



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

TECHNICAL REPORT

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Introduction

In 2002 a report¹ highlighting health disparities between individuals with intellectual disabilities (ID) and their peers without disabilities was issued by the Surgeon General. Recent studies report that these differences continue to persist. The “cascade of disparities” that exists between people with ID and their peers without disabilities is well documented². In fact, research shows that 5% of adults with ID report overall poor health, a marked difference as compared to the 1% of adults without disabilities answering the same question³. According to CDC, adults with any disability experience three times the risk of heart disease, diabetes, stroke, and cancer as compared to the general population⁴.

For decades, The Centers for Disease Control and Prevention (CDC) has engaged in multiple strategies to attempt to close the gaps in health disparities between people with disabilities and their peers without disabilities. One strategy the CDC employed was entering into a three-year and eight-month cooperative agreement with The Arc of the United States in August 2012 to create the HealthMeet® program. 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 and raised public awareness of health issues that impact people with ID. Finally, in an effort to better understand the health of people with intellectual disabilities (ID), HealthMeet® conducted a survey of caregivers of people with ID intended to address the following questions:

1. What health concerns do caregivers of people with ID have regarding their loved one with ID?
2. Do families have access to doctors and insurance to support their loved one?
3. What is the current situation for these caregivers/families related to insurance and out of pocket costs?
4. What is the health of caregivers who provide care to a loved one with a disability?
5. How much planning for the future has been done to deal with what would happen when a caregiver can no longer provide care?

This report showcases the findings from that survey.

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- 1 U.S. Department of Health and Human Services (2002). Report of the Surgeon General’s Conference on Health Disparities and Mental Retardation. Author: Washington, DC. Retrieved: <https://www.nichd.nih.gov/publications/pubs/closingthegap/Pages/index.aspx>.
 - 2 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.
 - 3 Havercamp, S.M. and Scott, H.M. (2014). National surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disability and Health Journal* 8(2), 165-172.
 - 4 The Centers for Disease Control and Prevention. (2014) CDC Vital Signs. Retrieved from: <http://www.cdc.gov/vitalsigns/pdf/2014-05-vitalsigns.pdf>

Methods

With permission, The Arc adapted a survey instrument (see [Appendix A](#)) from Marks, Sisirak, & Plachy (2007)⁵. The survey was targeted to individuals (paid or unpaid) who provide care to a person with an intellectual disability and was available in English on-line through FluidSurveys from October of 2013 through July of 2014; hard copies were made available upon request. Recruitment of survey participants was done in a number of ways including emails to chapters of The Arc via a bi-weekly e-newsletter, use of The Arc's social media platforms (Facebook and Twitter), paid Google ads, and dissemination through national partners' email lists. In addition, HealthMeet® participants were targeted through emails as well as mailed postcards. Additionally, postcards were used at conference exhibits sponsored by HealthMeet®.

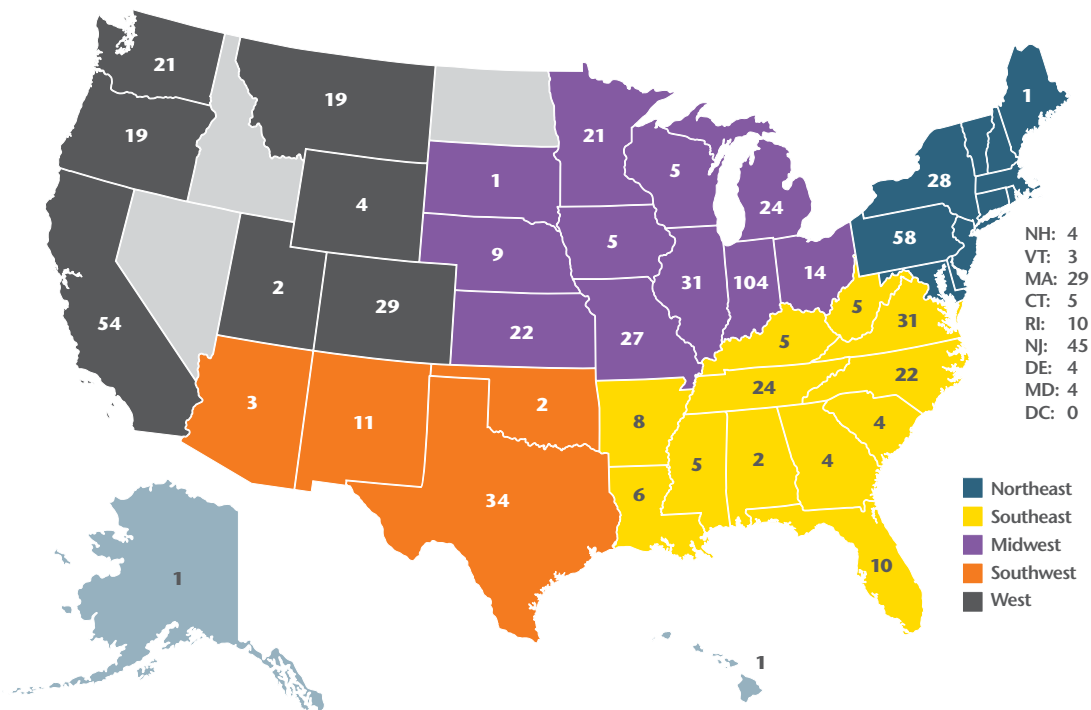
Data was collected, coded, and then analyzed using SPSS 20.

Results

Respondent demographics

In total, over 1000 individuals (n=1036) from 47 states, the District of Columbia, as well as two individuals from outside the United States participated in the survey. Figure 1 provides a breakdown of the states from which participants hailed – each state has a number indicating the number of respondents. The highest number of respondents came from Indiana (n = 104). Nevada, Idaho, North Dakota, and the District of Columbia, were unrepresented by respondents in this survey. Each color on the map indicates a region of the US; states shaded gray had no respondents.

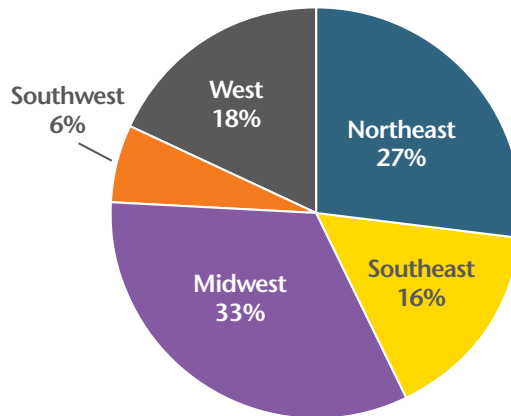
FIGURE 1: STATES IN WHICH PARTICIPATING CAREGIVERS RESIDE



5 Marks, B., Sisirak, J., & Plachy, T. (2007). Head-to-Toe Sign and Symptoms Checklist for Lay Health Workers. HealthMatters Program 2012, Chicago, IL.

