Health Care Disparities of Ohioans With Developmental Disabilities Across the Lifespan

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ABSTRACT

We explored health care differences across the lifespan comparing people with developmental disabilities to people without developmental disabilities. Health care disparities are inequities occurring during the provision of and in access to health care that are experienced by socially disadvantaged populations. We discovered significant disparities between persons with and without developmental disabilities in health status, quality, utilization, access, and unmet health care needs. Our results highlight the need to educate health care clinicians on the care of patients with developmental disabilities of all ages.

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INTRODUCTION

Developmental disability training is lacking in medicine and public health even though this population has major health needs and poor health outcomes. Developmental disabilities are severe, chronic conditions that impair cognitive and/or physical functioning, are manifest before the age of 22 years, result in functional limitations in at least 3 major activities of daily living, and require assistance throughout the lifespan.[1] Transitioning from pediatric to adult care can be challenging for young adults with developmental disabilities because of their increased health and support needs.[2-4] Unfortunately, the health needs of adults with developmental disabilities are rarely addressed in medical training. Using Ohio Medicaid Assessment Survey (OMAS) data, we explored differences on a range of health indicators between populations of those who have developmental disabilities and those do not across their lifespans.

METHODS

We conducted a retrospective cross-sectional analysis of the 2015 OMAS. This stratified, random digit-dialing telephone survey is designed to collect health and health care data from Ohio's Medicaid and non-Medicaid populations. In 2015, researchers completed 42,876 interviews with adults and 10,122 proxy interviews for children aged 0 to 18 years (completed by the adult most knowledgeable about the child's health). The OMAS uses single imputation to handle missing data; all indicators used had fewer than 10% missing responses. Details on the survey design are available elsewhere.[5]

We constructed 2 mutually exclusive groups, (those who had developmental disabilities and those who did not), which were further subdivided by age: children (0 to 18 years), those in health care transition (19 to 30 years), adults (31 to 64 years), and older adults (65 years and older). A successful health care transition requires finding appropriate adult medical and specialty health care. This effort is challenging for young adults with disabilities, as many clinicians who treat older adults are uncomfortable caring for this population. Consequently, many young adults with disabilities continue to see pediatric clinicians well into adulthood.[6] Consistent with previ-

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ous studies,[7] we defined health care transition as ranging from 19 to 30 years to fully capture young adults with developmental disabilities in transition.

The group comprised children whose adult proxy replied yes to each of the following questions: (1) Does [child] currently have a developmental disability? (2) Is [child] limited or prevented in any way in [his/her] ability to do things most children of the same age can do? (3) Is this because of any medical, behavioral or other health condition? (4) Is this a condition that has lasted or is expected to last for at least 12 months? A response of no to any of these questions resulted in the child being assigned to the no disability group.[9]

The adult survey questionnaire was administered to individuals aged 19 years and older and was completed by a proxy, if necessary. Adults were assigned to the developmental disability group if they endorsed having developmental disabilities and reported at least 1 special health care need, including needing assistance with activities of daily living or receiving special therapies, treatment, or counseling.[8] The special health care need requirement was intended to capture those persons meeting criteria for the federal definition of developmental disabilities. Respondents were classified to the no disability group if they denied having developmental disabilities or denied having any special health care needs.

Statistical Analyses

We conducted bivariate comparisons between the 2 groups on selected health indicators. We used weights provided in

