

The Working Together Challenge: Results

Six Recommendations for Policymakers and Other Leaders Working to Improve Services and Supports for Working Age Persons with Disabilities

About the Working Together Initiative

In the spring of 2015, the National Academy of Social Insurance launched *Working Together* as an initiative to generate ideas that improve services and supports for workingage persons with disabilities or that promote access to quality services and supports. Our goal is to help identify and highlight research areas, promising new practices, or proven ideas for policymakers and other leaders to prioritize, especially amidst concerted efforts to boost employment among working-age persons with disabilities.

This year, the Academy is celebrating the 50th anniversary of Medicaid and Medicare, as well as the 80th anniversary of Social Security, and the 25th anniversary of the Americans with Disabilities Act (ADA). Together, these programs provide access to quality, affordable health care and income supports that enable millions of Americans and their families to remain healthy, independent, and engaged in the community. Without the ADA and these social insurance programs, persons with disabilities would have much fewer opportunities (and more barriers) to enter or stay in the workforce. As we look to the future, there are many opportunities – with various leaders and stakeholders working together – to provide quality services and supports that promote full participation and employment.

The Working Together initiative began with a crowd-sourcing challenge to harness the collective knowledge of an interdisciplinary community of disability, health, and social insurance experts. Using IdeaScale, an online crowd-sourcing platform, Academy members and other experts were invited to participate by submitting ideas or voting on previously submitted ideas. Participants could also comment on the submitted ideas, which led to a rich discussion of how to improve them. Over 250 experts participated in the challenge, and more than 30 submissions were collected online from May to June 2015. After voting closed at the end of June, an Advisory Committee (see list) reviewed the submissions and identified six key themes/areas to recommend for further action by the policy community.

Results of the Working Together Challenge

The Advisory Committee grouped many of the submitted ideas into six recommendations:

- 1) Continue to fill gaps in the existing research.
- 2) Develop options to address the added costs of living (and working) with a disability.
- 3) Further research into new employment support programs to identify the most effective models.
- 4) Evaluate managed care models in the context of supporting individuals with disabilities.
- 5) Improve the financing and delivery of long-term services and supports (LTSS).
- 6) Examine the potential impact (and cost) of a national paid family leave program.

1) Continue to Fill Gaps in the Existing Research

There is an abundance of research available on this topic, but major gaps in the existing body of research/data constitute a barrier to improving services and supports for working age persons with disabilities. Many research measures remain inadequate, and in some cases there is little agreement between how we measure non-clinical and functional outcomes. We need more data and research on various approaches to improving services and supports. For example:

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- How can we gather more data on factors that contribute to successful employment outcomes?
- How do we measure the prevalence and effectiveness of employment supports?
- What impact has telehealth had on improving services and supports, and how do we increase its effective use? How do we develop more effective methods for its use?
- Is there a need for a national longitudinal disability survey? Can we facilitate administrative data linkages with existing national survey data?

We might also examine the World Health Organization's framework for measuring health and disability at both individual and population levels. Known as the International Classification of Functioning, Disability, and Health (or ICF), are there ways that this framework might promote accommodation and employment?

2) Address the Added Costs of Living (and Working) with a Disability

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People with disabilities must make many costly adjustments to how they live and work, according to current research, though further study is needed. Providing affordable and accessible housing, as well as addressing costs for supportive housing, through Medicaid and other federal programs has attracted the attention of states and

could make a big difference. Identifying policies and mechanisms for alleviating the financial strain on workers with disabilities could go far to encourage sustainable employment for this population. In tandem, it may also be useful to look at training and costs employers may incur in hiring persons with disabilities.

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Further Research into New State and Federal Employment Support Programs

Gathering data on new programs being implemented in a number of states like Wisconsin, in addition to looking at evidence from more established programs like those in Washington State, could help policymakers design better employment support programs. For example, Wisconsin's new Better Bottom Line initiative, established in 2014, is based on a National Governors Association initiative from 2012-13, which educated private-sector and public-sector employers about accommodating people with disabilities in the workplace. It also supported state governments and private sector business entities to develop blueprints to promote hiring/retention of individuals with disabilities, and is establishing public-private partnerships to implement those plans that increase employment of individuals with disabilities. At the state level, we could look at the impact of Medicaid expansion and Medicaid buy-in programs for working persons with disabilities with a higher income but still not enough to afford private insurance.