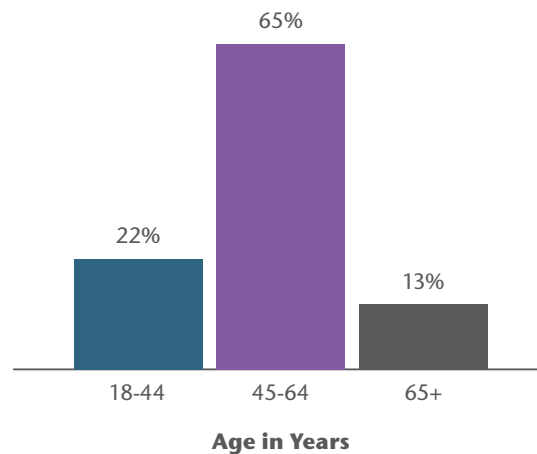
The most represented region was the Midwest (33%), followed by the Northeast (27%), West (18%), Southeast (16%), and Southwest (6%). Alaska and Hawaii had one respondent each (0.1%). Figure 2 illustrates respondents per region.

FIGURE 2: RESPONSE BY REGION



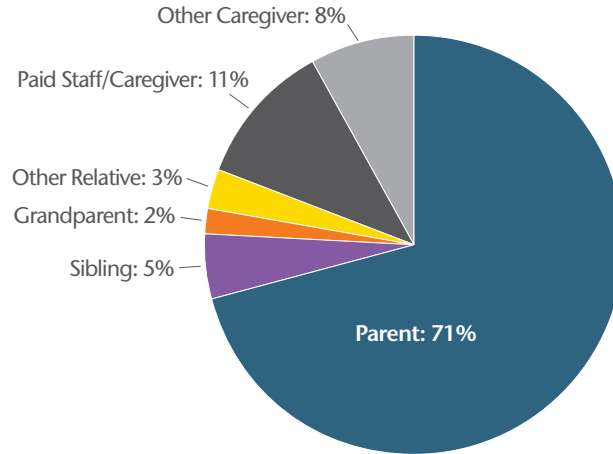
The average respondent age was 52.4 years old ($n = 810$, $sd = 11.4$, range 17 – 91 years). Over half (65%) of respondents were between 45 and 64 years of age. Figure 3 illustrates the age categories of respondents.

FIGURE 3: AGE OF RESPONDENTS



Over half (55%, $n = 569$) of respondents indicated that they were an unpaid caregiver of a person with ID who lives with them, the majority of whom were parents (89%, $n = 506$). Four percent ($n = 23$) indicated that they were a sibling; 2.3% ($n = 13$) a grandparent; and 1% ($n = 8$) indicated they were another relation. Figure 4 shows the categories of respondent relationships.

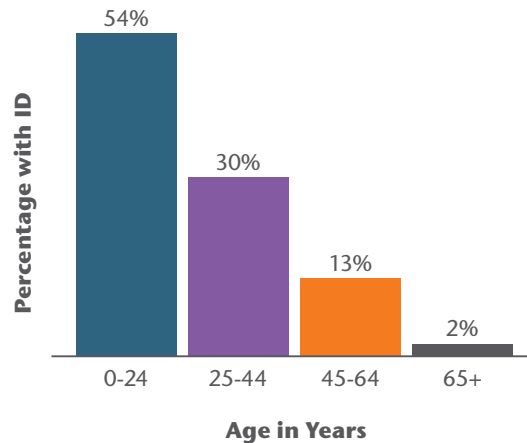
FIGURE 4: RESPONDENT RELATIONSHIP



Demographics of individuals with ID receiving care

The average age of recipients of care was 27.1 years old (n = 825, sd= 15.8, range 1 year – 87 years). The majority of the people for whom the respondents provided care were males (61%). Figure 5 shows age categories of people with ID. The vast majority of the individuals for whom caregivers were providing care were in the birth to 24-year-old range (54%).

FIGURE 5: AGE OF PEOPLE WITH ID

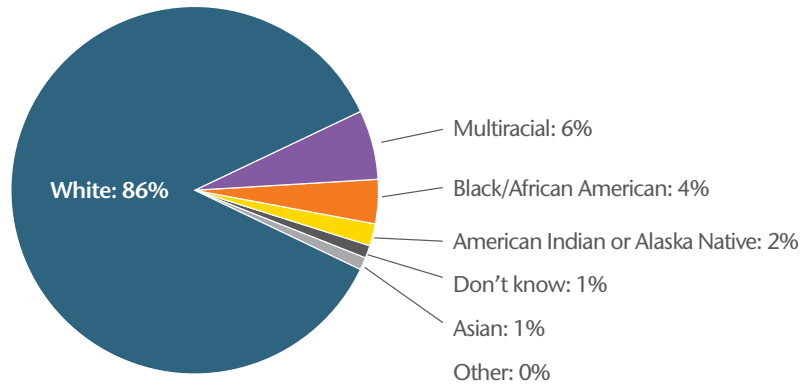


Of the respondents (n = 837) who indicated race, 86% reported the person they provide care for is white (compared to 72% of the U.S general population in 2010⁶). Seven percent (n = 57) indicated that the person is of Hispanic or Latino ethnicity (compared to 16% of the U.S. general population⁶). People for whom survey participants provided care were not representative samples of the U.S. in terms of race and were in general over-represented by white non-Hispanic respondents. Figure 6 illustrates racial descriptors.

6 U.S. Census (2010). Profile of General Population and Housing Characteristics: 2010 Demographic Profile Data. Retrieved: http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=DEC_10_DP_DPDP1&src=pt.

FIGURE 6: RACE OF PERSON WITH ID

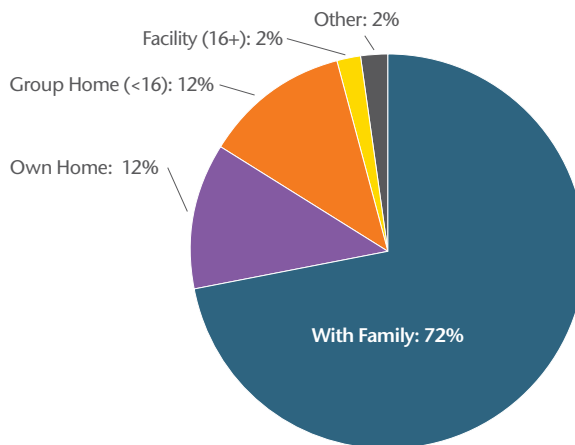
(n = 837)



Of the respondents who indicated the place of residence of the person with ID (n = 821), the majority resided with family (n = 589, 71.7%), 12% (n = 101) lived in their own home, 12% (n = 98) lived in a group home for 15 or fewer people; 1.6% (n = 13) lived in a facility for 16 or more people; 2.4% (n = 20) reported the person lived in type of setting not listed. Figure 7 illustrates the type of residence for responders.

FIGURE 7: RESIDENCE OF PEOPLE WITH ID

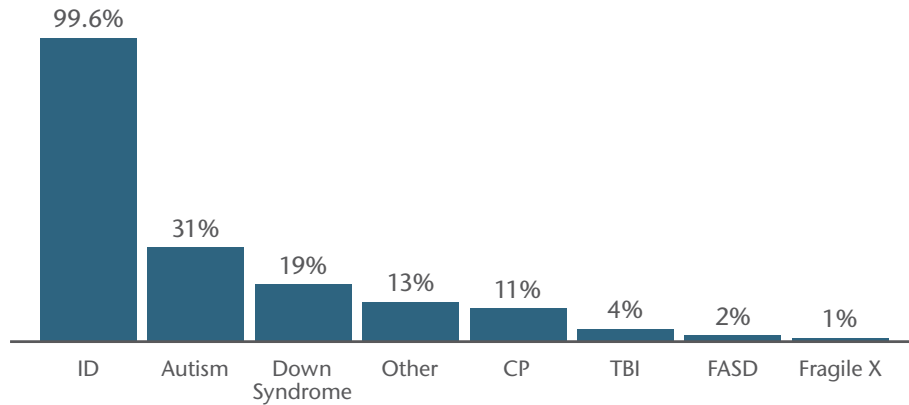
(n = 821)



Respondents indicated that 99.6% (n = 837) of the people to whom they provided care had an intellectual disability. Additional diagnoses included: autism, Down syndrome cerebral palsy (CP), traumatic brain injury (TBI), fetal alcohol spectrum disorder (FASD), and Fragile X as shown in Figure 8.

