Received: 5 September 2022 | Accepted: 31 October 2022

DOI: 10.1002/ajmg.a.63059

ORIGINAL ARTICLE

AMERICAN JOURNAL OF medical genetics PART A WILEY

Personal social networks of people with Down syndrome

Brian G. Skotko[1,2] | Kavita Krell[1] | Kelsey Haugen[1] | Amy Torres[1] | Amber Nieves[3,4] | Amar Dhand[3,4,5]

[1]Down Syndrome Program, Division of Medical Genetics and Metabolism, Department of Pediatrics, Massachusetts General Hospital, Boston, Massachusetts, USA

[2]Department of Pediatrics, Harvard Medical School, Boston, Massachusetts, USA

[3]Division of Stroke and Cerebrovascular Diseases, Department of Neurology, Brigham and Women's Hospital, Boston, Massachusetts, USA

[4]Division of Hospital Neurology, Brigham and Women's Hospital, Boston, Massachusetts, USA

[5]Department of Neurology, Harvard Medical School, Boston, Massachusetts, USA

Correspondence
Brian G. Skotko, Massachusetts General Hospital, 125 Nashua Street, Suite 821, Boston, MA, USA.
Email: bskotko@mgh.harvard.edu

Abstract

Studies in the neurotypical population have demonstrated that personal social networks can mitigate cognitive decline and the development of Alzheimer disease. To assess whether these benefits can also be extended to people with Down syndrome (DS), we studied whether and how personal networks can be measured in this population. We adapted a personal networks instrument previously created, validated, and implemented for the neurotypical population. We created two versions of the survey: one for participants with DS, ages 25 and older, and another for their study partners, who spent a minimum of 10 h/wk in a caregiver role. Participants with DS gave concordant data to those of study partners. Their personal networks included a median network size of 7.50, density 0.80, constraint 46.00, and effective size 3.07. Personal networks were composed of 50% kin, 80% who live within 15 miles, and 80% who eat a healthy diet. In this proof-of-principle study, we demonstrated that the personal networks of people with DS can be quantitatively analyzed, with no statistical difference between self-report and parent-proxy report. Future research efforts can now evaluate interventions to enhance personal networks for preventing Alzheimer disease in this population.

KEYWORDS

Alzheimer disease, dementia, Down syndrome, personal networks, social networks, trisomy 21

1 | INTRODUCTION

People with Down syndrome (DS) are living longer than they ever have before, thanks to continued advances in science and medicine (Antonarakis et al., 2020; de Graaf et al., 2017). Yet, as their population size continues to grow within the United States (Antonarakis et al., 2020; de Graaf et al., 2017, 2022), more adults with DS will also be diagnosed with Alzheimer disease—caused, in part, by the extra *APP* gene, encoding amyloid plaques, located on their triplicated chromosome 21 (Antonarakis et al., 2020; Ballard et al., 2016; Lott & Head, 2019). By some estimates, ~50% of adults with DS will show symptomatic signs of dementia by the age of 60 (Bayen et al., 2018; Sinai et al., 2018; Strydom et al., 2010). To date, no pharmaceutical options have proven to be effective in treating dementia for this population (Ballard et al., 2016).

Studies in the neurotypical population have demonstrated that personal networks—the persons around an individual who provide support, circulate information, and influence health behaviors (Dhand et al., 2016)—can mitigate cognitive decline and the development of Alzheimer disease (Fratiglioni et al., 2004). In one nationally representative cohort study of 3310 adults, ages 62–90, researchers found that individuals at most risk for early dementia had smaller network sizes, less community involvement, and more reliance on family members (Kotwal et al., 2016). In a prospective study of 2249 women, ages 78 and older, large personal networks had a protective effect on cognitive functioning (Crooks et al., 2008). In another prospective study of 823 seniors free of dementia at enrollment, the risk of Alzheimer disease was more than doubled in lonely people (Wilson et al., 2007). Loneliness was also associated with lower cognitive levels at baseline as well as with further cognitive decline in subsequent years (Wilson et al., 2007). The exact mechanisms by which personal networks

Abbreviation: DS, Down syndrome.

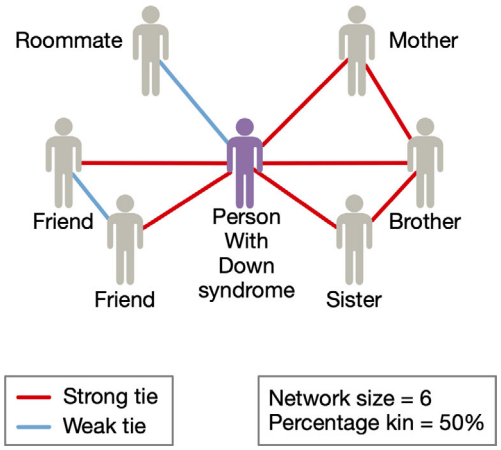

FIGURE 1 Sociogram example for a person with Down syndrome

lessen cognitive decline are multifactorial. Researchers suggest that social relationships increase cognitive stimulation ("use it or lose it"; Hultsch et al., 1999), buffer patients from expected adverse cognitive effects of brain volume loss (Perry et al., 2021), and temper stress-related neurological effects (Fratiglioni et al., 2004).

In the neurotypical population, social connection has also been linked to better physical health including longevity. In a meta-analytic review of 148 studies (308,849 participants in total), researchers found that people with stronger social relationships had a 50% increased likelihood of survival than those with weaker social relationships (Holt-Lunstad et al., 2010). On average, people with DS have a shortened life span (58 years; de Graaf et al., 2017) compared with the neurotypical population (77 years; CDC, 2022).

