

# Caregivers evaluate independence in individuals with Down syndrome

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## Abstract

Independence is both a sense of autonomy and self-reliance coupled with the skills to complete tasks without assistance. Questionnaire of caregivers of individuals with Down syndrome asked about factors related to independence on six topics: safety, communication, self-care, daily living, social/leisure, and vocational/employment. Responses from 408 caregivers to an independence questionnaire were received, and summarized using means and frequencies. Top goals by topic were safety from sexual abuse, communicating wants and needs, toileting independently, living independently/semi-independently, engaging in leisure time appropriately, and reading and writing. Independence is a complex, multifactorial phenomenon which varies among individuals with DS.

## KEYWORDS

Down syndrome, independence, trisomy 21

## 1 | INTRODUCTION

The United Nations have set the goals of accessibility, defined as enabling individuals with disabilities to live independently and participate fully in all aspects of life, and living independently and being included in the community (United Nations, 2006). Broadly, independence involves the abilities to take actions to manage one's affairs and to provide for oneself; this entails relying on one's own efforts, resources, judgment, and abilities, without requiring support from others (Sandjojo et al., 2019). Independence may be an important component of genetic counseling at the time of a new diagnosis of Down syndrome (DS), and one that families ask a geneticist about when envisioning the future; the existing literature includes functional abilities but limited studies defining independence in DS (de Graaf et al., 2018; Skotko et al., 2009). Independence may be impacted by a variety of factors; for example, age and presumably increased likelihood of dementia is a risk factor for decreased independence as measured through adaptive skills in adults with DS (Makary et al., 2015). Independent living also has to do with the cognitive abilities of the individuals, such as getting around places (Van Gameren-Oosterom et al., 2013; Yang et al., 2018).

More concretely, independence is the ability to complete tasks without assistance, which varies significantly in individuals with DS (Bertoli et al., 2011; de Graaf et al., 2018; Krell et al., 2021; Matthews et al., 2018). Functional status may contribute to independence in DS and intellectual and developmental disabilities (IDD). Indeed, speech ability and training led to positive changes in the social behavior of individuals with DS and an increase in autonomy and communication (Barbosa et al., 2018). Physical fitness tests and changes in activities of daily living (ADLs) in individuals with intellectual disabilities may indicate changing independence (Oppewal et al., 2015). Importantly, independence for individuals with intellectual disability can be promoted through interventions, including video prompts, video self-modeling, staff training, use of technology, and remote support services (Allen et al., 2015; Bouck et al., 2017; Sandjojo et al., 2018; Tassé et al., 2020). Improving independence is valuable; individuals with intellectual disability with a higher degree of personal autonomy with institutional and family support, report better health and quality of life (Alonso-Sardón et al., 2019).

The caregiver perspective is important when evaluating functional status and its role on independence to tasks and independent participation in life. Previous focus groups of caregivers of adults with

intellectual disability about independence/limitation in life participation demonstrated themes of the broad concept of independence, a highly variable level of independence, and the support needed to attain independence (Sandjojo et al., 2019). A questionnaire of 49 caregivers to adults with DS regarding independence and limitations in life participation demonstrated: communication and reading difficulties led to the greatest limitations and were rated as significant/chronic, managing weight and physical fitness led to moderate/occasional limitations, and fatigue and memory problems led to mild/infrequent problems (Koritsas & Iacono, 2009).

Independence is important, and accurate portrayals of life for adults with DS informed by discussions with families is valuable (Skotko, 2005). Given the limited number of studies evaluating independence among individuals with DS, we began this study to better understand caregivers' perceptions of independence in their loved ones with DS. Specifically, we aimed to describe the current status of factors related to independence regarding skills that have been achieved and skills that may be a priority for the future. Identifying and prioritizing factors for independence can help guide support services and research to maximize the areas of greatest importance to improve independence from the perspective of caregivers. Further, geneticists may gain from knowledge about future independence goals when counseling families about a new diagnosis of Down syndrome, when guiding for adolescents with Down syndrome who are transitioning to adult services, and when caring for individuals with Down syndrome through the lifespan.

## 2 | METHODS

A prospective questionnaire of caregivers of individuals with DS was designed to provide insight on independence.

### 2.1 | Participants

Caregivers of individuals with DS were invited to complete the questionnaire. "Caregiver" was intended to include parents, siblings, and individuals responsible for providing day-to-day care for an individual with DS and, thus, capable of answering questions related to independence. Questionnaire respondents self-identified with the role of caregiver and answered questions to clarify their relationship to the individual with DS. Caregivers were identified through the LuMind IDSC Foundation (<https://www.lumindidsc.org/>). LuMind IDSC is a 501(c)3 nonprofit organization that focuses on advancing biomedical research to develop treatments to improve cognition, including memory, learning, and speech in DS. LuMind IDSC has an online community of 300,000, of which nearly 15,000 have registered their email to receive email communication. Inclusion criteria included: caregiver of an individual with DS, consent to complete the electronic questionnaire, and English speaking. Exclusion criteria included: non-English speaking or lack of access to a computer to complete the electronic questionnaire.

### 2.2 | Recruitment

A hyperlink to the electronic questionnaire was shared by email and social media with the LuMind IDSC group members. The questionnaire was available in December 2019 and January 2020. Two emails were sent for recruitment: on the first date, of the 14,628 emails, 7148 were opened, and the hyperlink was clicked in 175 (2.45% of the 7148), and on the second date, 7390 emails were opened, and the click rate was 2.36% (174 of the 7390). Social media postings on Facebook, Twitter, LinkedIn, and Instagram occurred on three dates in December 2019. A review of Facebook data showed responses to posting to guide the duration of the questionnaire. On the first date, the Facebook post reached 35,000 with the following responses: 3100 reactions, 5226 clicked on the link of the post, 247 shares, and 51 comments. On the second date, 8000 were reached with 27 reactions, 153 clicked on the link of the post, 23 shares, and no comments. On the third date, 15,000 were reached with 367 reactions, 989 clicked on the link of the post, 39 shares, and 8 comments.