FIGURE 8: DIAGNOSES OF PEOPLE WITH ID

(n = 837)



Respondents were asked which type of health insurance coverage the person they provided care to had: 60% had Medicaid, 40% had private coverage, 26% had Medicare, and 5% had another type. Only 1% of respondents indicated that the person for whom they provide care did not have health insurance. This was a much lower rate than that of the US general population which was 9.1% in 2015⁷.

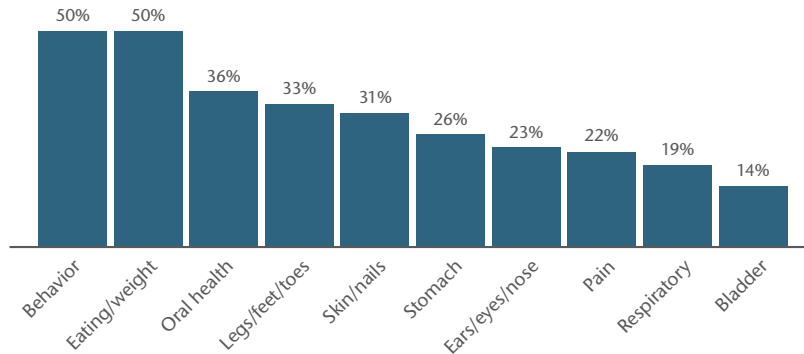
Respondents were also asked about chronic health conditions of the person for whom they provide care to which 46% indicated that the person with ID does have a chronic health condition. Of that 46%, 53% indicated that the person was unable to perform typical daily activities due to that condition.

Categories of Health Concerns

To address question #1, *What health concerns do caregivers of people with ID have regarding their loved on with ID?*, caregivers were asked about 11 different categories of health concerns illustrated in Figure 9 below. Caregivers reported an average of 3.2 areas of health concern categories per person. Categories of health concerns were not mutually exclusive as respondents were asked to “check all that apply”.

FIGURE 9: CAREGIVER HEALTH CONCERNS ABOUT PERSON WITH ID

(n = 1036)



Under each category of health concern respondents were asked to indicate concerns about specific symptoms. Again, respondents were asked to “check all that apply” and so answers are not mutually exclusive. That data is presented in the order of concern.

7 Barnett, J.C. & Vornovitsky, M. (2016). Health Insurance Coverage in the United States: 2015. Retrieved: <https://www.census.gov/library/publications/2016/demo/p60-257.html>.

BEHAVIOR

As illustrated in Figure 9, 50% (n = 514) of respondents indicated that they have 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%). Additional behavioral concerns are shown in Table 1.

TABLE 1: BEHAVIORAL CONCERNS

(n = 514)

CONCERN	NUMBER	PERCENT
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 ⁸	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

Chi square tests of independence were conducted and found that there were no statistically significant differences in the presence of behavioral concerns with respect to respondent age category, relation to person with ID, the individual with IDD's sex, race, or type of residence.

There was, however, a statistically significant difference in the presence of behavioral concerns with respect to whether or not the respondent reporting having significant

8. In the survey, "elopement" was defined as "attempting to escape home or program".

health concerns of their own, whether the caretaker was paid or unpaid, and the age of the individual receiving care; respondents self-reporting health concerns were more likely to have behavioral concerns as compared to those who did not self-report health concerns [$X^2(1, N = 834) = 22.094, p = .000$]. Unpaid caregivers were less likely to report concerns about behavior as compared to paid caregivers [$X^2(1, N = 839) = 5.066, p = .0024$]. Respondents were more likely to report having behavioral concerns for individuals aged 0-18 as compared to those aged 25-34 [$X^2(9, N = 814) = 17.717, p = .039$]; there were no statistical differences between the remaining age categories with respect to behavioral concerns.

EATING/WEIGHT

As indicated, 50% of the respondents indicated having a concern related to eating habits and/or weight gain/loss. The most common concern was weight loss/gain (68%). Additional concerns are displayed in Table 2.

TABLE 2: CONCERNS ABOUT FOOD INTAKE/WEIGHT CHANGES

(n = 514)

CONCERN	NUMBER	PERCENT
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

Chi square tests of independence yielded no statistically significant differences between the presence of concern(s) about eating habits/weight of the person with ID with respect to race, age, and place of residence of the person with ID. Additionally, there was no statistically significant differences between the presence of concern(s) about eating habits/weight of the person with ID with respect to the respondents' relation to the person with ID. There was however, a statistically significant difference between presence of concern(s) about eating habits/weight of the person with ID with respect to the age of the respondent, sex of the person with ID, whether the caregiver was paid or unpaid, and the respondents' perception of their own health. Respondents aged 45-64 were more concerned about eating habits and/or weight loss/gain as compared to their peers aged 18-44 or 65 and above [$X^2(2, N = 803) = 110.163, p = .006$]. Caregivers were more likely to have concerns if the person with ID was a female [$X^2(1, N = 1012) = 5.192, p = .023$]. Unpaid caregivers were more likely to have concerns as compared to paid [$X^2(1, N = 842) = 5.740, p = .017$]. Additionally, respondents who reported having significant health issues that they felt impacted their ability to care for the person with ID were significantly more likely to have concerns about the person with ID's eating habits or weight [$X^2(1, N = 837) = 8.677, p = .003$].

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.

TABLE 3: CONCERNS ABOUT ORAL HEALTH

(n = 109)

CONCERN	NUMBER	PERCENT
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

Chi square tests of independence yielded no statistically significant differences between the presence of concern(s) about the oral health of the person with ID with respect to race, sex, age, whether the caregiver was paid or unpaid, or residence of the person with ID. Respondents were more likely to have concerns about the oral health of the individual with ID if the respondent has their own health concerns [$X^2(1, N = 836) = 14.688, p = .000$] or are over the age of 45 [$X^2(2, N = 802) = 10.233, p = .006$]. There was no significant difference between presence of health concerns with regard to the respondents' relationship to the individual with ID.

LEGS/FEET/TOES/ABILITY TO WALK

Survey participants were asked, "Are there any concerns about the person's legs, feet, toes or ability to walk?" to which 33% (n = 339) indicated "yes." "Walking differently" was the cause for the greatest concern (32%), followed by toenail concerns (29%), and difficulty climbing stairs (29%). Additional concerns are displayed in Table 4.