An open question follows: can these benefits observed in the neurotypical population also be expected for people with DS who all have an intellectual disability to some degree? To answer this question, we must first assess whether and how personal networks can be measured in people with DS. Derived from a standardized survey made for clinical populations (PERSNET; Dhand et al., 2018) the personal networks of a participant may be visualized into a sociogram (Figure 1). With a sociogram, we may further quantify the characteristics of the network including metrics of structure (e.g., network size) and composition (e.g., percentage kin).

In this proof-of-principle study, we studied the personal networks in a cohort of adults with DS. We asked: can adults with DS reliably self-report their own personal networks? What is the range of quantitative characteristics of personal networks in a DS cohort?

2 | PATIENTS AND METHODS

2.1 | Patients

We recruited people with DS, ages 25 and older, who were patients in our Massachusetts General Hospital Down Syndrome Program, a multidisciplinary tertiary clinic that sees patients about once yearly. Each participant needed to be verbal with English as their primary language and able to respond to questions. Patients who had a diagnosis of dementia were excluded. Each participant also needed to have a study partner, 18 years or older, who served as a caregiver and spent at least 10 h each week with the participant with DS. The study partner must also be verbal with English as their primary language.

This study was deemed exempt by the Massachusetts General Brigham Institutional Review Board for written informed consent. If the participant with DS did not have a legal guardian, the study coordinator obtained informed, implied verbal consent from the participant with DS and their study partner. If the participant with DS had a legal guardian, the study coordinator obtained informed verbal consent from the legal guardian of the person with DS along with the study partner (if different than the legal guardian), and assent was established with the participant with DS. At all times, if dissent from the participant with DS was detected, the study procedures would be stopped.

2.2 | Survey

We adapted the PERSNET personal networks instrument previously created, validated, and implemented by Dhand et al. (2016, 2018) and Prust et al. (2021). We created two versions of the survey: one for participants with DS and another for the study partners. Our adaptations aimed to reduce the reading level of the questions so that our participants with DS could best understand their intent (see Supplementary Appendix S1 for complete surveys). The first set of questions was aimed at creating a master list of people who are important to the person with DS. We used three questions to elicit a list from participants with DS: (1) Who do you discuss important stuff with?; (2) Who do you often hang out with?; (3) Who helps you when you feel sick? The questions for the study partner used the same language: (1) Who does your loved one discuss important stuff with?; (2) Who does your loved one often hang out with?; (3) Who helps your loved one when he/she feels sick?

After generating a master list of names from these questions and removing duplicates, our team next asked a series of questions to measure the closeness of the relationships to the person with DS. For the participants with DS, we asked, "How close do you feel to…?" The answer options were "very close" or "not very close." The survey for the study partner used parallel language, "Compared to everyone you've listed, how close do you think your loved one feels to each person?" The answer options were again "very close" or "not very close."

We then measured the closeness of relationships between the social connections, using the first names generated by the study partner. We asked, "Is [person A] a total stranger, very close, or in-between with [person B]?" We defined "total strangers" as two people who would not know one another if they met on the street; "in-between" as relationships in the middle of total strangers and very close, typically people who know each other's name and face; and "very close" as two people who as close or closer to each other than

they are to you. Study partners were also asked this question of the master list of names generated by the participants with DS (see study procedure below).

For the study partners only, we asked additional descriptive questions about the master list of names that they had generated: Which person or persons support your loved one most often? What is the sex of each person in your loved one's network? What is the race of each person in your loved one's network? What is the ethnicity of each person in your loved one's network? As far as you know, does this person have any of the following (answer options: "Down syndrome," "Other disability," "No disability/typical," or "Do not know")? On average, how often does your loved one communicate with each person in his/her network by video chat (e.g., FaceTime), phone, or in person (Do NOT consider texting/instant messaging/Facebook; answer options: "daily," "weekly," "monthly," "less often," "do not know")? For how many years has your loved one known the following people (answer options: "<3 years," "3–6 years," ">6 years," and "do not know")? How far does each person live from your loved one? (answer options: "same house," "≤5 miles," "6–15 miles," "16–50 miles," and "50+ miles")? Are any of the following barriers to your loved one's relationship with each of the following (answer options: "transportation," "availability of caregivers to coordinate," "scheduling conflicts," "language issues/speech intelligibility," and/or "none")? For each person, in what way are they connected to your loved one (answer options: "spouse," "family," "friend," "advisor," "co-worker," or "other")? How old is each person? Has your loved one exercised at least three to four times a week over the past 3 months? Which people in your loved one's network do you think have exercised at least three to four times a week in the past 3 months? Did your loved one eat a healthy diet regularly over the past 3 months? Which people in your loved one's network do you think ate a healthy diet regularly over the past 3 months?

On both the surveys for participants with DS and their study partners, we also collected sociodemographic variables about the person with DS including gender, race, ethnicity, educational level, zip code, dating status, and living arrangement.

2.3 | Study procedures

After inclusion and exclusion criteria were reviewed, our study team reviewed the project's information sheet with the dyads over the phone (Figure 2). We obtained informed consent or assent verbally from the patients with DS, based on their age and legal guardianship status. As needed, we obtained informed consent verbally from parents and/or legal guardians.

Once consent was obtained, we surveyed study partners and participants with DS separately. First, the study partners were e-mailed a unique link to their survey. We collected and managed study data using Research Electronic Data Capture (REDCap) electronic data capture tools hosted at Massachusetts General Hospital (Harris et al., 2009, 2019).

After the caregiver completed their survey, our research team scheduled a videoconference session with the participant with DS alone, initially. In the interview, our research team asked the questions directly to the participants and entered their responses into REDCap, which was not shown to the participants. After the participant had completed their survey, the study partner was then invited to join the session. During this portion of the videoconference, the previous answers of the participant with DS were not altered. New questions—which were a priori felt to be too cognitively challenging for most people with DS to answer alone—were asked when the study partner was available to assist. Specifically, we asked the study partner to identify whether the names generated by the person with DS were "real and alive (such as a best friend), real but not alive (such as a deceased grandparent), or not real (such as Spiderman)." Then, we asked study partners to assess the closeness of relationships between the social connections, using the first names generated by the person with DS: "Is [person A] a total stranger, very close, or in-between with [person B]?"