At the federal level, the Social Security Administration's Youth Transition Demonstration provided employment services and enhanced work incentives to young people on the disability rolls in 10 sites across the country. A preliminary evaluation of this initiative by Mathematica Policy Research found that the individuals in 3 of the 10 sites were more likely to have worked for pay after enrollment in the demonstration project. In addition, the Centers for Medicare & Medicaid Services could develop demonstration projects to explore evidence-based supported employment, or demonstrations to explore how enhanced matches or bonuses could be used in the Medicaid program to support people moving out of segregated work settings and into integrated settings.

More research is needed to better understand the factors associated with successful employment outcomes, particularly for persons with mental health conditions, substance use disorders, and intellectual and developmental disabilities. Traditional vocational rehabilitation has not served these populations effectively, with a small percentage having access to the evidence-based models developed to serve individuals living with mental health conditions.

The economic value of employment support for employers and for the macro-economy also bears further scrutiny, particularly given the trend of using the workplace to help improve the health and productivity of working Americans and their families. Recognition of worksite best practices that create a welcoming atmosphere for workers with disabilities may also be a good source of private sector models, although there is still controversy over the benefit for employees and employers and when these benefits are realized.

4) Evaluate Managed Care Models in the Context of Supporting Individuals with Disabilities

Continued innovation within managed long-term services and supports models for persons with disabilities may provide opportunities for independence at home and in the community, self-direction of services, and supports for family and other informal caregivers. The maturation of these managed care programs will provide a new body of data from which to consider the effectiveness of these models in improving care and services and/or reducing costs, as well as potential improvements to these models.

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Innovation in managed care programs come in a variety of forms. In some states like Texas and Tennessee, companies like Amerigroup are playing a major role in coordination efforts. Kansas is experimenting with a new approach through two pilots within the state's Medicaid managed care program, KanCare. The Social Security Alternative Pilot (SSAP) provides health coverage and employment support services to individuals who meet Social Security Administration disability criteria, as an alternative to relying on Social Security benefits and Medicaid. It includes benefits planning, funding for personal care and

employment support services, Medicaid-like health care coverage, and assistance in obtaining employment. The new Supplemental Security Income Employment Support Pilot within KanCare also provides personal and employment support services to employed individuals with disabilities and helps others to attain employment.

The potential for expanding Medicaid self-directed home care, currently offered by some but not all states, presents another area for evaluation. This model focuses on making sure individuals with disabilities get the kind of care they want, when they want it, and by a caregiver of their own choosing. When Medicaid beneficiaries are able to hire family members, this becomes a source of income support for the family unit and potentially a source of employment for another person with disabilities. Expansion of consumer-directed home care programs might require a higher federal match, particularly in the case of employment of workers with disabilities or other incentives.

5) Improve the Financing and Delivery of LTSS

Not enough is known about how the LTSS needs of persons with disabilities change over time, which creates a significant obstacle to developing a better system for LTSS financing and service delivery. The demise of the CLASS Act means the U.S. has no broadly available, affordable LTSS insurance. Many participants feel that current LTSS policies on the private market are either too expensive or too limited in duration, and regardless, are not available for individuals

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with disabilities. Additional research should be done to determine what changes might be

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needed to the CLASS Act to make it actuarially sound, or to determine how a social insurance approach might yield another viable alternative to providing LTSS. Another idea worth examining is a Medicaid LTSS "wrap" for employer-sponsored or exchange coverage to support workers with disabilities, regardless of income.

