




The Arc
HealthMeet.

The Arc's Caregiver Survey on the Health Status of People with Intellectual Disability

RESEARCH BRIEF

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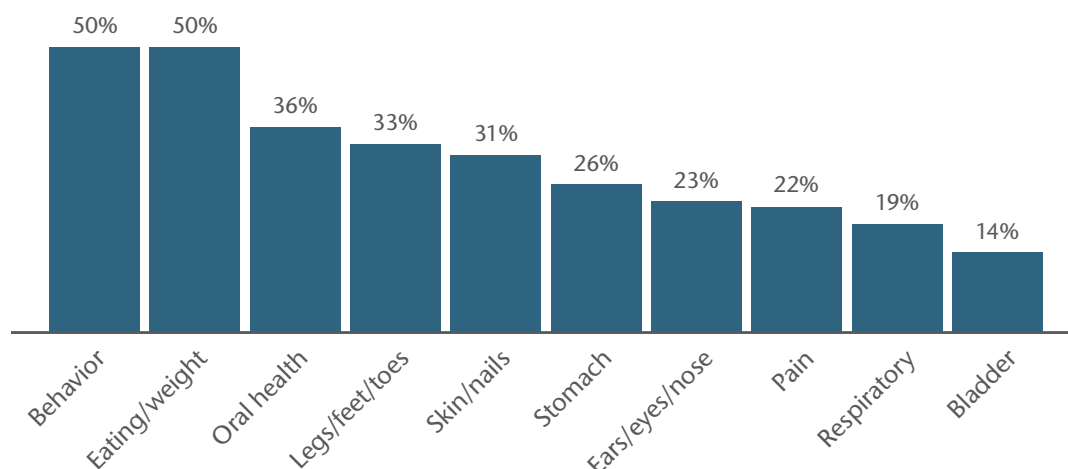
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Decades worth of studies have demonstrated the health disparities¹ which exist between people with intellectual disabilities (ID) and their peers without disabilities. In response, The Centers for Disease Control and Prevention (CDC) have engaged in multiple strategies in an attempt to close this gap. One strategy was a cooperative agreement with The Arc of the United States in to create [HealthMeet®](#). The mission of HealthMeet® was to reduce health disparities and increase the longevity and quality of life for people with ID by providing free community-based health assessments, individualized recommendations for follow-up care, and exercise and nutrition programs. In addition to assessments, HealthMeet® provided training and education for individuals with ID, their families, direct service professionals, health care professionals, and nursing and medical students while raising public awareness of health issues that impact people with ID. Finally, in an effort to better understand the health of people with ID, HealthMeet® conducted a survey of caregivers. This brief aims to summarize the top three health concerns expressed by participants: behavior, healthy eating and weight, and oral health. The full technical report [can be found here](#).

Categories of Health Concerns

Survey participants were asked to “check all that apply” for 11 different categories of health concerns. The top three concerns were behavior (50%), eating/weight (50%), and oral health (36%).

FIGURE 1: CAREGIVER HEALTH CONCERNS ABOUT PERSON WITH ID (N = 1036)



Behavior

As illustrated in Figure 1, half (50%, n = 514) of respondents indicated that they had a concern about their loved one’s behavior. The behaviors causing the greatest amount of concern were aggressiveness to self or others (53%) and mood changes (43%). Table 1 displays a full list of behavioral concerns (participants were able to “check all that apply”).

1 A health disparity is defined by the U.S. Department of Health and Human Services as “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.” From: http://www.healthypeople.gov/sites/default/files/PhaseI_o.pdf.

TABLE 1: BEHAVIORAL CONCERNS

(n = 514)

CONCERN	#	%
Aggressive to self/others	271	53
Mood changes	223	43
Change in behavior	162	32
Decrease/Increase in energy level	160	31
Repeats self	149	29
Decreased interest in activities	133	26
Property destruction	122	24
Restless/unable to sit still	114	22
Unclear speech	88	17
Isolates	86	17
Appears weak/unsteady/dizzy/difficulty with balance	72	14
Doesn't know what day it is	65	13
Rocking	65	13
Seeing/hearing things	64	12
Elopement attempts ²	60	12
Loss of skills	64	12
Recent loss or stress	58	11
Unusual movements	54	11
Appears confused/lost	45	9
Eating non-food items	43	8
Increased interest in sexual activity	38	7
Inappropriate sexual behavior	33	6
Increase/change in seizures	29	6
Doesn't respond to name	23	4
Increased tobacco use	9	2
Increased alcohol use	5	1

- ▶ Unpaid caregivers (e.g., family) were less likely to report concerns about behavior as compared to paid caregivers.
- ▶ Respondents were more likely to report having behavioral concerns for individuals aged 0-18 as compared to those aged 25-34.

Eating/Weight

Fifty percent of survey respondents indicated having a concern related to the eating habits and/or weight gain/loss of the individual with ID. The most common concern was weight loss/gain (68%). Again, respondents were able to “check all that apply”.

