counseling demonstration and evaluation. *Public Policy & Aging Report*, 20(1), 27-31.

Policymakers have faced significant challenges in searching for sound solutions to meet the needs of elders with disabilities due to rising health care costs, the growing number of aging baby boomers, and shortages of direct-care workers in the current long-term care system. This paper examined the effects and benefits of the Consumer-directed (CD) models of home care and, specifically, Cash and Counseling. The CD approach gave older consumers feelings of autonomy, enhanced well-being, and independence, and no adverse health effects. Their caregivers were satisfied with the model because they were able to direct their finances and choose goods and services that best fit older peoples' individual needs, compared to traditional services.

40. Simon-Rusinowitz, L., Loughlin, D. M., Ruben, K., & Mahoney, K. (2010). What does research tell us about a policy option to hire relatives as caregivers? *Aging & Public Policy Report*, 20(1), 32-37.

Meeting the long-term care needs of vulnerable populations has become a priority policy issue due to the growing population of older adults and people with disabilities and the shortage of care workers. Accordingly, participants are demanding more flexible public services. Two models are: 1) participant-direction (aka consumer-direction and self-direction), which offers older adults and people with disabilities more control over their care services, and 2) Cash and Counseling, which allows participants to manage their budget, hire, supervise, and fire their care workers (including relatives), and purchase other personal assistance goods and services.

41. Squillace, M., & Firman, J. (2006, June 29). *The myths and realities of consumer-directed services for older persons*. Retrieved from <http://nasuad.org/hcbs/article/myths-and-realities-consumer-directed-services-older-persons>

This publication summarizes and synthesizes some of the most important things that research and demonstration programs have learned about consumer direction. The paper provides leaders and practitioners with a common framework of understanding for our next challenge: To build upon current knowledge and to make "consumer direction" an integral part of the options available for all older persons who may need long-term care. Read the 12 common consumer direction myths and then learn the reality.

42. Stanhope, V., Ingoglia, C., Schmelter, B., & Marcus, S. (2013). Impact of person-centered planning and collaborative documentation on treatment adherence. *Psychiatric Services*, 64(1), 76-79. doi:10.1176/appi.ps.201100489

Tailoring service planning to clients' personal life goals, or person-centered planning, has emerged as a recovery-oriented practice. This study examined the impact of person-centered planning and collaborative documentation on service engagement and medication adherence within community mental health centers (CMHCs). Person-centered planning and collaborative documentation were associated with greater engagement in services and higher rates of medication adherence.

43. Symanski-Tondora, J. L., Miller, R., Slade, M., & Davidson, L. (2014). *Partnering for recovery in mental health: A practical guide to person-centered planning*. Chichester, West Sussex, UK: Wiley.

A guide for conducting person and family-centered recovery planning with individuals with serious mental illnesses and their families. It is derived from the authors' extensive experience in articulating and implementing recovery-oriented practice and has been tested with roughly 3,000 providers who work in the field as well as with numerous post-graduate trainees in psychology, social work, nursing, and psychiatric rehabilitation. It has consistently received highly favorable evaluations from health care professionals as well as people in recovery from mental illness.

44. Taylor, J. E., & Taylor, J. A. (2013). Person-centered planning: Evidence-based practice, challenges, and potential for the 21st century. *Journal of Social Work in Disability & Rehabilitation*, 12(3), 213-235. doi:10.1080/1536710X.2013.810102

The article examines the historical development and evidence base, as well as the current challenges and potential of person-centered planning for adults with intellectual disabilities. Adapted from the source document. Person-centered planning emerged in the 1990s as an innovative practice to assist persons with intellectual and developmental disabilities. The foundational purpose of person-centered planning is to assist the individual in developing service planning that reflects the needs and desires of the focal person with the disability. Despite its popularity with disability practitioners, advocates, and policy stakeholders, debate emerged at the beginning of the 21st century as to the viability of person-centered planning as an evidence-based practice.

45. Timberlake, M. T., Leutz, W. N., Warfield, M. E., & Chiri, G. (2014). "In the driver's seat": Parent perceptions of choice in a participant-directed Medicaid waiver program for young children with autism. *Journal of Autism and Developmental Disorders*, 44(4), 903-914. doi:10.1007/s10803-013-1942-4

This study investigated families' experience of choice within a participant-directed Medicaid waiver program for young children with autism. Fourteen parents or grandparents participated in in-depth interviews about their experience of choosing personnel, directing in-home services, and managing the \$25,000 annual allocation. Key findings included families' preference to hire providers with whom they have a prior relationship, parent empowerment and differences of opinion about parents as teachers. Professionals implementing participant directed service models could benefit from understanding the strong value parents' placed on the personalities and interpersonal skills of providers. Parents' descriptions of directing rather than merely accepting autism services revealed increased confidence in their ability to choose and manage the multiple components of their children's HCBS autism waiver program.

46. Voigt, I., Wrede, J., Diederichs-Egidi, H., Dierks, M., Hummers-Pradier, E., & Junius-Walker, U. (2010). *PrefCheck: Patient-centered treatment planning with older multimorbid patients. Method and design. Zeitschrift Für Gerontologie Und Geriatrie*, 43(5), 303-309.

The aim of the study is to develop and test a consultation guide (PrefCheck) for general practitioners based on geriatric assessment results. The goal of the consultation guide is to facilitate priority setting and treatment planning based on building a partnership with geriatric patients with multiple chronic diseases.