Table 1. Health Indicators of Respondents

Indicator	Developmental Disability % (95% CI)	No Developmental Disability % (95% CI)	Prevalence Ratio % (95% CI)[a]
Health status: fair or poor			
0-18 y[b]	27.7 (22.7-32.6)	1.1 (0.8-1.4)	25.3 (18.5-34.6)[c]
19-30 y[d]	42.8 (33.0-52.6)	6.7 (5.9-7.6)	6.3 (4.9-8.2)[c]
31-64 y[e]	71.0 (66.6-75.3)	11.3 (10.7-11.8)	6.3 (5.8-6.8)[c]
≥65 y[f]	76.0 (67.4-84.6)	4.3 (3.8-4.9)	4.3 (3.8-4.9)[c]
Utilization[g]			
≥2 Overnight hospitalizations			
0-18 y	8.5 (5.5-11.4)	0.7 (0.5-.0.9)	12.3 (7.7-19.6)[c]
19-30 y	14.2 (7.0-21.5)	2.3 (1.8-2.8)	6.1 (3.5-10.7)[c]
31-64 y	13.8 (10.8-16.8)	2.2 (2.0-2.5)	6.2 (4.8-7.9)[c]
≥65 y	17.5 (10.2-24.8)	4.6 (4.0-5.1)	3.8 (2.5-5.9)[c]
≥2 Emergency department visits			
0-18 y	23.8 (19.1-28.6)	7.0 (6.3-7.7)	3.4 (2.7-4.3)[c]
19-30 y	37.0 (27.4-46.6)	11.6 (10.5-12.7)	3.2 (2.4-4.2)[c]
31-64 y	36.8 (32.2-41.4)	6.3 (5.9-6.8)	5.8 (5.0-6.7)[c]
≥65 y	34.5 (24.1-44.9)	5.7 (5.0-6.3)	6.1 (4.4-8.4)[c]
Quality[g]			
Primary care physician usually or always spends enough time with patient			
0-18 y	91.6 (88.0-95.1)	90.8 (89.9-91.8)	1.01 (0.97-1.05)
19-30 y	70.0 (54.5-85.5)	82.6 (80.5-84.7)	0.85 (0.68-1.06)
31-64 y	83.2 (78.9-87.5)	90.8 (90.2-91.5)	0.92 (0.87-0.96)
≥65 y	75.5 (63.9-87.0)	92.7 (91.9-93.5)	0.81 (0.70-0.95)[c]
Primary care physician usually or always explains things well			
0-18 y	94.7 (91.4-98.0)	96.4 (95.8-96.9)	0.98 (0.95-1.02)
19-30 y	89.7 (80.7-98.6)	94.5 (93.2-95.7)	0.95 (0.86-1.05)
31-64 y	84.5 (80.0-89.0)	96.0 (95.5-96.4)	0.88 (0.84-0.93)[c]
≥65 y	83.0 (73.2-92.9)	95.0 (94.4-95.7)	0.87 (0.78-0.98)[c]
Access[g]			
Usual source of care			
0-18 y	98.8 (97.5-100.0)	95.5 (95.0-96.0)	1.03 (1.02-1.05)[h]
19-30 y	88.5 (83.0-93.9)	83.2 (82.0-84.4)	1.06 (1.00-1.13)
31-64 y	93.0 (90.2-95.9)	91.4 (90.9-91.9)	1.02 (0.99-1.05)
≥65 y	96.7 (93.2-100.0)	96.1 (95.6-96.6)	1.01 (0.97-1.04)
Delayed treatment			
0-18 y	10.1 (6.8-13.4)	2.4 (2.0-2.8)	4.2 (2.9-6.0)[c]
19-30 y	23.2 (15.1-31.3)	14.3 (13.1-15.5)	1.6 (1.1-2.3)[h]
31-64 y	32.5 (27.9-37.1)	15.6 (15.0-16.3)	2.1 (1.8-2.4)[c]
≥65 y	14.9 (7.6-22.2)	6.9 (6.2-7.6)	2.2 (1.3-3.6)[h]
Problem getting needed care			
0-18 y	13.7 (10.1-17.4)	2.1 (1.7-2.5)	6.4 (4.7-8.9)[c]
19-30 y	16.2 (9.0-23.4)	5.4 (4.6-6.2)	3.0 (1.9-4.8)[c]
31-64 y	23.1 (19.1-27.1)	4.9 (4.5-5.3)	4.7 (3.9-5.8)[c]
≥65 y	17.5 (8.5-26.5)	2.4 (2.0-2.8)	7.3 (4.2-12.6)[c]
Received same-day care urgent needs			
0-18 y	47.5 (41.3-53.7)	61.1 (59.6-62.7)	0.78 (0.68-0.89)[c]
19-30 y	34.7 (14.5-55.0)	38.6 (34.2-43.0)	0.90 (0.50-1.63)
31-64 y	28.9 (22.3-35.4)	42.8 (40.9-44.6)	0.68 (0.54-0.85)[h]
≥65 y	12.5 (1.1-24.0)	42.2 (39.5-44.9)	0.30 (0.12-0.74)[h]