² In the survey, “elopement” was defined as “attempting to escape home or program”.

TABLE 2: CONCERNS ABOUT FOOD INTAKE/WEIGHT CHANGES

(n = 514)

CONCERN	#	%
Weight loss/gain	350	68
Coughing/choking while eating	77	15
Trouble chewing	63	12
Excessive liquid intake	60	12
Burps a lot	57	11
Refusing favorite foods	45	9
Difficulty swallowing	36	7

- ▶ Caregivers aged 45-64 were more concerned about the eating habits and/or weight loss/gain of the person with ID as compared to caregivers aged 18-44 or 65 and above;
- ▶ Caregivers were more likely to have food intake/weight change concerns if the person with ID was a female;
- ▶ Unpaid caregivers were more likely to have concerns as compared to paid caregivers; and
- ▶ Respondents who reported having significant health issues felt that impacted their ability to care for the person with ID. These respondents were also significantly more likely to have concerns about the person with ID’s eating habits or weights.

The Arc has continued to educate individuals with ID about healthy eating and ways to stay physically active by creating the [Health and Fitness for All](#) program, which uses the HealthMatters curriculum and additional strategies. This program will continue to give additional chapters of The Arc and other disability organizations throughout the U.S. the knowledge and skills needed to help battle obesity among individuals with ID.

Oral Health

In response to the question, “Do you have concerns about the person’s oral health (mouth or dental issues),” 35% (n = 366) indicated “yes”. About one third of all respondents indicated concerns with bruxism (teeth grinding), halitosis (bad breath), and dry/cracked lips. One quarter (24%) indicated a concern about swollen or bleeding gums. Table 3 displays additional oral health concerns. Participants were invited to “check all that apply”.

TABLE 3: CONCERNS ABOUT ORAL HEALTH

(n = 109)

CONCERN	#	%
Grinding teeth	119	33
Bad breath	109	30
Dry/cracked lips	103	28
Bleeding/swollen gums	88	24
Increased drooling	49	13
Sores on lips	15	4
White patches on tongue	15	4

- ▶ Survey respondents were more likely to have concerns about the oral health of the individual with ID if the respondent had their own health concerns or were over the age of 45;
- ▶ There was no significant difference between presence of health concerns with regard to the respondents' relationship to the individual with ID.

As a part of the final product for HealthMeet® each participating chapter produced a [toolkit](#) highlighting one of their specific achievements from the project. Specific to oral health, The Arc of Luzerne County and ACHIEVA/The Arc of Greater Pittsburgh created The State of Pennsylvania: The Arc's Oral Health Initiatives [toolkit](#) to help improve oral health care for individuals with ID. This toolkit includes: The Arc of Luzerne County: Enhancing Oral Health Care for People with Intellectual Disabilities and ACHIEVA/The Arc of Greater Pittsburgh: Oral Health Initiative.

Conclusion and recommendations

Survey data consistently indicated that the respondent's perception of their own health was a significant predictor of concern for other categorical health concerns (with the exception of skin and nail health); if the respondent believed that they had a significant health issue, they were more likely to have health concerns about the individual for whom they provided care. It is unclear as to why this is so. It may be due to unpaid caregivers not having received the same training that paid caregivers do, or it may be due to the nature of the relationship between the unpaid caregiver (often family) and the person with ID.

While respondents reported a higher rate of preventive care among people with ID than reported for individuals with disabilities generally as well as the general population of the United States, concerns about the health of the person for whom they provide care remains present. Additionally, attainment of preventive care, with the exception of dental visits and oral health, is not associated with reduced concern for various health issues. This suggests health concerns are not necessarily resolved through contact with medical professionals. It may be that symptoms are unresolved or are not being relayed to medical professionals by caregivers. It is also possible that some areas of concern are due to side effects of medications being taken.

Findings from this survey justify existing work as well as identify new avenues for future research as well as priorities for advocacy efforts for people with ID:

- ▶ Research to explore the role of caregiver health in regard to the health of people with ID is needed. Resulting data may indicate reasons caregivers with significant health issues report more health concerns and identify new targets for health interventions.
- ▶ Access to care alone does not necessarily improve health outcomes for people with disabilities.³ Medical care should not be provided based solely on the assumption that preventive care is sufficient to overcome health disparities for people with ID. Rather, a medical home model⁴ which is comprehensive, coordinated, patient-centered, accessible, safe, and high quality should be used.
- ▶ Supporting caregivers could prove to be a way to significantly improve the health of people with ID. Making caregivers' health a priority may be a crucial step forward in overcoming health disparities in the ID community.

3 Krahn, G.L., Hammond, L. & Turner, A. (2006). A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental Retardation Developmental Disabilities Reviews* 12(1), 70-82.

4 Agency for Healthcare Research and Quality. (n.d.). Defining the PCMH. Retrieved: <https://www.pcmh.ahrq.gov/page/defining-pcmh>