2.4 | Analyses

The analyses for personal networks have been previously described in length (Dhand et al., 2016). In brief, "network size" is the quantity of members within the patient's personal network excluding themselves. This quantity contains both the number of individuals identified and used within the direct network as well as any additional individuals beyond five for each name-generating question, allowing for an unbounded network size. Thus, this value may be the same as or larger than the number of individuals observed in the graphical network.

"Constraint" is a measurement of how tightly connected members of the network are to the network, in general. This statistic is derived from Burt's Aggregated Constraint value, which includes data on the number of network members, their ties, the strength of their ties, and second order ties. This statistic is then multiplied by 100 to better integrate with modeling. The scale for this measurement is from a theoretical zero to maximum of 125, with zero being a perfectly "open" or "bridging" network and 125 representing perfectly "closed" or "constrained" networks.

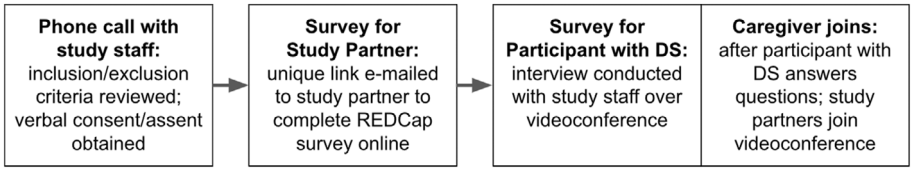

FIGURE 2 Flow diagram of survey methodology. DS, Down syndrome; REDCap, Research Electronic Data Capture

"Density" is a measurement of how dense the patient's personal network is based upon the quantity of ties between network members excluding the patient. This statistic is determined by taking the number of actual ties between network members and dividing it by the total number of possible ties that could possibly be made between network members. The scale for this measure is from a theoretical zero to maximum of 1, which would represent a perfectly "dense" network.

"Effective size" describes how many unique informational "groups" exist within the network—that is, the number of unique voices in the network based upon the number and strength of ties. Networks in which everyone knows everyone very well will result in lower effective sizes, while networks in which there are many persons are not interconnected will result in larger effective sizes. Mathematically, the statistic is determined by taking the total strength of direct ties to the proband and subtracting from it the average strength of ties to each network member; strong ties are assigned a value of 1 and weak ties a value of 0.5 The scale for this measure is from minimum of a theoretical zero to the network size value of a given network.

"Max degree" is the largest number of ties that any network member has within the network (excluding the proband and ties to the proband). The scale for this measure is from a minimum of zero to the network size – 1.

"Mean degree" is the average number of ties for all network members (excluding the proband and ties to the proband). The scale for this measure is from a minimum of zero to the network size – 1.

The composition variables include information about the network members, such as the proportion of individuals who eat a healthy diet or exercise. These variables can be considered indicators of the social milieu around the patient, which may influence the health habits of the patient.

The graphical representation of the personal networks ("sociograms") was generated using R version 4.1.2 (Vienna, Austria). We adapted code to process from https://github.com/AmarDhand/PersonalNetworks.

A Fisher's exact test was used to compare the demographics between self-report and proxy-report. We used a Pearson correlation coefficient and the Wilcoxon's signed rank test, a nonparametric paired test, to compare the network metrics between self-report and proxy-report. Missing responses were excluded from analyses.

3 | RESULTS

3.1 | Participants

Of the 43 dyads, 5 did not have responses from the corresponding person with DS (3 decided not to participate due to the emerging demands of the coronavirus disease of 2019 (COVID-19) pandemic, 1 no longer had a study partner who spoke English as a primary language, and 1 was lost to follow-up). As reported by the study partners, the participants with DS had a mean age of 36.3 years (SD = 8.9, range 25–55, $N = 43$). They included both males and females and were predominantly non-Hispanic whites (Table 1). The majority had a high school education or less. About 20% were dating someone. For the overwhelming majority of adults who do not live alone, they had a mean of 3.8 persons in their households, including themselves (SD = 2.0, range 2–12, $N = 37$).

The participants with DS ($N = 38$) gave concordant responses to those from their study partners about their own sociodemographic characteristics, except for race, ethnicity, and educational level (Table 1). Participants with DS were more likely to skip questions about race and ethnicity. Participants with DS tended to report a higher level of education. For those who did not report living alone, they had a mean of 4.0 persons in their households, including themselves (SD = 2.2, range 2–10, $N = 30$).

3.2 | Personal network characteristics

The participants with DS gave concordant responses to those from their study partners for all the personal network quantitative characteristics (Table 2). All study partners and participants with DS were able to answer the survey questions so that sociograms could be generated (Figures 3 and 4). According to participants with DS, the median network size was 7.50, constraint 46.00, density 0.80, and effective size 3.07. Side-by-side sociograms for each dyad are available in the Supplementary Figure S1. Individual network metrics for self-reports and proxy-reports are also available in the Supplementary Tables S1 and S2.

The composition of the personal networks, based on study partner responses only, described a milieu of social characteristics around the participant (Table 3). About 50% of network members were family. There was an equal proportion of male and female members, and nearly all members were of the race and ethnicity that was concordant with that of the participant with DS. The SD of ages was high at 16 years, meaning the networks had older and younger persons around the participant. Only 6% of network members had DS or another disability, themselves. About 38% of network members had some barriers to interacting with the participant, defined as transportation, availability for caregivers to coordinate, scheduling conflicts, and language issues/speech intelligibility. Most network members were known to the participant for more than 6 years, and 80% were geographically proximate. The network members were reported to have healthy lifestyles: 60% of network members exercised at least three to four times weekly, and 80% ate a healthy diet regularly. One participant with DS identified two network members who were real, but not alive (i.e., two deceased grandparents). No participants identified network members who were not real.