### 2.3 | Consent

The initial page of the electronic questionnaire contained consent information and the purpose of the questionnaire. It required caregivers to click "Next" below a question asking if they wished to participate in this project.

### 2.4 | Questionnaire

Demographic questions about the caregiver (age, educational level, location, and average household income) and the individual with DS (age, race, gender, location, living situation, and medical diagnoses) were asked. We were inspired by Matthews et al. that evaluated independence on the dimensions (1) Communication (similar to our Communication), (2) Social activities (similar to our Social/leisure), (3) Everyday tasks (similar to our Daily living), (4) Domestic activities (similar to our Self-care) (Matthews et al., 2018). Eleven experts, including Down syndrome organization leaders, clinicians, and researchers (of which some were also parents or siblings of a person with Down syndrome), provided input on the draft survey in an open-ended fashion; based on that feedback we re-organized the survey questions into dimensions and added the two dimensions of Safety and Employment. Note that the Finances and Technology category in Matthews et al. includes some of the independence aspects that were important in our Employment dimension in our survey (Matthews et al., 2018). With regard to the independence of the caregiver, the Matthews et al. (2018) paper did not cover this broader aspect of independence for the family, so the survey questions were developed solely by the group of 11 experts.

Qualified caregivers of dependents with DS answered questions about their loved ones' independence in the following categories: safety (13 items), self-care (14 items), daily living (18 items), social/

leisure (13 items), vocational/employment (17 items), and communication (19). Caregivers then answered a self-care question about their independence, specifically, the caregiver's ability to be independent of the individual with DS which contained 12 items. These were answered as "achieved already," "Not achieved but not important," "Not achieved but important to me now," "Not achieved but may be important to me in the future," and "Do not know." Each question contained an open response text box of "Other (please explain)." For each of the seven categories, respondents also ranked their top three choices among the item stems regarding importance. The choices ranked as the 1st priority were sorted in the six independence categories; the top five 1st choices were graphed.

## 2.5 | Analysis

Descriptive statistics including mean and frequency were calculated to summarize responses. In addition, analysis was conducted based on age (0–4, 5–9, 10–14, 15–19, 20–29, 30–39, 40–49, 50–59 years) of individual with Down syndrome to evaluate for age effects; this age-based analysis included calculation of mean, *SD*. The mean value of all of the items in the subscale achieved was summed, and that total was compared among the different age groups. Means were compared through an ANOVA to evaluate for differences between age groups.

Approval was obtained through the Institutional Review Board of Cincinnati Children's Hospital.

## 3 | RESULTS

We received 408 responses to our questionnaire, which were included in our analysis. Nearly all (93%) questionnaires were completed by parents, though some were completed by siblings (4%), other caregivers (3%), or others (2%). Demographic details of questionnaire respondents showed that most were age 35–64 years, and most were college graduates or higher (Table 1). Most (80%) caregivers were 35–64 years old. Date of birth was listed on 349 questionnaires, and most (92%) of the persons with DS were 35 years of age or younger (36% 13–22 years of age), with the average age of the persons with DS of 17.9 years (range from infant to 60 years). Demographic details of the individual with DS who was the focus of the respondent's questionnaire responses showed: most lived with the questionnaire respondent with a variety of living situations, and the most common medical comorbidities were sleep apnea, obesity, and attention deficit hyperactivity disorder (ADHD) (Table 1). Fewer questionnaire respondents answered race and sex information, but of those responses, most were white or Caucasian, and predominantly female (Table 1).

In general, independence was viewed as an essential topic. When asked their wishes as a caregiver, 88% felt they wish for the loved one with DS to "Be as independent as possible," 10% wish for the loved one with DS to "Achieve some independence," and 6% felt that independence was not a priority. Specific aspects of independence

are described below regarding safety, communication, self-care skills, daily living skills, social/leisure skills, and vocational/employment skills.

Safety responses were described and ranked in priority. In response to the question "I feel the following SAFETY topics are important for my loved one with Down syndrome," caregivers identified the topics which they had greatest concern for the safety. The most frequent response to many topics was "Not achieved but important to me now" including: internet safety, bullying, sexual abuse, verbal abuse, stranger danger, safely crossing a street/parking lot, and kitchen/cooking safety (Table 2). This indicates that the individuals with Down syndrome had not yet achieved safety in these areas, and these topics remained potential areas of concern from the caregiver's perspective. The most frequent response to some of the safety topics was "Achieved already"; these were: bolting/elopement, water safety, staying with a babysitter or other caregiver, and left home alone indicating that caregiver's felt these topics were achieved and no longer a concern (Table 2). The top three 1st choice safety concerns were: (1) sexual abuse (29% ranked as 1st choice), (2) stranger danger (12% ranked as 1st choice), and (3) bolting/elopement (11% ranked as 1st choice) (Figure 1).

Communication was assessed through the question "I feel the following Communication topics are important for my loved one with Down syndrome." Responses showed that the most frequent response to many of the topics was "Already achieved," including communicating wants and needs, using verbal communication, and ability to participate in a conversation, among others (Table 2). Some topics were most often "Not Achieved but Important to Me Now," such as: writing to communicate, understanding what he/she read, and sharing personal information appropriately. The top three 1st choice communication concerns were: (1) communicating wants and needs (30% ranked as 1st choice), (2) be understood by others (12% ranked as 1st choice), even with limited language, and (3) use verbal communication (10% ranked as 1st choice).