continues

Table 1. Health Indicators of Respondents *(continued)*

Indicator	Developmental Disability % (95% CI)	No Developmental Disability % (95% CI)	Prevalence Ratio % (95% CI)[a]
Waited 2 or more days for urgent needs			
0-18 y	29.9 (24.3-35.5)	16.1 (14.9-17.3)	1.9 (1.5-2.3)[c]
19-30 y	38.2 (17.7-58.6)	34.3 (30.0-38.6)	1.1 (0.64-1.9)
31-64 y	48.0 (40.8-55.3)	30.2 (28.5-31.9)	1.6 (1.4-1.9)[c]
≥65 y	44.0 (24.6-63.4)	29.0 (26.4-31.5)	1.5 (0.97-2.4)
Usually or always received needed after-hours care from primary care physician			
0-18 y	59.4 (53.0-65.7)	61.6 (60.0-63.2)	0.96 (0.86-1.08)
19-30 y	53.8 (24.0-83.6)	59.6 (53.7-65.5)	0.90 (0.51-1.59)
31-64 y	44.9 (35.6-54.2)	48.5 (45.6-51.4)	0.92 (0.75-1.15)
≥65 y	46.8 (23.9-69.8)	56.5 (51.8-61.2)	0.83 (0.50-1.36)
Problem seeing a specialist[i]			
0-18 y	24.6 (19.2-30.0)	19.3 (17.0-21.6)	1.3 (0.99-1.6)
19-30 y	52.3 (38.6-66.1)	26.8 (23.7-30.0)	2.0 (1.5-2.6)[c]
31-64 y	47.6 (41.8-53.4)	19.7 (18.4-21.0)	2.4 (2.1-2.8)[c]
≥65 y	45.8 (32.5-59.1)	12.9 (11.5-14.2)	3.6 (2.6-4.9)[c]
Unmet health care need[g]			
Dental			
0-18 y	8.3 (5.1-11.4)	3.3 (2.8-3.8)	2.5 (1.7-3.8)[c]
19-30 y	34.2 (24.7-43.8)	14.0 (12.8-15.2)	2.4 (1.8-3.3)[c]
31-64 y	34.4 (29.9-38.9)	10.0 (9.5-10.6)	3.4 (3.0-3.9)[c]
≥65 y	20.8 (12.2-29.3)	5.0 (4.5-5.6)	4.1 (2.7-6.3)[c]
Vision			
0-18 y	5.0 (2.6-7.3)	1.8 (1.4-2.2)	2.8 (1.7-4.6)[c]
19-30 y	28.7 (19.4-38.0)	8.0 (7.0-8.9)	3.6 (2.6-5.1)[c]
31-64 y	31.3 (26.9-35.7)	9.5 (9.0-10.0)	3.3 (2.8-3.8)[c]
≥65 y	24.4 (14.9-34.0)	5.5 (4.9-6.1)	4.4 (2.9-6.6)[c]
Prescription			
0-18 y	9.7 (6.4-13.0)	1.7 (1.4-2.0)	5.7 (3.9-8.4)[c]
19-30 y	24.8 (16.2-33.4)	12.4 (11.2-13.5)	2.0 (1.4-2.9)[h]
31-64 y	28.3 (24.1-32.5)	14.2 (13.5-14.8)	2.0 (1.7-2.3)[c]
≥65 y	24.6 (15.1-34.0)	9.3 (8.5-10.1)	2.6 (1.8-3.9)[c]
Other (eg, medical examination, medical supply)			
0-18 y	10.6 (7.3-13.9)	1.7 (1.4-2.0)	6.3 (4.4-9.1)[c]
19-30 y	27.5 (18.6-36.3)	6.3 (5.5-7.2)	4.3 (3.1-6.2)[c]
31-64 y	26.2 (22.0-30.5)	6.1 (5.6-6.5)	4.3 (3.6-5.2)[c]
≥65 y	10.5 (5.2-15.7)	2.3 (1.8-2.7)	4.6 (2.7-7.9)[c]
≥1 Unmet need			
0-18 y	19.6 (15.2-24.0)	5.7 (5.0-6.3)	3.5 (2.7-4.4)[c]
19-30 y	55.9 (46.1-65.8)	25.6 (24.1-27.1)	2.2 (1.8-2.6)[c]
31-64 y	61.2 (56.6-65.8)	25.4 (24.6-26.1)	2.4 (2.2-2.6)[c]
≥65 y	50.1 (39.7-60.3)	16.8 (15.8-17.8)	3.0 (2.4-3.7)[c]