4 | DISCUSSION

In this proof-of-principle study, we demonstrated that the personal networks of people with DS can be quantitatively analyzed, with no

TABLE 1 Demographics of participants with DS, as reported by study partners and the participants with DS

	As reported by study partner ($N = 43$)		As reported by participant with DS ($N = 38$)		
Variable	***N***	**%**	***N***	**%**	***p* value**
Sex					0.7348
Male	24	55.8	20	52.6	
Female	19	44.2	17	44.7	
Other	0	0.0	1	2.6	
Race					0.0015
Black or African American	0	0.0	0	0.0	
White	41	95.3	27	71.1	
American Indian/American Native	0	0	1	2.6	
Asian	1	2.3	1	2.6	
Native Hawaiian or other Pacific Islander	0	0	0	0	
Other	1	2.3	1	2.6	
Blank	0	0.0	8	21.1	
Ethnicity					<0.0001
Hispanic	2	4.7	1	2.6	
Not Hispanic	39	90.7	18	47.4	
Unknown	1	2.3	10	26.3	
Blank	1	2.3	9	23.6	
Educational level					0.0033
Some high school or less	13	30.2	1	2.6	
High school graduate	23	53.5	28	73.7	
Some college	2	4.7	6	15.8	
Associate's degree	2	4.7	2	5.3	
Prefer not to answer	2	4.7	1	2.6	
Blank	1	2.3	0	0.0	
Currently dating someone					0.1416
Yes	9	20.9	14	36.8	
No	33	76.7	24	63.2	
Blank	1	2.3	0	0	
Living status					0.5333
Living alone	5	11.6	7	18.4	
Not living alone	38	88.4	31	81.6	

Abbreviation: DS, Down syndrome.

TABLE 2 Social networks summary metrics, as reported by study partners ($N = 43$) and participants with Down syndrome ($N = 38$)

	Study partner median [interquartile range]	Participant with down syndrome median [interquartile range]	*r*	*p*-value
Network size	8.00 [6.00, 10.50]	7.50 [5.25, 11.00]	0.26	0.71
Constraint	52.09 [40.56, 61.46]	46.00 [36.62, 56.53]	0.05	0.12
Density	0.90 [0.67, 1.00]	0.80 [0.67, 0.99]	−0.03	0.32
Effective size	2.70 [1.76, 4.20]	3.07 [1.69, 4.41]	0.01	0.31
Maximum degree	5.00 [4.00, 7.00]	6.00 [4.00, 7.75]	0.15	0.46
Mean degree	4.00 [3.43, 5.00]	4.57 [3.47, 5.30]	0.50	0.64

Note: *r*, Pearson correlation coefficient.