6) Examine the Potential for a National Paid Family Leave Program

Family leave, e.g. a year of paid leave to support a new child, is a widely supported concept, but establishing these programs is a challenge in part because the costs are not well understood. Given the demographic trends, we may want to consider whether this concept could be extended to assist people dropping out of the workforce temporarily to care for parents with a disability or at the end of life. The California State Disability Insurance (SDI) system, which allows for paid family leave up to 12 weeks when caring for family members, is one model with fresh data that may provide new insights into the cost and frequency of providing such a benefit at the federal level. European countries commonly have family leave programs and may also provide useful data.

What's Next?

With its interdisciplinary, nationwide membership, the Academy is poised to work with a variety of partners and to lead efforts to advance our collective knowledge of the changing needs of persons with disabilities.

The Academy is looking to launch several new projects to advance some of the recommendations outlined above. For example, in the area of paid family leave the Academy recognizes the valuable role it could play in assembling cost estimates based on differing parameters (length, one or both parents, including care for sick family member, etc.). With its interdisciplinary, nationwide membership, the Academy is poised to work with a variety of partners to lead efforts to advance our collective knowledge of the changing needs of persons with disabilities. The Academy will also continue to educate policymakers, key

stakeholders, and the public about the many important areas to tackle in order to truly boost employment among working-age persons with disabilities. If you are interested in partnering with the Academy, please contact: **Pamela Larson**, CEO, National Academy of Social Insurance at plansiong or 202-452-8097.

Throughout 2015, the National Academy of Social Insurance is commemorating the 50th anniversary of Medicare and Medicaid with a series of special activities, including this *Working Together* Challenge. Working with a variety of partners, the Academy is committed to providing the public and the policy community with a platform for educational dialogue around the history and future of these two vital programs. The Academy's *Medicare and Medicaid at 50 and Beyond* Celebration Program is made possible thanks to support from



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Congratulations and Thank You!

The Academy would like to congratulate the following *Working Together Challenge* participants for their contributions and winning ideas:

- Thomas Fraker, Senior Fellow, Mathematica Policy Research
- Lex Frieden, Professor of Health Informatics, University of Texas Medical School Houston
- Denise Hoffman, Senior Researcher, Mathematica Policy Research
- Daniel Mont, Honorary Senior Research Fellow, University College London
- Hans Riemer, Council Member, Montgomery County Council
- Claire Winiarek, Disability Policy Engagement Director, Anthem Inc.

Each winner receives complimentary registration to the Academy's 2016 annual policy research conference, and a travel stipend to facilitate their attendance at the conference in Washington, DC (a \$500-\$1,000 value).

The Academy would also like to thank the following individuals for their active participation:

- Sean Dunbar, Health Policy Director, Anthem, Inc.
- Monique Morrissey, Economist, Economic Policy Institute
- **Zenaida Samaniego**, Former Chief Actuary of the U.S. Department of Labor, Employee Benefits Security Administration

Working Together Advisory Committee Members

- Christine Baker, Director, State of California, Department of Industrial Relations, Committee Chair
- Lisa Ekman, Director of Federal Policy, Health and Disability Advocates
- Merrill Friedman, Senior Director, Disability Policy Engagement, Anthem, Inc.
- Andy Imparato, Executive Director, Association of University Centers on Disabilities
- Sachin Jain, Chief Medical Officer, CareMore/Anthem
- Gina Livermore, Senior Researcher, Mathematica Policy Research
- Frank Neuhauser, Researcher, University of California, Berkeley
- Patricia Owens, Health and Disability Policy Consultant
- Jeff Price, President, National Association of Disability Examiners
- Susan Reinhard, Senior Vice President, AARP Public Policy Institute
- Kim Rutledge, Assistant Legislative Director, United Domestic Workers of America
- TJ Sutcliffe, Director of Income and Housing Policy, The Arc
- Rebecca Vallas, Director of Poverty to Prosperity Program, Center for American Progress
- Joshua Wiener, Distinguished Fellow, RTI International
- Gooloo Wunderlich, Senior Program Officer, National Academies, Committee on National Statistics
- Edward Yelin, Professor of Medicine and Health Policy, University of California, San Francisco

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