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“Canaries in the mine...” the impact of Affordable Care Act implementation on people with disabilities: Evidence from interviews with disability advocates

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ABSTRACT

Background: The Affordable Care Act (ACA) has many provisions that could improve health care for people with disabilities, including Medicaid expansion and the ability to purchase qualified health plans (QHPs).

Objective: To explore how ACA provisions affected people with disabilities' health care experiences during the first enrollment period and to suggest hypotheses for future research.

Method: We conducted semi-structured interviews with disability community leaders (N = 16) from a maximum variation sample of 10 U.S. states between March and April 2015. Our interdisciplinary team used qualitative description and a series of immersion-crystallization cycles to identify themes.

Results: Four themes for people with disability emerged. (1) State-based climate influenced ACA implementation decisions (e.g., Medicaid expansion) and thus individual experiences. (2) Medicaid coverage was viewed as more relevant, affordable and comprehensive than QHPs. (3) Despite expanded coverage, pre-enrollment challenges included accessing enrollment resources (e.g., website, helpline) and obtaining detailed plan information and post-enrollment barriers to needed care due to inadequate provider networks, high co-pays, or visit/service limitations. (4) Navigators with prior experience working with people with disabilities attenuated the identified barriers.

Conclusion: Our results depict a complex interplay between the ACA, state efforts and community outreach that influenced people with disabilities' experience. While coverage gains were generally positive, challenges emerged in plan selection and accessing care following enrollment. Attending to contextual factors like state climate and navigator experience as part of ACA implementation may determine health care access, and, ultimately, the health status, of people with disabilities and other population groups.

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Introduction

The Affordable Care Act (ACA) has many provisions that could improve health and care access for people with disabilities.² The

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² The American with Disabilities Act as a person who has, had a history, or is perceived to have a physical or mental impairment that substantially limits one or more major life activities (American with Disabilities Act, 42 U.S.C. § 12101 (1990)).

most prominent are the optional Medicaid expansion to cover all adults with incomes of up to 138 percent of the federal poverty level (FPL), including those who do not qualify for disability-based Medicaid because their conditions do not involve long-term and severe work impairments³; the creation of Marketplaces to purchase qualified health plans (QHPs) and premium subsidies for certain individuals with incomes at or below 400% of the FPL; and insurance reforms such as the prohibition of pre-existing condition exclusions as well as annual and lifetime spending limits for

³ See for instance MACPAC. People with disabilities. ND. Available from: <https://www.macpac.gov/subtopic/people-with-disabilities/>.

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essential health benefits.⁴ Despite its anticipated potential, we found a paucity of research exploring the ACA's impact on health care access for people with disabilities.

Early quantitative evidence on the effect of the ACA suggests substantial gains in coverage between 2013 and 2014 among the adult population.^{1–3} Similar or higher increases for people with health limitations indicating a disability have also been observed.^{3–6} However, gains in insurance coverage are not synonymous with gains in access to appropriate health care.⁷ People with disabilities have lower uninsurance rates than people with no disabilities, but both insured⁸ and uninsured⁹ people with disabilities face more barriers to accessing health care than people without disabilities. Very few quantitative¹⁰ or qualitative^{11,12} studies have examined health care access beyond expanded coverage from the ACA, and these have focused on either general population or specific population groups based in income, race and ethnicity, but not based on disability.

To address these gaps, the National Council on Disability, via cooperative agreement with the Urban Institute, has conducted three reports on the ACA's effect on people with disabilities.^{13–15} We conducted this qualitative descriptive study as one part of this effort with the goal to explore how the ACA affected health care for people with disabilities and the factors that shaped this experience across states with diverse implementation characteristics. This manuscript describes themes related to Medicaid expansion and provision of QHPs, two central provisions of the ACA.⁵ We conducted interviews between March 2015 and April 2015; 12 months after the end of the first open enrollment period (October 1, 2013 to March 31, 2014). Our use of an inductive qualitative approach provides an ideal opportunity to identify problems, suggest hypotheses, and inform theory formulation and concept development in relation to the impact of ACA provisions on people with disabilities that can be tested in subsequent research.