Responses regarding self-care skills were assessed through the question "I feel the following self-care topics are important for my loved one with Down syndrome" and varied: from already achieved (dressing, putting on shoes, toileting, grooming, and showering), to of importance now (healthy eating, self-reporting feelings and health, and understanding sexuality, to of importance in the future (shaving, cutting fingernails, and taking medications; Table 3). Of most significant concern among self-care skills were: healthy eating/portion control (23% ranked as 1st choice), using the toilet independently (21% ranked as 1st choice), and self-reporting feelings and health (11% ranked as 1st choice).

Daily living skills were assessed through the question "I feel the following daily living topics are important for my loved one with Down syndrome." Of these, the skills which were most frequently listed as important for the future included: navigating public transportation alone, living independently/semi-independently, and doing errands, among others (Table 3). Some daily living skills were most often responded as achieved already, such as drinking and eating independently, carrying out domestic activities. The daily living skills

**TABLE 1** Demographic information from the 408 survey respondents and corresponding individuals with Down syndrome

Question	Response	N	%
Respondent's relationship to the loved one with Down syndrome	Parent	376	93
	Sibling	15	4
	Other Caregiver	11	3
	Other	10	2
Respondent age	Under 18	0	0
	18–24	2	1
	25–34	19	5
	35–44	76	19
	45–54	144	36
	55–64	109	27
	65+	53	13
Highest educational level of respondent	Elementary School	0	0
	Middle School	1	<1
	High School Graduate	66	16
	College Graduate	210	52
	Post-Graduate Degree	125	31
Respondent's approximate average household income	Under \$49,999 (under €44,730)	51	13
	Between \$50,000 and \$99,999 (between €44,731 and 89,463)	117	30
	Between \$100,000 and \$149,999 (between €89,464 and 134,195)	93	24
	Between \$150,000 and \$199,999 (between €134,196 and 178,927)	37	9
	Over \$200,000 (over 178,928)	44	11
	Prefer not to answer	53	13
<b>Regarding individual with Down syndrome</b>		<b>N</b>	<b>% of responses</b>
Does the loved one with Down syndrome live where you live?	Yes	357	91
Does the loved one with Down syndrome live	Independently	9	27
	In a group home	8	24
	With family	9	27
	Other	7	21
Which race/ethnicity best describes the loved one with Down syndrome? (please choose only one)	White or Caucasian	31	97
	Hispanic or Latino	1	3
What is the loved one with Down syndrome's gender?	Female	22	69
	Male	10	31
My loved one with Down syndrome has an additional diagnosis, which has been confirmed by a medical professional, (choose all that apply) of	Sleep Apnea	120	32
	Obesity	46	12
	Attention Deficient Hyperactivity Disorder (ADHD)	36	10
	Autism or Autism Spectrum Disorder (ASD)	29	8
	Celiac Disease	23	6
	Mental Health diagnosis	21	6
	Obsessive Compulsive Disorder (OCD)	18	5
	Dementia or Alzheimer's disease	12	3
	Regression	6	2
	Crohn's disease	2	1

**TABLE 1** (Continued)

Regarding individual with Down syndrome	N	% of responses
Moya Moya	1	<1
Medically complex	11	3
Mobility	17	5
None of the above	123	33
Other	134	36

**TABLE 2** 326 responses about safety and communication topics from survey of Down syndrome caregivers

	Achieved already, N (%)	Not achieved but not important, N (%)	Not achieved but important to me now, N (%)	Not achieved but may be important to me in the future, N (%)	Do not know, N (%)
Question: I feel the following SAFETY topics are important for my loved one with Down syndrome					
Social media safety	39 (12)	41 (13)	106 (33)	<b>134 (41)</b>	4 (1)
Internet safety	39 (12)	34 (10)	<b>128 (39)</b>	120 (37)	4 (10)
Bullying	77 (24)	20 (6)	<b>133 (41)</b>	77 (24)	16 (5)
Sexual abuse	59 (18)	12 (4)	<b>164 (50)</b>	76 (23)	14 (4)
Verbal abuse	69 (21)	11 (3)	<b>154 (48)</b>	72 (22)	18 (6)
Stranger danger	86 (26)	10 (3)	<b>184 (57)</b>	38 (12)	7 (2)
Safely crossing a street/parking lot	129 (40)	10 (3)	<b>164 (50)</b>	21 (6)	1 (<1)
Bolting/elopement (running away from caregiver)	<b>186 (57)</b>	18 (6)	95 (29)	17 (5)	8 (2)
Kitchen/cooking safety	77 (24)	15 (5)	<b>167 (51)</b>	65 (20)	1 (<1)
Water safety	<b>164 (50)</b>	14 (4)	126 (39)	17 (5)	4 (1)
Staying with a babysitter or other caregiver	<b>246 (76)</b>	9 (3)	49 (15)	11 (3)	7 (2)
Left home alone for greater than 2 h	<b>122 (38)</b>	14 (4)	69 (21)	114 (35)	6 (2)
Go out alone	44 (14)	28 (9)	97 (30)	<b>148 (46)</b>	7 (2)
I feel the following communication topics are important for my loved one with Down syndrome					
Communicating wants and needs	<b>195 (61)</b>	2 (1)	113 (35)	11 (3)	1 (<1)
Browse picture books without reading	<b>298 (93)</b>	2 (1)	17 (5)	4 (1)	0 (0)
Write his/her own name	<b>241 (75)</b>	5 (2)	58 (18)	19 (6)	0 (0)
Understand what he/she writes	<b>161 (50)</b>	10 (3)	105 (33)	42 (13)	2 (1)
Comprehend reading aloud	<b>150 (47)</b>	12 (4)	124 (39)	28 (9)	8 (2)
Write to communicate	103 (32)	16 (5)	<b>141 (44)</b>	58 (18)	5 (2)
Read for pleasure	103 (32)	24 (7)	<b>125 (39)</b>	63 (20)	7 (2)
Understand what he/she reads	98 (30)	17 (5)	<b>148 (46)</b>	45 (14)	14 (4)
Use verbal communication	<b>214 (67)</b>	3 (1)	95 (30)	5 (2)	4 (1)
Be understood by others, even with limited language	<b>170 (53)</b>	1 (<1)	139 (43)	11 (3)	1 (<1)
Use telephone	<b>159 (49)</b>	5 (2)	93 (29)	60 (19)	5 (2)
Use computer to play	<b>216 (67)</b>	19 (6)	46 (14)	37 (12)	3 (1)
Use a computer for internet and e-mail	99 (31)	21 (7)	90 (28)	<b>105 (33)</b>	7 (2)
Sharing personal information appropriately	51 (16)	11 (3)	<b>168 (52)</b>	82 (25)	11 (3)
Getting to/making/asking questions at doctor appointments	39 (12)	20 (6)	120 (37)	<b>136 (42)</b>	8 (3)
Ability to consent to medical treatment	48 (15)	29 (9)	88 (27)	<b>146 (45)</b>	11 (3)
	<b>195 (61)</b>	8 (2)	89 (28)	21 (7)	9 (3)