TABLE 4: CONCERNS RELATED TO LEGS/FEET/TOES

(n = 339)

CONCERN	NUMBER	PERCENT
Walking differently	109	32
Toenails are thick/break easily or discolored	99	29
Difficulty climbing stairs	99	29
Feet are cold to touch	90	27
Skin on feet is red, dry, cracked, or peeling	80	24
Legs/ankles are swollen	76	22
Blisters/calluses	59	17

Chi square tests of independence yielded no statistically significant differences between the presence of concern(s) about legs/feet/toes of the person with ID with respect to race of person with ID, sex, relation to respondent, whether the caregiver was paid or unpaid, or residential setting. There were significant differences with respect to age of the individual with ID [$X^2(3, N = 818) = 37.609, p = .000$], age of the respondent [$X^2(2, N = 804) = 6.066, p = .048$], and respondent health [$X^2(1, N = 836) = 4.996, p = .018$]. Respondents aged 18-44 were more likely to report concerns about legs/feet/toes as compared to their peers; additionally, respondents were more likely to report concerns about individuals 65+.

Finally, respondents who indicated that they have significant health issues were more likely to report concerns about legs/feet/toes.

SKIN/NAILS

Survey respondents were asked, “Do you have concerns about this person’s skin and nail health?” to which 32% (n = 325) responded “yes.” The most common concerns expressed was dry skin (64%). Table 5 displays additional concerns.

TABLE 5: CONCERNS ABOUT SKIN AND NAILS

(n = 325)

CONCERN	NUMBER	PERCENT
Dry skin	208	64
Rashes/redness/open sores on skin	128	39
Scratching/complaint of itching	94	29
Unusual lumps/bumps under skin	44	14
Nails look blue	25	8
Unusual moles or marks on skin	24	7
Lice or bugs are present	2	1

Chi square tests of independence yielded no statistically significant differences between the presence of concern(s) about skin/nail health of the person with ID with respect to race, sex, and age of person with ID, relation to respondent, whether the caregiver was paid or unpaid, or residential setting. Respondents aged 18-64 [$X^2(2, N = 802) = 8.953, p = .011$] and siblings [$X^2(2, N = 841) = 23.032, p = .002$] were more likely to express concerns about skin/nails as compared to their peers. There was no significant difference between the presence of skin/nail concerns with respect to caregiver report of significant health issues.

STOMACH

Over one quarter (26%) of caregivers answered “yes” to the question, “Do you have concerns regarding the person’s stomach health?” One third of respondents indicated having concerns about unusual stools (34%) while 30% reported concerns about lack of bowel movement for three days (constipation). Table 6 displays respondents’ concerns.

TABLE 6: CONCERNS ABOUT STOMACH HEALTH

(n = 268)

CONCERN	NUMBER	PERCENT
Unusual stools	91	34
Constipation	79	30
Heartburn	70	26
Vomiting	26	10

Chi square tests of independence yielded no statistically significant differences between the presence of concern(s) about stomach health of the person with ID with respect to race, sex, residential setting, whether the caregiver was paid or unpaid, or age of respondent. There was, however, a statistically significant difference between presence of stomach concerns with respect to the age of the individual with ID [$X^2(3, N = 817) = 13.621, p = .003$], relation [$X^2(7, N = 842) = 17.119, p = .017$], and respondent health [$X^2(1, N = 837) = 22.033, p = .000$].

Respondents were more likely to have concerns about stomach health if the person with ID was 45 years or older, the respondent was a grandparent, or the respondent reporting having significant health concerns of their own.

EARS/EYES/NOSE

In response to the question, “Are you concerned about this person’s ears, eyes, or nose health?”, 233 (23%) indicated “yes.” The inability to hear well (31%) or see clearly (32%) were the most commonly reported concerns. Table 7 displays additional concerns.

TABLE 7: CONCERNS RELATED TO EARS, EYES, AND NOSE

(n = 233)

CONCERN	NUMBER	PERCENT
EARS		
Unable to hear well	73	31
Responding to sound differently	47	20
Ear discharge	26	11
Pulling at ear	26	11
Redness around ears	19	8
EYES		
Unable to see clearly	75	32
Rubbing eyes	55	24
Eye drainage	23	10
Whites of eyes are discolored	18	8
Swollen/bruised eyelids	15	6
NOSE		
Green/yellow mucus	21	9

Chi square tests of independence yielded no statistically significant differences between the presence of concern(s) about ear/eye/nose health of the person with ID with respect to age of person with ID, sex, race, residence, age of caregiver, or relation. There was, however, a significant difference with respect to the respondent’s own health [$X^2(1, N = 828) = 11.237, p = .001$] in which respondents who reported significant health issues were more likely to have concerns about the person with ID’s ear/eye/nose health. Additionally, unpaid caregivers were more likely to have concerns as compared to paid caregivers [$X^2(1, N = 832) = 6.932, p = .008$].

PAIN

Survey respondents were asked, “Are you worried that the person is in pain?” to which 22% (n = 230) indicated “yes.” The two most common indicators of pain noted by the respondents were complaints of pain (42%) and facial expressions of pain and/or holding a body part (37%). Table 8 contains additional indicators of pain respondents were asked about.

TABLE 8: CONCERNS REGARDING PAIN

(n = 230)

CONCERN	NUMBER	PERCENT
Complaining of pain	96	42
Facial expressions indicate pain or holding a body part	84	37
Difficulty standing, sitting, or bending over	59	26
Crying, holding body part, rocking, head banging, jumping	56	24
Breathing fast/heavy	30	13
Joints are swollen/warm to touch	29	13

Chi square tests of independence yielded no statistically significant differences between the presence of concern(s) about the person with ID's pain with respect to race, residence, age of caregiver, or relation. There was, however, a significant difference with respect to the respondent's own health [$X^2(1, N = 833) = 13.069, p = .000$] in which respondents who reported significant health issues were more likely to have concerns about the person with ID's ear/eye/nose health and the age of the person [$X^2(3, N = 813) = 17.803, p = .000$]. Caregivers were more likely to have concerns about pain if the person with ID was 24 years or less or 65 years and older. Additionally, caregivers were more likely to report concerns if the person with ID was female [$X^2(1, N = 1010) = 7.008, p = .008$].

BREATHING/RESPIRATORY

In response to the question, "Are there concerns about breathing or respiratory issues?" 19% (n = 197) indicated "yes." A common concern was coughing/wheezing (50%) followed by shortness of breath (34%). Table 9 displays the remaining concerns noted.

TABLE 9: CONCERNS REGARDING BREATHING OR RESPIRATORY ISSUES

(n = 197)

CONCERN	NUMBER	PERCENT
Coughing/wheezing	98	50
Short of breath	67	34
Chest congestion	23	12
Hoarse or no voice sounds	18	9
Discolored sputum	7	4
Coughing/vomiting blood	4	2
Holding chest	4	2

Chi square tests of independence yielded no statistically significant differences between the presence of concern(s) about breathing or respiratory health of the person with ID with respect to age of person with ID, race, residence, age of caregiver, or relation. **There was, however, a significant difference with respect to the respondent's own health [$X^2(1, N = 836) = 7.230, p = .007$] in which respondents who reported significant health issues were more likely to have concerns about the person with ID's breathing or respiratory issues.**

BLADDER

Respondents were asked, “Do you have any concerns about the person’s bladder or ability to urinate?” to which 15% (n = 147) indicated “yes.” The common concerns were related to urination as can be seen in Table 10.