Note: Because individuals with developmental disabilities represent a small percentage of the population, some outcomes were endorsed by a small number of respondents.

[a] Prevalence ratios and *P* values are for the difference in health indicators between people with and without developmental disabilities within each age-group.

[b] Developmental disability, n = 419; no developmental disability, n = 7,701.

[c] $P < .001$.

[d] Developmental disability, n = 148; no developmental disablility, n = 5,225.

[e] Developmental disability, n = 779; no developmental disability, n = 19,369.

[f] Developmental disability, n = 178; no developmental disability, n = 10,044.

[g] During the past 12 months.

[h] $P \leq .01$.

[i] Among respondents who needed specialist care (19.3% of children with a developmental disability and 78.4% of children with no developmental disability did not need specialist care; 34.7% of adults with a developmental disability aged 19 years and older and 67.1% of adults with no developmental disability aged 19 years and older did not need specialist care).

the OMAS public release data to produce population-level estimates. The Rao-Scott χ^2 test was used to test for associations. Because the adult and child survey questions were similar, we were able to compare health indicators across the different age-groups. All analyses were conducted in SAS version 9.4 (SAS Institute Inc).

RESULTS

Demographic information by age-group and disability status can be found in Supplemental Table 1 at http://www.annfammed.org/content/15/5/471/suppl/DC1. Study findings are reported in Table 1; key findings are summarized here. Adults with developmental disabilities were less likely to have a primary care clinician that spends enough time with them compared with a peer group without developmental disabilities of the same age. Among those with developmental disabilities, older adults were the least likely to have clinicians who explained things well (83.0%). People with developmental disabilities in all 4 age-groups experienced access barriers, particularly having problems getting needed care and delayed treatment. Finally, children and older adults with developmental disabilities experienced the greatest disparities in unmet health care needs.

DISCUSSION

We found significant health care disparities for those with developmental disabilities in all 4 age-groups. Although previous research highlighted the difficulty in transitioning from pediatric to adult care for young adults with disabilities,[6] we did not find the young adult age-group (19 to 30 years) to have unique health care disparities. These findings highlight the importance of disability competency for health care clinicians. Health equity in care quality and unmet health care needs may be achieved by incorporating disability education into the undergraduate medical curriculum. Unfortunately, 81% of medical students reported having had no clinical training in disabilities,[9] and 58% of medical school deans reported that a curriculum for patients with disabilities was not a high priority.[10] Physicians in practice and in training have shown inadequacies in their knowledge of disabilities.[10]

This study is limited by its cross-sectional design, the requirement of spoken English or Spanish, and Ohio residency. Despite careful weighting, response bias and inconsistencies related to self-reported data may have occurred.

With advances in medicine, persons with developmental disabilities are living much longer; medical education, however, has not changed accordingly. To reduce the health care disparities experienced by adults and children with disabilities, medical schools should incorporate training specific to developmental disabilities into their curricula.

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Key words: disability; developmental disability; developmental delay; intellectual disability; special needs; transition; health care transition; health care disparities; disparity; adult health; elderly health; aging adults; health equity; public health; health parity; minority populations

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