(Continues)

TABLE 2 (Continued)

	Achieved already, N (%)	Not achieved but not important, N (%)	Not achieved but important to me now, N (%)	Not achieved but may be important to me in the future, N (%)	Do not know, N (%)
Able to verbalize, sign or use assistive communication device to express wants and needs					
Expresses emotions appropriately	<b>158 (49)</b>	3 (1)	146 (45)	13 (4)	3 (1)
Ability to participate in a conversation (verbal, sign language or via a communication devise)	<b>202 (63)</b>	3 (1)	104 (32)	12 (4)	1 (<1)

Note: Green, important in ≥75%; yellow, important in 50%–74%; orange, important in <50%; bold, most frequent response for each safety topic.

### Top five “1<sup>st</sup> Choice” priorities for each Independence Category

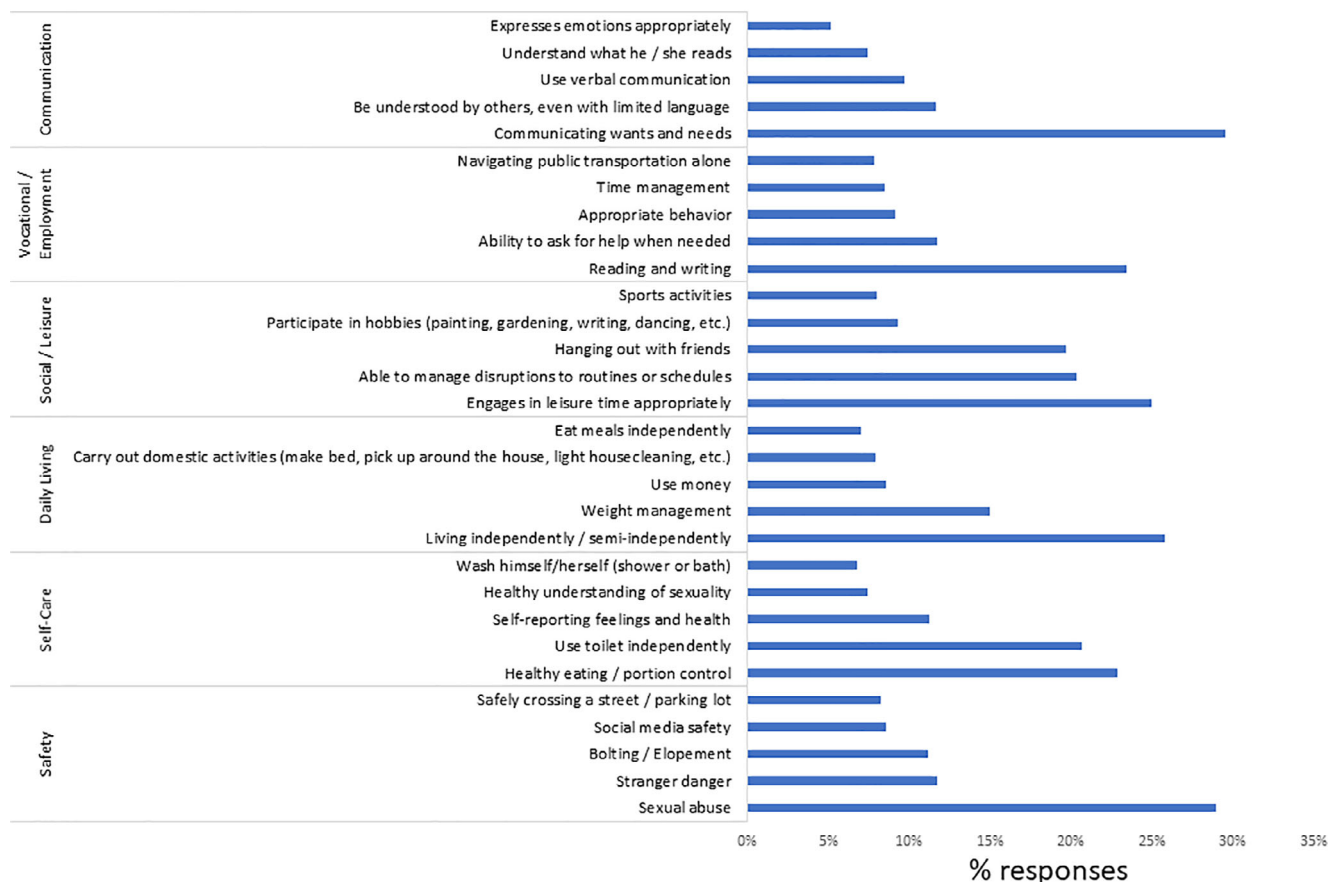


FIGURE 1 Top five prioritized choices for each independence category from questionnaire responses from 408 caregivers of individuals with Down syndrome

of most significant concern were: living independently/semi-independently (26% ranked as 1st choice), weight management (15% ranked as 1st choice), and using money (9% ranked as 1st choice).

On the question “I feel the following social/leisure time topics are important for my loved one with Down syndrome,” social/leisure topics were all most frequently reported as “Already Achieved,” with highest achievement of the topics: listening to music, watching TV, and walking (Table 4). Top concerns for social/

leisure skills were: engaging in leisure time appropriately (25% ranked as 1st choice), able to manage disruptions to routines or schedules (20% ranked as 1st choice), and hanging out with friends (20% ranked as 1st choice).

Vocational/employment topics were assessed in the question “I feel the following vocational/employment topics are important for my loved one with Down syndrome,” and those most frequently achieved were: the ability to ask for help when needed, use verbal

**TABLE 3** 325 responses about self-care skills and daily living skills topics from survey of Down syndrome caregivers

	Achieved already, N (%)	Not achieved but not important, N (%)	Not achieved but important to me now, N (%)	Not achieved but may be important to me in the future, N (%)	Do not know, N (%)
I feel the following self-care topics are important for my loved one with Down syndrome					
Dress and undress self	<b>249 (77)</b>	3 (1)	56 (17)	16 (5)	1 (<1)
Putting on/tying shoes	<b>169 (52)</b>	30 (9)	101 (31)	25 (8)	0 (0)