TABLE 10: BLADDER-RELATED CONCERNS

(n = 147)

CONCERN	NUMBER	PERCENT
Trouble initiating urination	35	24
Discolored urine	34	23
Infection	31	21
Urine has foul odor	31	21
Burning/itching/pain with urination	12	8
Redness or sores in perineal area	11	8
Blood in urine	7	5
Lumps or swelling in groin	4	3

Chi square tests of independence yielded no statistically significant differences between the presence of concern(s) about bladder issues of the person with ID with respect to race or age of caregiver. There was, however, a significant difference with respect to the respondent’s own health [$X^2(1, N = 829) = 21.188, p = .000$], the age of the person with ID [$X^2(3, N = 810) = 26.400, p = .000$], the person’s residence [$X^2(4, N = 806) = 11.101, p = .025$], and the relation of the caregiver to the person with ID [$X^2(7, N = 834) = 23.951, p = .001$]. Caregivers who had concerns about their own health as well as siblings and other family members were more likely to have concerns about the person’s bladder issues. Caregivers were also more likely to have concerns if the person lived in a group home and less likely to have concerns if the person lived in the home of a family member. Finally, caregivers were more likely to report bladder concerns for individuals aged 45 and older.

Preventive Health Activities

The question, “Do families have access to doctors and insurance to support their loved one?”, was addressed by asking respondents about additional health indicators: 96% (n = 773) indicated that the person with ID had a regular doctor to go to if sick; 93% (n = 906) had a physical exam within the prior 12 months; 84% (n = 809) had a dental exam within the prior 12 months; and 69% (n = 671) had a flu vaccination within the previous 12 months. Respondents reported higher levels of preventive care for the persons with ID than the rates for the general population of the United States and rates reported in the CDC’s Disability and Health Data System (DHDS). Rates of contact with medical professionals, flu vaccinations, and dentist visits were all higher for both adults and children cared for by survey respondents as shown in Table 11.

TABLE 11: PREVENTIVE HEALTH BEHAVIORS

PREVENTIVE BEHAVIOR	GENERAL US POPULATION [9],[10],[11]	DHDS ^{[12],[13]}	PEOPLE WITH IDD PROVIDED CARE BY RESPONDENTS
CONTACT WITH MEDICAL PROFESSIONAL IN PAST YEAR			
Children (0 - 17 years)	92.40%	--	93.60%
Adults (18+ years)	83.20%	68.60%	92.50%
FLU VACCINATIONS IN PAST YEAR			
Children (0 -17 years)	56.60%	--	59.10%
Adults (18+ years)	41.50%	37.90%	71.60%
DENTAL VISIT IN PAST YEAR			
Children (0-18 years)	83%	--	85.10%
Adults (18 – 64 years)	61.70%	65.40%	83.50%
Seniors (65+ years)	60.60%	--	65.20%

For many of the health indicators there was no statistically significant differences between preventive behavior and presence of caregiver concerns with one exception: **visiting a dentist in the previous year was significantly associated with lower rates of concerns about oral health** [$X^2(2, N = 954) = 12.849, p = .002$].

WOMEN'S HEALTH

As previously mentioned, 40% of the respondents (n = 403) indicated that they were caring for a female of whom 26% (n = 85) were 18 years of age or under while 55% (n = 180) were between the age of 19-44 years old. Thirty percent (n = 69) of respondents providing care to women over the age of 18 indicated that they had concerns about women's health issues (see Table 12).

The American Cancer Society recommends that women between the ages of 45-54 receive a mammogram annually. Women over the age of 55 should have a mammogram every two years, while women 40-44 should have the option of receiving one¹⁴. There were 27 women between the ages of 45-55 receiving care from a respondent; 56% of them had a mammogram in the preceding 12 months. There were 30 women over the age of 55 who received care from a respondent; 70% had received a mammogram within the prior 12 months. Respondent concern about women's health was not significantly related to completion of a mammogram in the previous 12 months.

9. <http://www.cdc.gov/nchs/fastats/physician-visits.htm>
10. <http://www.cdc.gov/flu/pdf/fluview/vax-coverage-1213estimates.pdf>
11. <http://www.cdc.gov/nchs/fastats/dental.htm>
12. <http://dhds.cdc.gov/dataviews/>
13. http://nccd.cdc.gov/OralHealthData/rdPage.aspx?rdReport=DOH_DATA.ExploreByTopic&isTopic=ADT&isYear=2010&go=GO
14. American Cancer Society (2015). American Cancer Society recommendations for early breast cancer detection in women without breast symptoms. Retrieved: <http://www.cancer.org/cancer/breastcancer/moreinformation/breastcancerearlydetection/breast-cancer-early-detection-acs-recs>.

With regard to pap screens (or pap smears), the American Cancer Society recommends women between the ages of 21-30 have a pap test every three years while women 30-65 have one every five years¹⁵ to screen for cervical cancer. Nearly half (48%) of the respondents indicated that the person for whom they provide care had not received a pap test in the previous year¹⁶. Respondent concern about women’s health was not significantly related to completion of a pap test in the previous 12 months.

TABLE 12: WOMEN’S HEALTH

(n = 243)

	YES	NO	DON'T KNOW	NOT NEEDED
Concerns about women's health issues (aged 19+)	30%	70%	--	--
Mammogram	21%	42%	3%	34%
Pap smear	22%	48%	7%	23%

MEN’S HEALTH

Sixty percent (n = 621) of respondents indicated they were providing care to a male; for those who indicated an age, 62% (n = 304) were 19 or older. Twelve percent (n = 37) indicated they had a concern related to men’s health.

Out-of-pocket expenses

Question #3, “What is the current situation for these caregivers/families related to insurance and out-of-pocket costs?”, was addressed by asking survey respondents to estimate the amount of out-of-pocket health care costs spent over the last year. The majority of respondents reported paying some out-of-pocket health care expenses (75%, n = 563). There were no significant differences between amounts spent in past year with respect to residential setting.

With regard to out-of-pocket expenses, 75% of respondents indicated having spent some amount on health care costs over the last year, as compared to an estimated 85% of the general U.S. population¹⁵. Of those who did pay out-of-pocket expenses, 36% paid between \$100-\$499 while 22% paid in excess of \$2,000. In 2011, it is estimated that 8.2% of the U.S. population paid in excess of \$2,000. There was no significant difference between males and females with respect to out-of-pocket costs. Those who had private insurance were more likely to pay more in out-of-pocket costs as compared to those with Medicare or Medicaid [$X^2(12, N = 575) = 58.781, p = .000$]. In 2011, the average amount of out-of-pocket health care costs paid by the US general public was \$703.00¹⁷.

Figure 10 displays out-of-pocket costs reported.

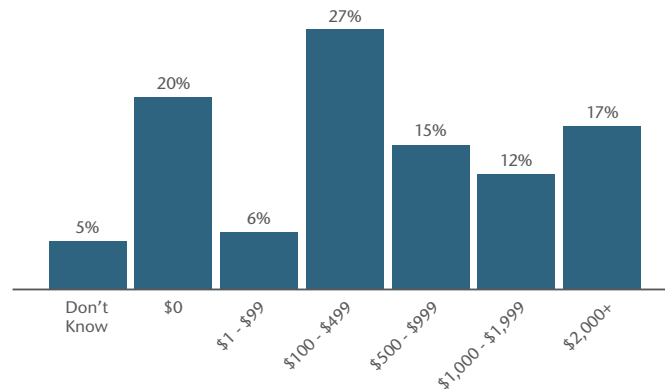
15 American Cancer Society (2012). New screening guidelines for cervical cancer. Retrieved: <http://www.cancer.org/cancer/news/news/new-screening-guidelines-for-cervical-cancer>

16 This survey was given in 2011 and asked about annual pap screens; revised pap screening guidelines were updated in 2012.