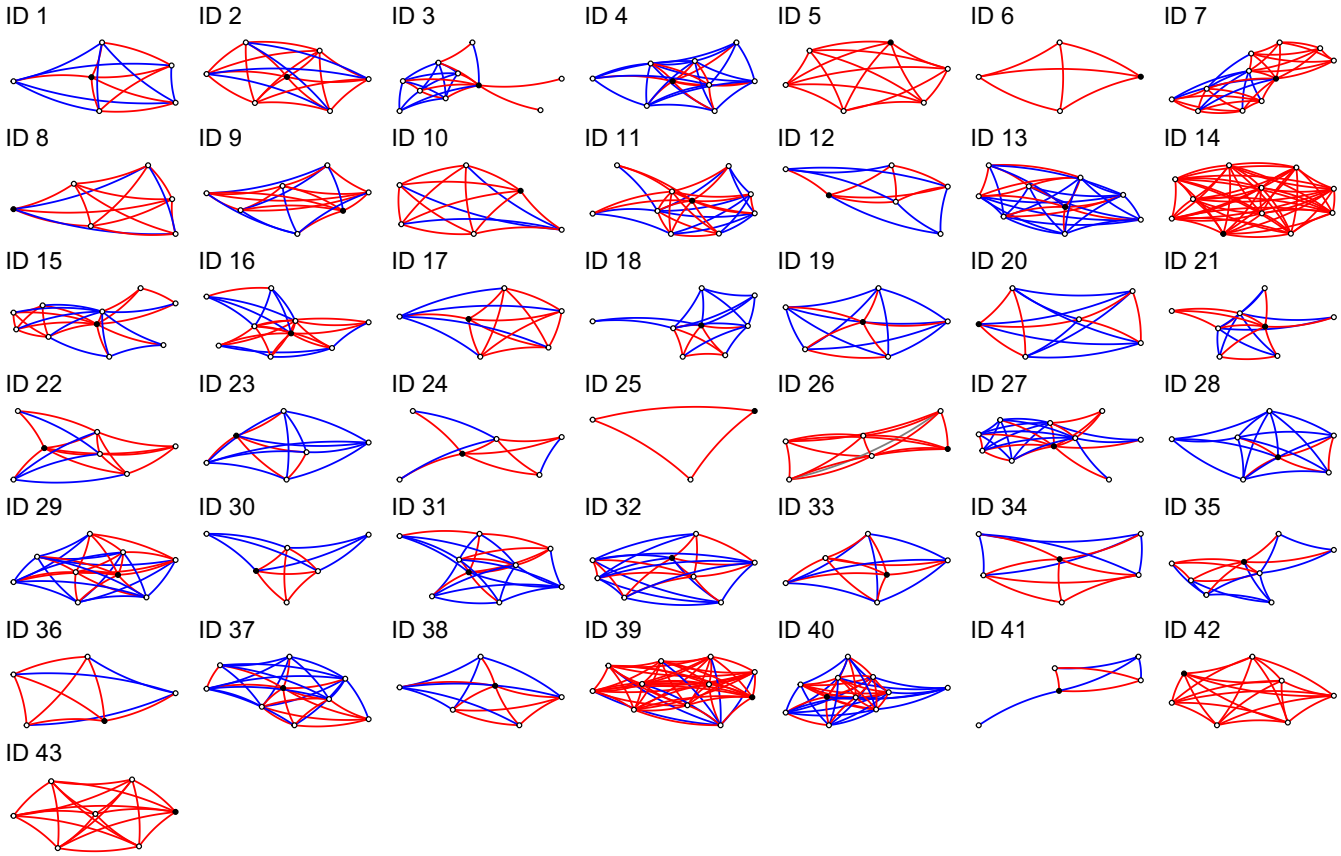

FIGURE 3 Personal networks of people with Down syndrome, as reported by their study partners ($N = 43$). In each personal network, a solid black dot represents the proband with Down syndrome, open dots represent other social connections, blue lines represent weak social ties between two persons, and red lines represent strong social ties between two persons

statistical difference between self-report and parent-proxy report. Since people with DS all have an intellectual disability to some degree, this finding is significant, demonstrating that our adaptation of the personal social networks survey could be understood reliably. As patient-centered research efforts expand, particularly for those with intellectual disabilities (Patient-Centered Outcomes Research Institute, 2021), this has significant implications for capturing the voices of adults with DS and other intellectual disabilities on these topic domains—and not just relying on parent-proxy reports (Santoro et al., 2022). With that said, the correlations ranged between weak and strong, suggesting that there would be value in including both the self-proxy and parent-proxy reports.

Sociograms of these social structural patterns could also be generated for each person with DS, demonstrating that future clinical trials could incorporate these measures as primary or secondary outcomes. In particular, future research efforts might evaluate interventions aimed at increasing the quantitative characteristics of these personal networks. Additional trials might focus on measuring what impact such changes might have on the mitigation of Alzheimer disease, which occurs at a higher frequency in this population. Increased personal network dimensions have been correlated with a decrease in Alzheimer disease in the neurotypical population (Crooks et al., 2008; Fratiglioni et al., 2004; Hultsch et al., 1999; Kotwal et al., 2016; Perry et al., 2021; Wilson et al., 2007). Cognitive interaction achieved in diverse and open personal networks may also help promote cognitive reserve (Peng et al., 2022; Perry et al., 2021). An open question remains: could enhancing the social networks of people with DS help prevent or delay the onset of Alzheimer disease or boost their cognitive reserve?

The structures of personal networks of persons with DS were, on average, large and open with a network size of about 8 and a constraint of about 46. Neurotypical individuals from a national cohort study, in comparison, had an average network size of 8 and constraint of 44 (Dhand et al., 2018). This openness in the network is accompanied by 3.1 unique informational groups (effective size). In comparison, neurotypical individuals had an effective size of 4.0 (Dhand et al., 2018). These results show similarity between persons with DS and neurotypical individuals. This might be surprising to those who hypothesize that people with DS have trouble sustaining meaningful friendships. Our results, however, are consistent, with a previous study in which sampled people with DS self-reported little trouble in making friends (Skotko et al., 2011).

The personal network members for people with DS were largely racially and ethnically concordant with the persons with DS. These persons were unlikely to have a disability of their own. About half were family members, and most were geographically proximate to the