Use toilet independently	<b>229 (71)</b>	4 (1)	79 (24)	12 (4)	0 (0)
Grooming, brushing teeth, combing and/or brushing hair	<b>190 (58)</b>	9 (3)	104 (32)	22 (7)	0 (0)
Wash himself/herself (shower or bath)	<b>190 (58)</b>	9 (3)	98 (30)	28 (9)	0 (0)
Shaving	78 (25)	51 (16)	55 (18)	<b>111 (36)</b>	16 (5)
Cutting fingernails and toenails	38 (12)	45 (14)	115 (36)	<b>122 (38)</b>	3 (1)
Female hygiene needs	<b>88 (35)</b>	36 (14)	26 (10)	52 (21)	51 (20)
Healthy eating/portion control	86 (26)	6 (2)	<b>186 (57)</b>	43 (13)	4 (1)
Take own medications	96 (30)	17 (5)	78 (24)	<b>119 (37)</b>	12 (4)
Self-reporting feelings and health	112 (34)	7 (2)	<b>160 (49)</b>	43 (13)	3 (1)
Understanding of puberty	<b>116 (37)</b>	15 (5)	83 (26)	84 (27)	19 (6)
Healthy understanding of sexuality	39 (12)	25 (8)	<b>124 (38)</b>	118 (36)	18 (6)
Someone “safe” to talk to about thoughts and feelings	<b>130 (41)</b>	8 (2)	101 (31)	68 (21)	14 (4)
I feel the following daily living topics are important for my loved one with Down syndrome					
Drink independently from a cup	<b>287 (88)</b>	1 (<1)	31 (10)	6 (2)	0 (0)
Eat meals independently	<b>282 (87)</b>	1 (<1)	38 (12)	4 (1)	0 (0)
Move around in or out of the house	<b>283 (87)</b>	3 (1)	30 (9)	7 (2)	1 (<1)
Navigating public transportation alone	16 (5)	64 (20)	52 (16)	<b>184 (57)</b>	8 (2)
Traveling alone (on planes, trains, etc.)	15 (5)	74 (23)	48 (15)	<b>179 (55)</b>	8 (2)
Living independently/semi-independently	22 (7)	27 (8)	64 (20)	<b>207 (64)</b>	5 (2)
Driving	4 (1)	<b>139 (43)</b>	21 (7)	132 (41)	27 (8)
Doing errands, including shopping in stores	42 (13)	25 (8)	82 (25)	<b>167 (52)</b>	6 (2)
Use money	33 (10)	25 (8)	<b>131 (40)</b>	<b>131 (40)</b>	4 (1)
Manage daily finances (keep track of cash, checking account, pay bills, etc.)	7 (3)	44 (14)	81 (25)	<b>180 (56)</b>	11 (3)
Carry out domestic activities (make bed, pick up around the house, light housecleaning, etc.)	<b>157 (48)</b>	6 (2)	99 (30)	63 (19)	0 (0)
Doing laundry, washing and drying	95 (29)	15 (5)	94 (29)	<b>119 (37)</b>	1 (<1)
Use a watch	104 (32)	27 (8)	79 (24)	<b>108 (33)</b>	5 (2)
Follow a schedule	<b>160 (50)</b>	4 (1)	90 (28)	67 (21)	2 (1)
Time management	65 (20)	12 (4)	<b>142 (44)</b>	99 (31)	4 (1)
Prepare simple meals (requiring no mixing or cooking, including sandwiches, cold cereal, etc.)	<b>163 (50)</b>	4 (1)	70 (22)	87 (27)	1 (<1)
Cook meals (fry eggs, make pancakes, etc.)	54 (17)	22 (7)	99 (30)	<b>145 (45)</b>	5 (2)
Weight management	64 (20)	8 (2)	<b>152 (47)</b>	88 (27)	12 (4)