17 Machlin, S. & Carper, K. (2014). Out-of-pocket health care expenses by age and insurance coverage, 2011. Statistical Brief #441. Agency for Healthcare Research and Quality. Retrieved: https://meps.ahrq.gov/data_files/publications/st441/stat441.shtml.

FIGURE 10: OUT-OF-POCKET HEALTH EXPENSES

(n = 743)



Unpaid Caregiver Health

Respondents were also asked about their own health concerns to address question #4: “*What is the health of caregivers who provide care to a loved one with a disability?*” Of the 569 unpaid caregivers with whom the person with ID lived, nearly 13% (n = 71) indicated that they consider themselves to have a significant health issue impacting their ability to provide care to the person with ID. Table 13 displays health concerns with which respondents self-identified as well as data from the general U.S. population and a study by Yamaki, Hsieh, and Heller (2009) in which they surveyed female caregivers in Illinois¹⁶. Nearly one-third (31.3%, n = 178) indicated having a muscle, joint, or back disorder. One quarter reporting having high blood pressure which is lower than the US general population of one-third and lower than data gathered by Yamaki and colleagues. Self-report of a history of heart disease and smoking was lower than the general population, however, self-report of high cholesterol was greater.

TABLE 13: UNPAID CAREGIVER HEALTH CONCERNS COMPARED TO US GENERAL POPULATION

(n = 569)

HEALTH CONCERN	NUMBER	PERCENT	GENERAL POPULATION	YAMAKI, ET AL. (2009) ^[18]
Muscle, joint, or back disorder	178	31.3	--	---
High blood pressure	140	24.6	32.5% ¹⁹	36% middle age 67% older
High cholesterol	123	21.6	13.4% ²⁰	40%/56%
Chronic illness	123	21.6	--	---
Diabetes	46	8.1	8.9% ²¹	12%/19%
Chest/neck/jaw pain or discomfort	43	7.6	--	---
Chest pain/discomfort, dizziness, shortness of breath when exercising	43	7.6	--	---
History of heart problems	38	6.7	11.5% ²²	---
Tobacco habit	35	6.2	16.8% ²³	---
History of lung disease	23	4	--	---

With respect to self-reported ability of respondents to provide care, chi square tests of independence indicated that respondents 75 years of age or older were more likely to report that they consider themselves to have a significant health issue impacting their ability to provide care to the person with ID as compared to their counterparts aged 35-64 years of age [$X^2(8, N = 715) = 27.758, p = .001$].

Future Planning

To address question #5, “How much planning for the future has been done to deal with what would happen when caregiver can no longer provide care?”, respondents were asked four questions related to their present caregiving situation, presented in Table 14. Participants were asked to indicate all that apply to their present caregiving situation.

18. Yamaki, K., Hsieh, K., & Heller, T. (2009). Health profile of aging family caregivers supporting adults with intellectual and developmental disabilities at home. *Intellectual and Developmental Disabilities*, 47(6), p. 425-436.

19. <http://www.cdc.gov/nchs/fastats/hypertension.htm>

20. <http://www.cdc.gov/nchs/fastats/cholesterol.htm>

21. <http://www.cdc.gov/nchs/fastats/diabetes.htm>

22. <http://www.cdc.gov/nchs/fastats/heart-disease.htm>

23. <http://www.cdc.gov/nchs/fastats/smoking.htm>

How much planning for the future has been done to deal with what would happen when caregiver can no longer provide care?

- ▶ Nearly half (45%, n = 255) of respondents indicated that they do not have a plan in place for future supports for the person with ID should they no longer be able to provide care.
- ▶ 43% of respondents indicated that they don't have financial resources to arrange for quality services in their absence.
- ▶ Nearly one-third indicated that they don't have help to provide care if unable and one-quarter indicated that they don't know where to get future planning resources.

TABLE 14: CURRENT CAREGIVING SITUATION

(n = 569)

STATEMENT	NUMBER	PERCENT
I do not currently have a plan in place for the future to provide support to the person I care for when I am no longer able to do so.	255	45%
I do not currently have the financial resources to arrange for a quality of life setting for the person I care for should something happen to me.	243	43%
I do not have help to provide care to the person with ID I care for if something happened to me, and I could no longer care for him/her.	172	30%
I do not currently know where to go to find resources to help me arrange for services in the future for the person I care for.	138	24%

Discussion & Conclusions

This survey sought to collect information related to caregiver concerns about the health of the person with IDD, access to health care, out-of-pocket costs, caregiver health, and future planning.

The two health categories which respondents were most concerned about were related to behavior and eating and/or weight. Over three quarters (77%) of respondents indicated having a concern related to aggressive behavior whether it was aimed at other people, objects, or self-aggression. Unpaid caregivers and those with their own health concerns were significantly more likely to have behavioral concerns about the person with ID.

A third area of concern was oral health. While 84% of people with ID had a dental exam in the previous year, which is higher than that of the US general population, respondents maintain concerns about halitosis and bleeding gums, two indicators of periodontal disease²⁴ (also known as gum disease). Side effects of some medications²⁵ (such as dry mouth) can contribute to periodontal disease.

24 <http://www.nidcr.nih.gov/oralhealth/Topics/GumDiseases/PeriodontalGumDisease.htm#howDoI>

25 <http://www.nidcr.nih.gov/oralhealth/Topics/GumDiseases/PeriodontalGumDisease.htm#riskFactors>

Survey data consistently indicated that the respondent's perception of their own health was a significant predictor of concern for all but one category of health concerns (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 training that paid caregivers complete and therefore not having the knowledge base, or it may be due to the nature of the relationship between the unpaid caregiver and the person with ID. Additionally, this finding may indicate that caregivers who have their own health issues simply have greater concerns due to their own health status and there is no actual medical diagnosis upon which to base the concern.

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, data indicate respondents have concerns about the health of the person for whom they provide care. Additionally, attainment of preventive care, with the exception of dental visits and oral health, is not associated with reduced concern for various health issues suggesting 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.

The 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. One needed area of study should seek to explore the role of caregiver health in regard to the health of people with ID. Such research could indicate reasons caregivers with significant health issues report more health concerns and identify new targets for health interventions.

In terms of advocacy, the survey supports existing literature that access to care alone does not necessarily improve health outcomes for people with disabilities (Krahn, Hammond, & Turner, 2006). Organizations should therefore seek to provide quality medical care and not simply assume that preventive care indicators, like contact with medical professionals, is enough to overcome health disparities for people with ID. An additional recommendation is that 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.

Limitations

While data collected from this survey is rich and brings us closer to understanding the health of people with ID and their primary caregivers, the present study does have some limitations. Chiefly, the sample is not generalizable to the larger population of people with ID in the United States. Respondents are over-represented by parents who comprised 71%. Individuals with ID were over-represented by white males, 24-years and younger, who lived in their family home. Unfortunately, data on the sex of the caregiver was not collected and so we do not know if there was a higher proportion of male or female participants. The survey was only available in the English language and thus may account for the low number of individuals of Hispanic/Latino ethnicity represented (7%). Additionally, the survey was disseminated using electronic means at conferences which may have resulted in it not being equally available to all minority groups. Finally, another limitation related to the sample is self-selection. Individuals participating in the survey were not randomly sampled but volunteered to complete the survey. This may have led to sample-bias in which individuals who are health-conscious may have been more likely to complete the survey.