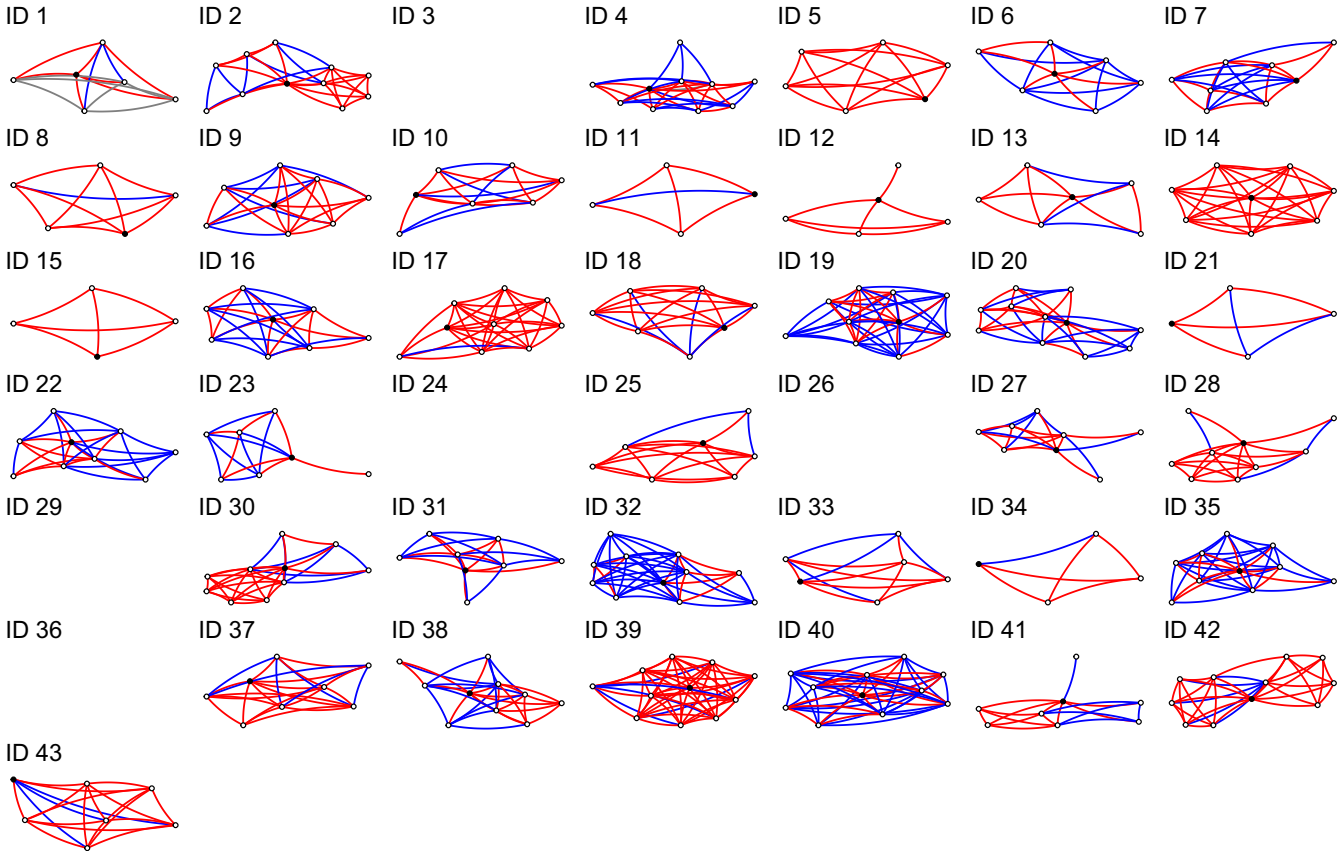

FIGURE 4 Personal networks of people with Down syndrome (DS), as self-reported ($N = 38$). In each personal network, a solid black dot represents the proband with DS, open dots represent other social connections, blue lines represent weak social ties between two persons, and red lines represent strong social ties between two persons. IDs 3, 24, 26, 29, and 36 represent the 5 participants with DS for whom we did not have responses.

adults with DS. These results might be explained, in part, by people with DS who continue to live with family members during their adulthood. An increasing number of adults with DS, though, are moving to group homes, where housemates and staff become potential built-in members of one's personal network. That much of this study was conducted during the COVID-19 pandemic might also contribute to network members being mostly within family homes or group homes. Most adults with DS also participate in day programs, frequently funded by the Massachusetts Department of Developmental Services. These day programs afford people with DS the opportunity to incorporate staff and other participants into their personal networks. Most day programming was closed for in-person experience during the COVID-19 pandemic. Future research might further examine the potential protective effects of these built-in social networks from group homes and day programs.

The majority of network members in our sampled population were likely to have healthy habits—that is, they are prone to exercising regularly and eating a healthy diet. Adults with DS are frequently obese—and subsequently develop associated comorbidities such as obstructive sleep apnea, liver dysfunction, diabetes type II, and hyperlipidemia (Capone et al., 2018). While this obesity can be explained, in part, by the reduced metabolic rate in adults with DS, the effects can still be mitigated with healthy lifestyle changes (Curtin et al., 2013; Fleming et al., 2008). Recent studies have documented that people with DS rarely achieve the minimum recommended exercise standards (Oreskovic et al., 2020). Future research might focus on interventions that could effectively tap into these personal network members as motivating role models for healthy habits.

Our research has limitations. By using a convenience sample, our results are subject to selection bias and might not be generalizable to the larger population of people with DS. Future studies might aim to replicate this study in a larger population so that personal network norms might even be established by age group for people with DS. Our research might also be prone to recall bias. People with DS might not remember to name all of the people in their current personal networks. However, the number of names were not statistically different from the names independently provided by their caregivers. If the proxy-reported sociodemographic variables are accepted as truth, people with DS demonstrated inaccuracy in reporting their own race, ethnicity, and educational level. Future research might explore other ways in which respondents with DS might better understand these questions. If these questions, however modified, remain too challenging for accurate responses, future research studies should incorporate proxy-reports when these sociodemographic variables are

TABLE 3 Characteristics of social network members, as reported by study partners ($N = 43$)

	Median [interquartile range]
Proportion of network members who are kin	0.50 [0.40, 0.75]
SD of network members' ages	16.41 [14.64, 18.74]
Diversity of men and women in the network (0, all one sex; 1, equally balanced men and women)	0.96 [0.72, 0.98]
Diversity of different races in the network (0, all one race; 1, equally balanced across all races)	0.00 [0.00, 0.28]
Diversity of different ethnicities in the network (0, all one ethnicity; 1, equally balanced across all ethnicities)	0.00 [0.00, 0.00]
Proportion of network members who have disability	0.06 [0.00, 0.28]
Proportion of network members who exercise 3–4 times a week	0.60 [0.37, 0.80]
Proportion of network members who eat a healthy diet regularly	0.80 [0.60, 1.00]
Proportion of network members who are in contact daily or weekly	0.43 [0.33, 0.60]
Proportion of network members who have been known for more than 6 years	0.80 [0.73, 1.00]
Proportion of network members who live in the same house or within 15 miles	0.80 [0.65, 1.00]
Proportion of network members who have a barrier in spending time with focal individual with DS	0.38 [0.00, 0.53]

Abbreviations: DS, Down syndrome; SD, standard deviation.

important. Study partners needed to be at least 18 years or older and spend at least 10 h each week with the participant with DS. To this extent, the study partners were quite involved in the lives of the participants with DS and, as such, we feel that the perceptions of these study partners were closer to "truth." However, people with DS might very well have truthful responses that are unknown, and thus unvalidated, by the study partners. Future research studies might incorporate observational components to more objectively assess social networks.

Importantly, through this research, we have demonstrated that the personal networks of people with DS can be solicited through self-report and quantitatively analyzed with standard metrics. The groundwork has now been laid to further explore the potential of "social therapeutics" (Dhand et al., 2022) to enhance the personal networks for adults with DS.