Note: Green, important in >75%; yellow, important in 50%–74%; orange, important in <50%; bold, most frequent response for each safety topic.

communication and have appropriate behavior (Table 4). Topics that were most frequently listed as important for the future including: reading and writing, organizational skills, and interpersonal skills. The top concerns among vocational/employment topics were reading and writing (23% listed as the 1st choice), able to ask for help when

needed (12% ranked as the 1st choice), and appropriate behavior (9% listed as the 1st choice).

For each of the six independence factors, caregivers could list “other” factors. No consistent topics were identified in the “other” open-response section which more than one caregiver reported.



**TABLE 4** 325 responses about social/leisure and vocational/employment topics from survey of Down syndrome caregivers

	Achieved already, N (%)	Not achieved but not important, N (%)	Not achieved but important to me now, N (%)	Not achieved but may be important to me in the future, N (%)	Do not know, N (%)
I feel the following social/leisure time topics are important for my loved one with Down syndrome					
Engages in leisure time appropriately	<b>180 (56)</b>	8 (2)	97 (30)	36 (11)	2 (1)
Able to manage disruptions to routines or schedules	<b>183 (57)</b>	4 (1)	110 (34)	23 (7)	3 (1)
Watching TV	<b>281 (87)</b>	10 (3)	15 (5)	13 (4)	5 (2)
Listening to music	<b>296 (91)</b>	6 (2)	9 (3)	10 (3)	4 (1)
Volunteering	<b>119 (37)</b>	33 (10)	48 (15)	116 (36)	7 (2)
Playing games (card games)	<b>164 (50)</b>	20 (6)	70 (22)	64 (20)	7 (2)
Participate in hobbies (painting, gardening, writing, dancing, etc.)	<b>176 (54)</b>	6 (2)	82 (25)	56 (17)	3 (1)
Sports activities	<b>193 (59)</b>	20 (6)	61 (19)	47 (14)	4 (1)
Walking	<b>273 (84)</b>	1 (<1)	44 (14)	6 (2)	0 (0)
Hanging out with friends	<b>142 (44)</b>	4 (1)	128 (39)	45 (14)	6 (2)
Going out to eat	<b>244 (75)</b>	3 (1)	35 (11)	38 (12)	4 (1)
Religious activities (church, etc.)	<b>198 (61)</b>	37 (11)	41 (13)	32 (10)	14 (4)
Going to the movies	<b>231 (71)</b>	13 (4)	37 (11)	41 (13)	3 (1)
I feel the following vocational/employment topics are important for my loved one with Down syndrome					
Reading and writing	120 (37)	16 (5)	<b>146 (45)</b>	42 (13)	0 (0)
Driving	4 (1)	130 (40)	22 (7)	<b>135 (42)</b>	31 (10)
Navigating public transportation alone	12 (4)	63 (19)	66 (20)	<b>174 (54)</b>	10 (3)
Traveling alone (on planes, trains, etc.)	16 (5)	76 (23)	42 (13)	<b>177 (54)</b>	14 (4)
Time management	60 (19)	13 (4)	<b>144 (44)</b>	100 (31)	7 (2)
Interpersonal skills	107 (33)	4 (1)	<b>153 (47)</b>	54 (17)	7 (2)
Money management	14 (4)	29 (9)	<b>139 (43)</b>	138 (42)	5 (2)
Ability to ask for help when needed	<b>171 (53)</b>	4 (1)	120 (37)	28 (9)	1 (<1)
Respecting personal boundaries	133 (41)	4 (1)	<b>151 (47)</b>	32 (10)	3 (1)
Appropriate behavior	<b>157 (48)</b>	3 (1)	139 (43)	22 (7)	3 (1)
Ability to focus on task at hand	<b>147 (46)</b>	3 (1)	145 (45)	27 (8)	1 (<1)
Organization skills	90 (28)	9 (3)	<b>154 (48)</b>	66 (20)	5 (2)
Understand what he/she reads	91 (28)	16 (5)	<b>159 (50)</b>	53 (17)	2 (1)
Use verbal communication	<b>188 (58)</b>	5 (2)	115 (35)	13 (4)	3 (1)
Be understood by others, even with limited language	<b>154 (48)</b>	3 (1)	152 (47)	15 (5)	0 (0)
Use telephone	<b>153 (47)</b>	5 (2)	99 (31)	66 (20)	0 (0)
Use a computer for internet and e-mail	<b>108 (34)</b>	21 (7)	91 (28)	96 (30)	6 (2)

Note: Green, important in  $\geq 75\%$ ; yellow, important in 50%–74%; orange, important in  $< 50\%$ ; bold, most frequent response for each safety topic.

Analysis was conducted based on age of individual with Down syndrome (Table 5). Age effects were seen, such that there were differences in the % of individuals with Down syndrome who had attained skills by category over age groupings. In general, communication was the most frequently attained skill across the age groups (Figure 2), though proportion achieving this skill ranged from 53% in those age 0–4 years, to 68% in those age 30–49 years (Table 5). Across age groups, safety was the category of skill least often achieved, and ranged from 35% in those age 0–4 years to 44% in those age 40–49 years.