Another variable which deserves further exploration is presence of psychiatric diagnosis. While we know that 50% of participants indicated a concern about behavioral issues, we don't have additional details about the presence of any psychiatric diagnosis which may be a factor in the expression of behaviors of concern. Similarly, medical diagnoses were not indicated and thus could not be compared to health indicators (e.g., a symptom of diabetes is excessive thirst). Additionally, it is possible that medications taken by people receiving care may impact their physical health via side effects such as dry mouth, decreased energy levels, dizziness, or constipation (which were variables included in the health categories). Medications were not addressed in this survey.

The survey did not include questions related to male health to the same extent as it did female reproductive health; there was no corresponding question related to prostate cancer screenings. Future surveys should inquire as to the frequency of men's preventive health screenings.

Despite several questions related to caregiver health, there was no question asked related to use of services and supports either paid or unpaid, such as respite, day services, etc. This information would further contextualize issues unpaid caregivers face, particularly those who have health challenges of their own.

Finally, another limitation to the data is the completion rate; 64% of participants who initiated the survey completed it. This means that not all of the questions were answered by all of the respondents resulting in varied respondent numbers for each question.

The Arc’s Caregiver Assessment of the Health Status of People with Intellectual Disability

The Arc, a national nonprofit organization for people with intellectual and developmental disabilities is seeking to find out more about caregiver views of the health status of the people with intellectual disability for whom they provide care as part of our HealthMeet project. This project aims to help identify and reduce health disparities among people with intellectual disability.

This survey has two goals. First, this survey can be used as a checklist to help you evaluate any “red flag” health concerns that you may have about the person for whom you provide care. This checklist should not be used in place of seeing a doctor when you have concerns.

Second, the concerns that you have identified and the information you provide will be used to find out more about caregivers and health concerns that impact people with intellectual disability. By using this checklist, you give The Arc permission to use this information to help better understand and evaluate health issues impacting people with intellectual disability and their caregivers.

The information provided in this survey is confidential and will never be used to identify someone specifically. You will have the opportunity to provide contact information if you choose to do so. This information will only be used to send accessible health resources to you.

If you have any questions about this survey, please contact Jennifer Sladen at sladen@thearc.org. To find out more about The Arc, our HealthMeet project, and our work to serve people with intellectual disability and their families, visit www.thearc.org.

**This survey is adapted from the following: Adapted from Marks, B., Sisirak, J., & Heller, T. (2010). Health Matters: Establishing Sustainable Exercise and Nutrition Health Promotion Programs for Adults with Developmental Disabilities. Brookes Publishing: Philadelphia. All rights reserved. Adapted with permission from Marks, B., Sisirak, J., & Plachy, T. (2007). Head-to-Toe Sign and Symptoms Checklist for Lay Health Workers. HealthMatters Program 2012, Chicago, IL.*

Contact Information

NAME: _____

ADDRESS: _____

CITY, STATE: _____

ZIP CODE: _____

EMAIL: _____

PHONE: _____

- I would like to receive health resources and other information relating to people with intellectual and developmental disabilities.
- I have a story about my concerns regarding health or other related caregiving issues that I would like to share with The Arc. I give permission to The Arc to contact me to discuss these concerns.

Health Status of the Person You Care For...

Please answer these questions about the current health status and concerns for the person with intellectual disability you take care of.

ILLNESS

Has this person had a flu shot in the last 12 months?

- Yes No Don't Know

Has this person had a physical exam in the last 12 months?

- Yes No Don't Know

Does this person have chronic illness?

- Yes No

If so, is the person unable to perform his/her typical daily activities because of this illness?

- Yes No

BEHAVIOR CONCERNS

Do you have concerns about this person's behavior?

- Yes No

If so, please check behaviors you are concerned about.

- | | |
|--|---|
| <input type="checkbox"/> Acting as if he/she hears or sees things that are not there | <input type="checkbox"/> Increased numbers of or different types of seizures |
| <input type="checkbox"/> Aggressive to self or others | <input type="checkbox"/> Increased interest in sexual activities |
| <input type="checkbox"/> Increased alcohol use | <input type="checkbox"/> Less/no interest in activities |
| <input type="checkbox"/> Attempting to escape home or program | <input type="checkbox"/> Wanting to be alone most of the time |
| <input type="checkbox"/> Behaving differently | <input type="checkbox"/> Losing skills like feeding and toileting |
| <input type="checkbox"/> Destroying property | <input type="checkbox"/> Mood changes |
| <input type="checkbox"/> Doesn't know what day it is | <input type="checkbox"/> Not responding to name |
| <input type="checkbox"/> Eating non-food items | <input type="checkbox"/> Recent loss or stress |
| <input type="checkbox"/> Energy level increased or decreased | <input type="checkbox"/> Repeating his/herself over and over |
| <input type="checkbox"/> Engaging in inappropriate sexual activity | <input type="checkbox"/> Looks weak, unsteady, dizzy or having trouble with balance |
| <input type="checkbox"/> Increased interest in sexual activities | <input type="checkbox"/> Tobacco use increased |
| <input type="checkbox"/> Rocking back and forth a lot | <input type="checkbox"/> Unusual movements |
| <input type="checkbox"/> Seems confused or lost | <input type="checkbox"/> Speech seems garbled or unclear |
| <input type="checkbox"/> Restless and unable to sit still | |

EATING HABITS AND WEIGHT GAIN/LOSS

Do you have concerns about this person's eating habits or weight gain/loss?

- Yes No

Please check any concerns you have.

- Burps a lot
- Coughing or appearing to choke while eating
- Refusing to eat favorite foods
- Weight loss or gain
- Trouble chewing
- Difficulty swallowing or grimacing when swallowing
- Wants to drink liquids all the time

PAIN

Are you worried that the person is in pain?

- Yes
- No

Please check concerns regarding pain that you have.

- Breathing fast or heavily
- Complaining of pain
- Crying, holding, or rocking any part of his/her body, head banging, or jumping up and down
- Facial expressions of pain or is holding a body part immobile
- Difficulty standing, sitting, or bending over
- Joints are swollen or warm to touch

SKIN/NAIL HEALTH

Do you have concerns about this person's skin and nail health?

- Yes
- No

Please indicate the concerns you have.

- Fingernails or toenails look blue
- Scratching or complaining of itching
- Lice or bugs on skin
- Skin is dry
- Rashes, redness, or open sores on skin
- Unusual moles or marks on skin
- Unusual lumps or bumps on or under skin

EARS, EYES, AND NOSE HEALTH

Are you concerned about this person's ears, eyes, or nose health?

- Yes
- No

Please mark any ears/eyes/nose concerns you have.

- Liquid draining from ear
- Rubbing eyes
- Pulling at ear
- Swollen or bruised eyelids
- Redness around ear(s)
- Whites of eyes are red or yellow
- Responding to sound differently
- Unable to see clearly
- Yellow or green mucus coming from nose
- Unable to hear well
- Tears or pus-like materials coming from eyes

ORAL (MOUTH) HEALTH

Has this person had an annual dentist appointment in the last 12 months?