AUTHOR CONTRIBUTIONS

Conceptualization: Brian G. Skotko and Amar Dhand. *Data curation*: Brian G. Skotko. *Formal analysis*: Brian G. Skotko and Amar Dhand. *Funding acquisition*: Brian G. Skotko. *Investigation*: Brian G. Skotko, Kavita Krell, Kelsey Haugen, Amy Torres, and Amar Dhand. *Methodology*: Brian G. Skotko, Kavita Krell, Kelsey Haugen, Amy Torres, and Amar Dhand. *Project administration*: Kavita Krell, Kelsey Haugen, and Amy Torres. *Resources*: Brian G. Skotko and Amar Dhand. *Software*: Amar Dhand. *Supervision*: Brian G. Skotko and Amar Dhand. *Validation*: Amar Dhand. *Visualization*: Amar Dhand. *Writing – original draft*: Brian G. Skotko and Amar Dhand. *Writing – review and editing*: Brian G. Skotko, Kavita Krell, Kelsey Haugen, Amy Torres, Amber Nieves, and Amar Dhand.

ACKNOWLEDGMENTS

We would like to thank Nora Horick of Massachusetts General Hospital Biostatistics for her help with some of our statistical analyses. We further thank Liam McCafferty for his assistance with the REDCap programming.

CONFLICT OF INTEREST

Dr. Skotko occasionally consults on the topic of Down syndrome through Gerson Lehrman Group. He receives remuneration from Down syndrome nonprofit organizations for speaking engagements and associated travel expenses. Dr. Skotko receives annual royalties from Woodbine House, Inc., for the publication of his book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*. Within the past 2 years, he has received research funding from F. Hoffmann-La Roche, Inc., AC Immune, and LuMind Research Down Syndrome Foundation to conduct clinical trials for people with Down syndrome. Dr. Skotko is occasionally asked to serve as an expert witness for legal cases where Down syndrome is discussed. Dr. Skotko serves in a nonpaid capacity on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress and the Professional Advisory Committee for the National Center for Prenatal and Postnatal Down Syndrome Resources. Dr. Skotko has a sister with Down syndrome. Dr. Dhand is a co-founder of ECHAS, LLC, a stroke and heart attack detection app. He is also the inventor of SocialBit, a wearable social sensor.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Brian G. Skotko https://orcid.org/0000-0002-5232-9882
Kavita Krell https://orcid.org/0000-0002-7905-871X
Amar Dhand https://orcid.org/0000-0001-6470-7548

REFERENCES

Antonarakis, S. E., Skotko, B. G., Rafii, M. S., Strydom, A., Pape, S. E., Bianchi, D. W., Sherman, S. L., & Reeves, R. H. (2020). Down syndrome. *Nature Reviews. Disease Primers*, *6*(1), 9. https://doi.org/10.1038/s41572-019-0143-7

Ballard, C., Mobley, W., Hardy, J., Williams, G., & Corbett, A. (2016). Dementia in Down's syndrome. *The Lancet Neurology*, *15*(6), 622–636. https://doi.org/10.1016/S1474-4422(16)00063-6

Bayen, E., Possin, K. L., Chen, Y., Cleret de Langavant, L., & Yaffe, K. (2018). Prevalence of aging, dementia, and multimorbidity in older adults with down syndrome. *JAMA Neurology*, *75*(11), 1399–1406. https://doi.org/10.1001/jamaneurol.2018.2210

Capone, G. T., Chicoine, B., Bulova, P., Stephens, M., Hart, S., Crissman, B., Videlefsky, A., Myers, K., Roizen, N., Esbensen, A., Peterson, M.,

Santoro, S., Woodward, J., Martin, B., Smith, D., & Down Syndrome Medical Interest Group DSMIG-USA Adult Health Care Workgroup. (2018). Co-occurring medical conditions in adults with down syndrome: A systematic review toward the development of health care guidelines. *American Journal of Medical Genetics. Part A*, *176*(1), 116–133. https://doi.org/10.1002/ajmg.a.38512

CDC. (2022, August 23). Life expectancy. Retrieved from: https://www.cdc.gov/nchs/fastats/life-expectancy.htm

Crooks, V. C., Lubben, J., Petitti, D. B., Little, D., & Chiu, V. (2008). Social network, cognitive function, and dementia incidence among elderly women. *American Journal of Public Health*, *98*(7), 1221–1227. https://doi.org/10.2105/AJPH.2007.115923

Curtin, C., Bandini, L. G., Must, A., Gleason, J., Lividini, K., Phillips, S., Eliasziw, M., Maslin, M., & Fleming, R. K. (2013). Parent support improves weight loss in adolescents and young adults with Down syndrome. *The Journal of Pediatrics*, *163*(5), 8.e1. https://doi.org/10.1016/j.jpeds.2013.06.081

de Graaf, G., Buckley, F., & Skotko, B. G. (2017). Estimation of the number of people with down syndrome in the United States. *Genetics in Medicine*, *19*(4), 439–447. https://doi.org/10.1038/gim.2016.127

de Graaf, G., Buckley, F., & Skotko, B. G. (2022). People living with Down syndrome in the USA: Births and population. Retrieved from: https://docs.downsyndromepopulation.org/factsheets/down-syndrome-population-usa-factsheet.pdf

Dhand, A., Luke, D. A., Lang, C. E., & Lee, J.-M. (2016). Social networks and neurological illness. *Nature Reviews. Neurology*, *12*(10), 605–612. https://doi.org/10.1038/nrneurol.2016.119

Dhand, A., Podury, A., Choudhry, N., Narayanan, S., Shin, M., & Mehl, M. R. (2022). Leveraging social networks for the assessment and Management of Neurological Patients. *Seminars in Neurology*, *42*(2), 136–148. https://doi.org/10.1055/s-0042-1744532

Dhand, A., White, C. C., Johnson, C., Xia, Z., & De Jager, P. L. (2018). A scalable online tool for quantitative social network assessment reveals potentially modifiable social environmental risks. *Nature Communications*, *9*(1), 3930. https://doi.org/10.1038/s41467-018-06408-6