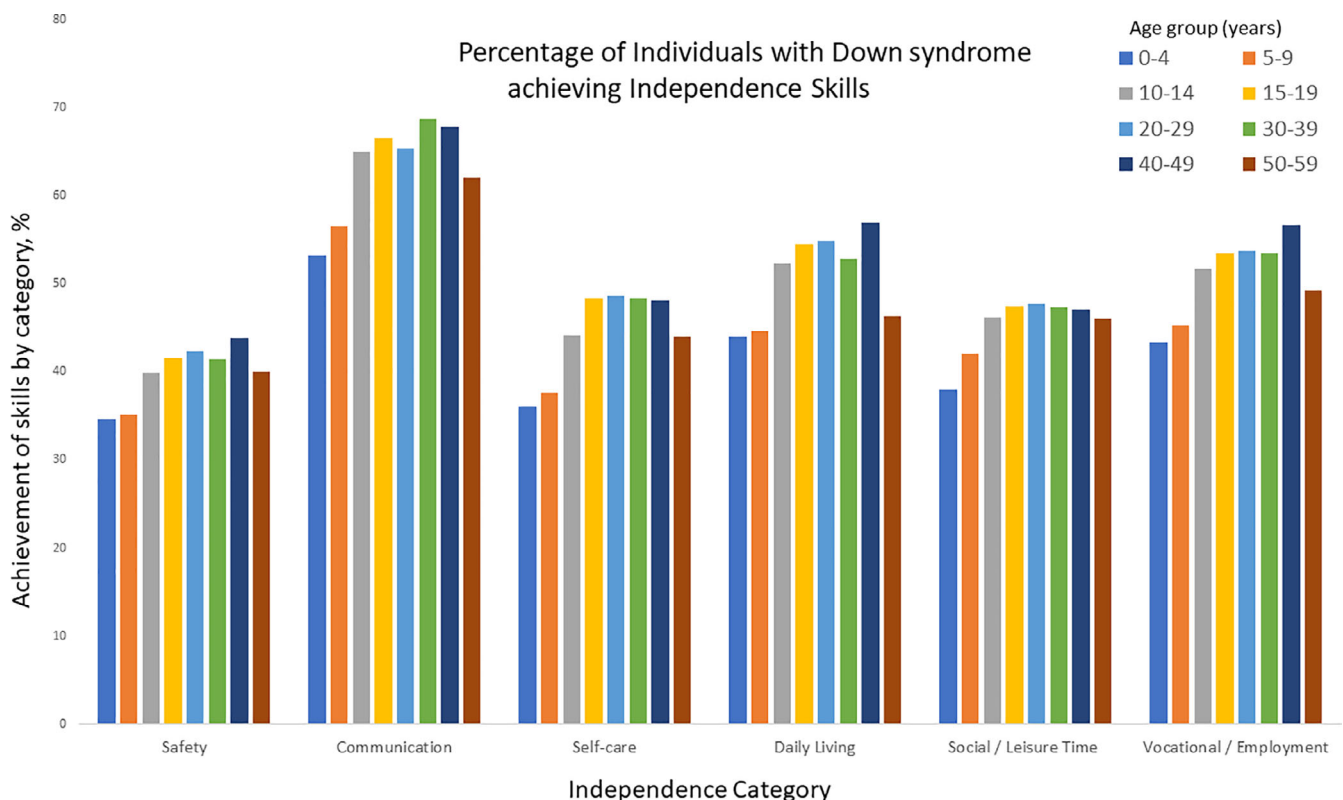
## 4 | DISCUSSION

Questionnaire of 408 caregivers of individuals with DS found that independence is a relevant topic and important to the vast majority of respondents. Among the factors considered, responses showed variability among achievement of skills, and no single task was able to be completed by all individuals. This study emphasizes the importance of considering each person as an individual rather than generalizing data to one person with DS.



**TABLE 5** Mean score for each independence categories by age of person with Down syndrome; calculated by summing the mean of % achieving the skills corresponding to each category

	Age of person with Down syndrome (years)									Between groups ANOVA results					
	0-4	5-9	10-14	15-19	20-29	30-39	40-49	50-59	No answer	Total cohort	Sum of squares	df	Mean square	F	p value
Safety	34.7	35.1	39.9	41.6	42.3	41.5	43.8	40.0	39.7	39.4	3141.7	8.0	392.7	13.7	<0.01
Communication	53.2	56.5	64.9	66.6	65.3	68.7	67.8	62.0	66.3	62.7	9076.3	8.0	1134.5	21.4	<0.01
Self-care	36.1	37.6	44.1	48.3	48.6	48.3	48.1	44.0	46.8	43.8	6477.0	8.0	809.6	26.6	<0.01
Daily living	44.0	44.6	52.3	54.5	54.9	52.8	56.9	46.3	54.0	51.0	6677.6	8.0	834.7	17.1	<0.01
Social/leisure time	38.0	42.1	46.1	47.4	47.7	47.3	47.1	46.0	47.3	45.0	3903.6	8.0	487.9	19.9	<0.01
Vocational/employment	43.3	45.3	51.7	53.4	53.8	53.5	56.7	49.2	54.4	50.6	5984.4	8.0	748.1	15.7	<0.01

**FIGURE 2** Percentage of individuals with Down syndrome achieving independence skills

Caregiver views of independence factors by topic showed:

- Safety was a crucial area for focus: Sexual abuse was the top priority in safety and the most frequently not achieved but important (50%) safety concern, with only 18% achieving safety from sexual abuse.
- Communication was a moderate concern: Communicating wants and needs was ranked as the first choice and was most frequently reported as achieved (61%), but 35% had not yet achieved this critical skill.
- Self-care was an important area: Toileting independently was prioritized, and 71% achieved this skill.
- Daily living skills were viewed as a future goal: Living independently / semi-independently was the top priority, and 64% had not achieved this goal but viewed it as necessary for the future; only 7% had achieved this goal.
- Social/leisure skills were an area of achievement: Engaging in leisure time appropriately was rated as the first priority, and 56% had already achieved this goal. The achievement was high across the factors listed in this grouping.