- Yes
- No
- Don't Know

Do you have concerns about the person’s oral health?

- Yes No

Please check your concerns regarding oral health.

- | | |
|--|--|
| <input type="checkbox"/> Bad breath, not just morning breath | <input type="checkbox"/> Dry, cracked lips |
| <input type="checkbox"/> Bleeding or swollen gums | <input type="checkbox"/> Grinding teeth |
| <input type="checkbox"/> Increased drooling | <input type="checkbox"/> Sores on lips |
| <input type="checkbox"/> White patches on tongue | |

BREATHING AND RESPIRATORY HEALTH

Are there concerns about breathing or respiratory issues?

- Yes No

Please select concerns you have regarding breathing or respiratory issues.

- | | |
|---|--|
| <input type="checkbox"/> Coughing or vomiting blood | <input type="checkbox"/> Hoarse or no voice sounds |
| <input type="checkbox"/> Coughing or wheezing | <input type="checkbox"/> Holding chest |
| <input type="checkbox"/> Green or blood streaked sputum (mucus) | <input type="checkbox"/> Short of breath |
| <input type="checkbox"/> Whistling or gurgling watery sounds with breathing | |

STOMACH HEALTH

Do you have concerns regarding the person’s stomach health?

- Yes No

Please mark any stomach health concerns you have.

- | | |
|--|--|
| <input type="checkbox"/> Unusual stools (black, pencil thin, light beige, large, bloody, diarrhea) | <input type="checkbox"/> Complaints of heartburn |
| <input type="checkbox"/> No bowel movement for three days | <input type="checkbox"/> Vomiting |

LEG, FEET, TOE AND WALKING CONCERNS

Are there concerns about the person’s legs, feet, and toes or ability to walk?

- Yes No

Please select any concerns you have about legs/feet/toes/walking.

- | | |
|--|---|
| <input type="checkbox"/> Blisters or calluses | <input type="checkbox"/> Feet cold to touch |
| <input type="checkbox"/> Trouble walking on stairs | <input type="checkbox"/> Walking differently |
| <input type="checkbox"/> Thick, crumbly, uneven, or discolored toenails | <input type="checkbox"/> Swollen ankles or legs |
| <input type="checkbox"/> Redness or broken, dry, cracked, or peeling skin in between toes or on bottom of feet | |

BLADDER ISSUES

Do you have concerns about the person’s bladder or ability to urinate?

- Yes No

Please select any bladder concerns you have.

- | | |
|---|--|
| <input type="checkbox"/> Blood in urine | <input type="checkbox"/> Infection concerns |
| <input type="checkbox"/> Bulges, lumps, or swelling in the groin area | <input type="checkbox"/> Dark yellow or brown urine |
| <input type="checkbox"/> Redness or sores in perineal area between legs | <input type="checkbox"/> Trouble starting to urinate |
| <input type="checkbox"/> Burning, itching, or pain with urination | <input type="checkbox"/> Urine has foul odor |

MEN'S AND WOMEN'S HEALTH CONCERNS

Do you care for a male or female?

- Male Female

If you care for a man, do you have any concerns related to men's health issues?

- Yes No

Please indicate what men's health concerns you have.

- Infection concerns Redness or sores on scrotum

If you care for a woman, has this person had a pap smear in the last 12 months?

- Yes No Don't Know

Has this person had a mammogram in the last 12 months?

- Yes No Don't Know

If you care for a woman, do you have concerns about women's health issues?

- Yes No

Please mark any women's health concerns you have.

- | | |
|--|---|
| <input type="checkbox"/> Menstrual flow | <input type="checkbox"/> Menstrual period stopped |
| <input type="checkbox"/> Menstrual period frequency/duration | <input type="checkbox"/> Infection concerns |
| <input type="checkbox"/> Pain in the breasts | |

Demographic Information

To help us know a bit more about the person you take care of and about yourself, please complete the following questions.

ABOUT THE PERSON YOU TAKE CARE OF...

How old is the person you take care of? _____

Does this person have an intellectual disability?

- Yes No

What type of intellectual/developmental disability diagnosis does this person have? Check any that apply.

- | | |
|--|--|
| <input type="checkbox"/> Autism | <input type="checkbox"/> Fragile X Syndrome |
| <input type="checkbox"/> Cerebral Palsy | <input type="checkbox"/> Traumatic Brain Injury |
| <input type="checkbox"/> Down syndrome | <input type="checkbox"/> Unspecified Intellectual Disability |
| <input type="checkbox"/> Fetal Alcohol Spectrum Disorder | <input type="checkbox"/> Other: _____ |

What kind of health coverage does this person have? Check all that apply.

- Medicaid
 Medicare
 Not Covered
 Private Insurance
 Other: _____

If this person was sick, do they have a regular doctor they could go to?

- Yes No Don't Know

As best as possible, how much do you think this person or you have paid to cover this person's out-of-pocket health care costs this past year?

Out-of-pocket costs are medical costs not covered by insurance.

Is this person Hispanic or Latino?

- Yes No Don't Know

Which one or more of the following would you say is this person's racial background?

Check any that apply.

- | | |
|--|--|
| <input type="checkbox"/> White | <input type="checkbox"/> Black or African American |
| <input type="checkbox"/> Native Hawaiian or Other Pacific Islander | <input type="checkbox"/> Asian |
| <input type="checkbox"/> American Indian or Alaska Native | <input type="checkbox"/> Don't Know/Not Sure |
| <input type="checkbox"/> Other, describe: _____ | |

Where does this person live right now?

- | | |
|---|---|
| <input type="checkbox"/> With his/her parents or family | <input type="checkbox"/> In a group home |
| <input type="checkbox"/> In his/her own home or apartment | <input type="checkbox"/> At a facility or institution |

Please indicate the city, state, and zip code where this person lives.

This information will be used only to better know the health concerns of people with intellectual disability in different areas of the country. This information will not be used to identify any person.

City, State: _____

Zip Code: _____

Has this person ever participated in The Arc’s activities or services?

- Yes
- No

Does this person currently participate in The Arc’s activities or services?

- Yes
- No

ABOUT YOU...

I am a...

- Parent
- Grandparent
- Other Relation
- Other Family Member
- Caregiver
- Other, describe: _____
- Paid Staff/Caregiver
- Sibling

How old are you? _____

Do you have any of the following (check all that apply)?

- A history of heart problems
- A history of lung disease
- Chest, neck, and/or jaw pains/discomfort at rest or during exertion
- A muscle, joint, or back disorder that could be aggravated by physical activity
- High blood pressure
- High cholesterol
- Diabetes
- A tobacco-using habit
- Chest pain/discomfort, dizziness, or extreme shortness of breath when physically exercising
- A chronic illness (please list): _____

Do you consider yourself to have significant health issues that impact your ability to care for the person with intellectual/developmental disabilities?

- Yes
- No

Please check any of the following statements that apply to your current caregiving situation.

- I do not have help to provide care to the person with ID I care for if something happened to me, and I could no longer care for him/her
- I do not currently have a plan in place for the future to provide support to the person I care for when I am no longer able to do so
- I do not currently have the financial resources to arrange for a quality life setting for the person I care for should something happen to me
- I do not currently know where to go to find resources to help me arrange for services in the future for the person I care for