Fleming, R. K., Stokes, E. A., Curtin, C., Bandini, L. G., Gleason, J., Scampini, R., Maslin, M. C. T., & Hamad, C. (2008). Behavioral health in developmental disabilities: A comprehensive program of nutrition, exercise, and weight reduction. *International Journal of Behavioral and Consultation Therapy*, *4*(3), 287–296. https://doi.org/10.1037/h0100858

Fratiglioni, L., Paillard-Borg, S., & Winblad, B. (2004). An active and socially integrated lifestyle in late life might protect against dementia. *The Lancet. Neurology*, *3*(6), 343–353. https://doi.org/10.1016/S1474-4422(04)00767-7

Harris, P. A., Taylor, R., Minor, B. L., Elliott, V., Fernandez, M., O'Neal, L., McLeod, L., Delacqua, G., Delacqua, F., Kirby, J., Duda, S. N., & REDCap Consortium. (2019). The REDCap consortium: Building an international community of software platform partners. *Journal of Biomedical Informatics*, *95*, 103208. https://doi.org/10.1016/j.jbi.2019.103208

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, *42*(2), 377–381. https://doi.org/10.1016/j.jbi.2008.08.010

Holt-Lunstad, J., Smith, T. B., & Layton, J. B. (2010). Social relationships and mortality risk: A meta-analytic review. *PLoS Medicine*, *7*(7), e1000316. https://doi.org/10.1371/journal.pmed.1000316

Hultsch, D. F., Hertzog, C., Small, B. J., & Dixon, R. A. (1999). Use it or lose it: Engaged lifestyle as a buffer of cognitive decline in aging? *Psychology and Aging*, *14*(2), 245–263. https://doi.org/10.1037//0882-7974.14.2.245

Patient-Centered Outcomes Research Institute. (2021, March 10). Intellectual and/or Developmental Disabilities | PCORI. Retrieved from: https://www.pcori.org/collection/intellectual-andor-developmental-disabilities

Kotwal, A. A., Kim, J., Waite, L., & Dale, W. (2016). Social function and cognitive status: Results from a US nationally representative survey of older adults. *Journal of General Internal Medicine*, *31*(8), 854–862. https://doi.org/10.1007/s11606-016-3696-0

Lott, I. T., & Head, E. (2019). Dementia in down syndrome: Unique insights for Alzheimer disease research. *Nature Reviews. Neurology*, *15*(3), 135–147. https://doi.org/10.1038/s41582-018-0132-6

Oreskovic, N. M., Cottrell, C., Torres, A., Patsiogiannis, V., Santoro, S., Nichols, D., Moore, C., & Skotko, B. G. (2020). Physical activity patterns in adults with Down syndrome. *Journal of Applied Research in Intellectual Disabilities: JARID*, *33*(6), 1457–1464. https://doi.org/10.1111/jar.12773

Peng, S., Roth, A. R., Apostolova, L. G., Saykin, A. J., & Perry, B. L. (2022). Cognitively stimulating environments and cognitive reserve: The case of personal social networks. *Neurobiology of Aging*, *112*, 197–203. https://doi.org/10.1016/j.neurobiolaging.2022.01.004

Perry, B. L., Roth, A. R., Peng, S., Risacher, S. L., Saykin, A. J., & Apostolova, L. G. (2021). Social networks and cognitive reserve: Network structure moderates the association between Amygdalar volume and cognitive outcomes. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *77*(8), 1490–1500. https://doi.org/10.1093/geronb/gbab192

Prust, M., Halm, A., Nedelcu, S., Nieves, A., & Dhand, A. (2021). Head-to-Head comparison of social network assessments in stroke survivors. *The Neurohospitalist*, *11*(1), 18–24. https://doi.org/10.1177/1941874420945889

Santoro, S. L., Donelan, K., & Constantine, M. (2022). Proxy-report in individuals with intellectual disability: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, *35*, 1088–1108. https://doi.org/10.1111/jar.13013

Sinai, A., Mokrysz, C., Bernal, J., Bohnen, I., Bonell, S., Courtenay, K., Dodd, K., Gazizova, D., Hassiotis, A., Hillier, R., McBrien, J., McCarthy, J., Mukherji, K., Naeem, A., Perez-Achiaga, N., Rantell, K., Sharma, V., Thomas, D., Walker, Z., … Strydom, A. (2018). Predictors of age of diagnosis and survival of Alzheimer's disease in Down syndrome. *Journal of Alzheimer's Disease*, *61*(2), 717–728. https://doi.org/10.3233/JAD-170624

Skotko, B. G., Levine, S. P., & Goldstein, R. (2011). Self-perceptions from people with down syndrome. *American Journal of Medical Genetics. Part A*, *155A*(10), 2360–2369. https://doi.org/10.1002/ajmg.a.34235

Strydom, A., Shooshtari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., Jokinen, N., Courtenay, K., Bass, N., Sinnema, M., & Maaskant, M. (2010). Dementia in older adults with intellectual disabilities—Epidemiology, presentation, and diagnosis. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(2), 96–110. https://doi.org/10.1111/j.1741-1130.2010.00253.x

Wilson, R. S., Krueger, K. R., Arnold, S. E., Schneider, J. A., Kelly, J. F., Barnes, L. L., Tang, Y., & Bennett, D. A. (2007). Loneliness and risk of Alzheimer disease. *Archives of General Psychiatry*, *64*(2), 234–240. https://doi.org/10.1001/archpsyc.64.2.234

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Skotko, B. G., Krell, K., Haugen, K., Torres, A., Nieves, A., & Dhand, A. (2022). Personal social networks of people with Down syndrome. *American Journal of Medical Genetics Part A*, 1–9. https://doi.org/10.1002/ajmg.a.63059