- Vocational/employment topics were viewed as a future goal: Reading and writing were the top priority, and 45% were viewed as an important goal to achieve in the future.

Independence is a complex phenomenon; our questionnaire respondents viewed dozens of factors as important to independence now or in the future for their loved one with DS. Across the six categories of independence factors, themes emerged which may guide future planning or current action. For example, the finding of low safety related to sexual abuse indicates that caregivers feel that most individuals with Down syndrome are not independently able to navigate this safety topic, and more assistance is needed to keep their loved ones safe from potential sexual abuse. Our survey did not ask specific details on caregiver's experiences with sexual abuse or the underlying reason that this topic remains of high importance to them. Unfortunately, caregivers have cause to be concerned for sexual abuse, and the American Academy of Pediatrics suggests explicitly educating parents about increased risk of sexual exploitation, and reminding them that likely perpetrators are people their child knows and trusts, not strangers (AAP, 2018; Bull, 2011). Our findings suggest there is a need for additional resources, education, and support at home and school to protect individuals with DS from sexual abuse.

Functional status played a role in independence through daily living skills and self-care skills. Importantly, there were many important skills that had not yet been achieved but were viewed as important to independence. Some were health-related such as healthy eating, taking medications, and understanding sexuality. These skills could be improved with additional resources and support provided during a medical visit (Bull, 2011; Tsou et al., 2020) or additional interventions designed to target these skills (Lazar, 2018). Similarly, many daily skills could be improved with behavioral training, visual supports, or assisted technology (Down Syndrome Association of Qld, 2021).

Caregiver perspectives aligned with many of the topics and independence factors listed in our questionnaire. Many of the topics were viewed as either achieved or of importance. However, some of the topics were viewed as "Not achieved, but not important," and lowest priority topics were travel-related: driving (40%), navigating public transportation alone (20%), traveling alone (23%; Tables 2–4). No consistent topics were identified to be missing from the listed topics in the questionnaire. Importantly, the questionnaire matched well with caregivers' priorities and factors associated with independence.

Our study is limited by the use of an unvalidated questionnaire, though as described, the factors listed in the questionnaire aligned well with caregiver views. Although the LuMind IDSC foundation is a large, international group with many members, the caregivers completing the questionnaire were all members of a single research group for DS, limiting the generalizability of results to those who are not members of the group. The demographic traits of our sample may not generalize to the population (e.g., 83% with college or post-graduate degrees). Future study could expand on our study using a national source, such as DS-Connect (National Institutes of Health, 2019; Pehrah et al., 2015) which may have greater generalizability to the U.S. population with DS. A larger cohort would also allow more

correlations between factors (e.g., safety issues, and demographic traits, or medical comorbidities) and would enhance educational opportunities from the data. For example, the relationship between medical conditions like obesity with concern about independence with portion sizes would be of interest to target interventions for obesity.

We are also limited to caregiver-reported information without external validation of responses regarding independence and skills achieved, or self-report from individuals with DS. In the future, it would be ideal to collect validated response from other sources (such as from IEP/IFSP or therapist evaluations) to confirm information. However, information (such as IEP/IFSP data) may be limited for adults with DS who are no longer receiving consistent therapies, are employed, in day programs, or live in group homes. Future validation work could also use a version of our survey to study independence in individuals with intellectual disability and to evaluate for known-groups validity expecting specific co-occurring conditions of higher prevalence in DS, such as AD, to be more important to caregivers of individuals with DS.

Other limitations include the limitations of electronic survey, such as: respondents to online questionnaires tend to be white, middle-class with access to computer technology, we are unable to confirm that all caregivers were indeed caregivers of individuals with DS, and we are unable to calculate a response rate. Extrapolating from the membership emails sent, and surveys received, our results reflect 2% of the LuMind membership. However, studies have suggested that achieving a high response rate requires considerable resources, and may offer little or no reduction of nonresponse bias (Hendra & Hill, 2019). Older caregivers who may not be comfortable with online questionnaires may have been less likely to respond. In the future, including phone or paper responses could improve the diversity of responses, though studies suggest that response rate of web surveys is only 10% lower than that of mail and telephone surveys (Fan & Yan, 2010). Additionally, our results may be limited in generalizability to other ethnic and cultural groups, given that 97% of respondents reported that their loved one with Down syndrome was white or Caucasian. Future research should prioritize diversity in both people with Down syndrome and in caregiver respondents, as understanding of lived experience and barriers is necessary for developing interventions to improve independence. Furthermore, our results may be limited in generalizability to caregivers of males with Down syndrome, as 69% of our respondents were caregivers for females with Down syndrome.

This questionnaire of caregivers of individuals with DS describes skills across six factors of independence and ranks the priority of factors to attaining independence now or in the future. This information is helpful for groups aiming to improve independence for adults with DS, including future research efforts.

## 5 | CONCLUSION

Caregivers of individuals with DS described variation in independence factors. Independence is a complex, multifactorial phenomenon. Important lessons learned include concerns with safety, especially

around sexual abuse, the need to improve self-care skills and communication, and future daily living skills and vocation or employment goals.

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## CONFLICT OF INTEREST

James Hendrix is a full-time employee of the LuMind IDSC Foundation. The other authors have no conflict of interest to declare.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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