Methods

A multidisciplinary research team with expertise in disability, health economics, health services research, qualitative methods, and implementation science participated in all phases of data collection and analysis. We applied an inductive qualitative descriptive approach to provide a rich, yet straight description of the event and experiences of interest.^{16,17} We interviewed disability leaders and advocates following prior work by our team suggesting that people with disability often had difficulty discerning what events were related to ACA expansion. Additionally, disability leaders and advocates work with multiple individuals with disabilities and serve as aggregators of experience and meaning for the broader disability community. The Oregon Health & Science University Institutional Review Board approved this study (#108883).

State and participant sampling

We used a maximum variation sampling approach to select

⁴ Patient Protection and Affordable Care Act, 42 U.S.C. § 1401 (2010) for insurance subsidies; § 2001 (2010) for Medicaid expansion, § 2704 (2010) for prohibition of pre-existing conditions and § 2711 (2010) for prohibition of annual and lifetime spending limits.

⁵ Other ACA provisions that participants mentioned as important for people with disabilities included the prohibition of denying insurance based on pre-existing conditions, the prohibition of annual and lifetime spending limits on most benefits and, to a lesser extent, the dependent coverage option for young adults up to age 26. We also discussed long-term support and services options of the ACA but implementation of these options was too recent for interview participants to be able to evaluate.

states for study participation. First, we compiled information on ACA implementation characteristics for all 50 states (e.g., approach to Medicaid expansion, Marketplace type). We then grouped states into ACA implementation clusters (e.g., expansion versus non-expansion) and worked with local and national partners to identify disability leaders or organizational contacts within each state. We used this information to identify 10 target states based on variation in ACA implementation choices, availability of existing contacts, and geographic distribution across the U.S. (Table 1).

Within each target state, we used a purposive sampling approach to identify participants who could provide broad perspectives on experiences with the ACA among people with disabilities. We targeted state-based community leaders and/or advocates who worked or volunteered for disability organizations such as state offices of disability and health, disability rights organizations or coalitions, independent living organizations, legal aid organizations and disability and health programs. We anticipated that individuals in these organizations were likely to be familiar with ACA implementation and would have a broad spectrum of knowledge regarding how key provisions impacted people with disability. To the extent possible, we selected participants with disabilities who displayed diverse demographic characteristics (e.g., gender, age). We emailed potential participants to introduce the study and followed up with a phone call within the week to discuss the opportunity. Sixteen out of 60 individuals (26.7%) agreed to participate; non-participants could not be reached or declined due to limited ACA knowledge.

Data collection

A masters-level senior research assistant with expertise in communications and qualitative methods facilitated 10 state-based interviews by phone between March and April 2015; at least one additional team member attended each interview and took detailed field notes. The semi-structured interview guide included open-ended questions with targeted probes designed to explore areas of the ACA especially relevant to people with disabilities, such as their experience with the Medicaid expansion, insurance enrollment, and insurance options available through the Marketplace. The guide was developed by the study team and refined following input from investigators at the National Council on Disability and Oregon Health & Science University (see acknowledgements). The guide was iteratively refined during data collection to enable clarification and exploration of concepts that emerged during the interviews; the final interview guide appears in online [Appendix A](#).

Data management and analysis

Interviews were audio recorded and professionally transcribed; interviews averaged 80 min in length (Range: 50–100 min). We checked transcripts for accuracy, removed identifiers from transcripts and fieldnotes, then transferred data to Atlas.ti (Version 7.0, Atlas.ti Scientific Software Development GmbH, Berlin Germany) for data management and analysis.

Four multidisciplinary team members used thematic analysis and a series of immersion-crystallization cycles to identify emergent themes.^{18,19} We used an inductive approach to provide a rich, yet straight forward description of the experience of interest, suggest hypotheses, and to inform theory formulation and concept development.^{16,17,20} We chose not to use existing theories or models to guide the process because we wanted to understand the health care experiences of PWD following ACA implementation in an unbiased way.²¹ We accomplished this in three steps. This involved reading and reviewing transcripts individually then discussing as a team the larger patterns within and across interviews.

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