

## ORIGINAL ARTICLE

# Designing an international survey for organisations serving people with Down syndrome

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## Abstract

**Background:** Down syndrome is the most common liveborn genetic condition. However, there are no surveys measuring societal services and supports for people with Down syndrome. We developed a questionnaire so that initiatives could be targeted towards countries most in need of assistance.

**Method:** We formed a geographically diverse group of physicians, family members of people with Down syndrome, and members of Down syndrome not-for-profit organisations to create a survey of societal services and supports. We used a modified Delphi method and disseminated the survey to Down syndrome non-profit organisations worldwide.

**Results:** Our survey consists of 61 items categorised within five domains: Education, Community Inclusion, Independence, Healthcare, and Social and Policy Issues.

**Conclusions:** We developed a survey to measure societal services and supports available to people with Down syndrome as perceived by organisational leaders. Our methods might serve as a blueprint for other populations of people with intellectual and developmental disabilities.

## KEYWORDS

down syndrome, quality of life, T21, trisomy 21

## 1 | INTRODUCTION

Researchers have quantified well-being for the general population worldwide (Organisation for Economic Co-operation and Development, 2017), well-being of children within the United States (The Annie E. Casey Foundation, 2018), social services for people with intellectual and developmental disabilities within the United States (Human Services Research Institute & The National Association of State Directors of Developmental Disabilities Services, 2018), legal protections for members of the lesbian, gay, bisexual, and transgender communities worldwide (Leveille, n.d.), and freedom worldwide (Puddington et al., 2018), among others.

While people with Down syndrome have been included in the development of some of these surveys, Down syndrome is associated with a unique combination of medical and psychosocial challenges (e.g., heart conditions that require surgery, inclusivity in educational environments, autonomy in romantic relationships) that require separate attention. Surveys of people with Down syndrome and their caregivers have separately assessed family dynamics (Skotko et al., 2016, 2011a, 2011b), perceptions of self (Skotko et al., 2011c), and quality of life (Gómez et al., 2020; Haddad et al., 2018; Morán et al., 2022). As these previous works have shown, the distinct phenotype of Down syndrome requires dedicated tools to measure. The majority of research so far has focused on the experiences of individuals with Down syndrome in specific geographical regions and has not measured differences among different societies. Therefore, it is crucial to develop a Down syndrome-specific survey that can be used on an international scale. This will lay the groundwork upon which organisations and societies could advocate for the development of and investment in resources that are specific to this population.

Our aim was to create an international stand-alone, holistic, country-level measure of societal services and supports for people with Down syndrome. While the genetic underpinnings for people with Down syndrome are the same across the globe, they can have significantly different opportunities and potentials depending on their social, economic, and political environments. Our work is motivated to identify such disparities—both the unmet needs as well as the corresponding ‘gold standard’ strategies for supporting people with Down syndrome. Doing so is imperative to ensure that people with Down syndrome can be included as full participants in their communities.

Since the early 1980s, non-profit Down syndrome organisations have been established across the globe, largely run by parent volunteers and funded with philanthropic contributions. To assess the societal services and supports for people with Down syndrome, we created a questionnaire to be completed by these organisational leaders who were best positioned to describe circumstances for people with Down syndrome in their countries. We chose to survey organisations, rather than individuals, because our questions primarily focused on law, policy, and societal structures, rather than individual-specific perceptions or experiences. Our approach was also a pragmatic one: until population-based databases are established for Down syndrome communities, a large-scale individual-based survey project is not yet feasible.

Therefore, the purpose of this manuscript is to describe, in detail, the process that we used to create the Down Syndrome Societal Services and Supports Survey (DS-4S), an instrument that could also be adapted to populations with other intellectual and developmental disabilities.

## 2 | METHODS

### 2.1 | Setting

This work was accomplished by the International Down Syndrome Societal Services and Supports Working Group (‘Working Group’), which was formed in 2018. This group was convened by Dr. Brian Skotko, upon advice from Down Syndrome International, a non-profit international umbrella organisation for regional and countrywide Down syndrome organisations around the globe. The primary goal was to assess the societal services and supports for people with Down syndrome around the world as perceived by organisational leaders. The Working Group had 19 members, consisting of physicians specialising in Down syndrome (Genetics, Allergy and Immunology, Neonatology, and Paediatrics), parents and siblings of people with Down syndrome, and leaders of various Down syndrome organisations from six continents. At the time of publication, the Working Group did not have any funding or disclosures other than those of the individual members detailed in the Declaration of Interests section.

Our Working Group continued to partner with Down Syndrome International for the distribution of the DS-4S. A Memorandum of Understanding formalised that their role in this project was solely to distribute the questionnaire to their membership list. Down Syndrome International had no role in determining the final survey items. Down Syndrome International was also blinded to which organisations had completed the survey.

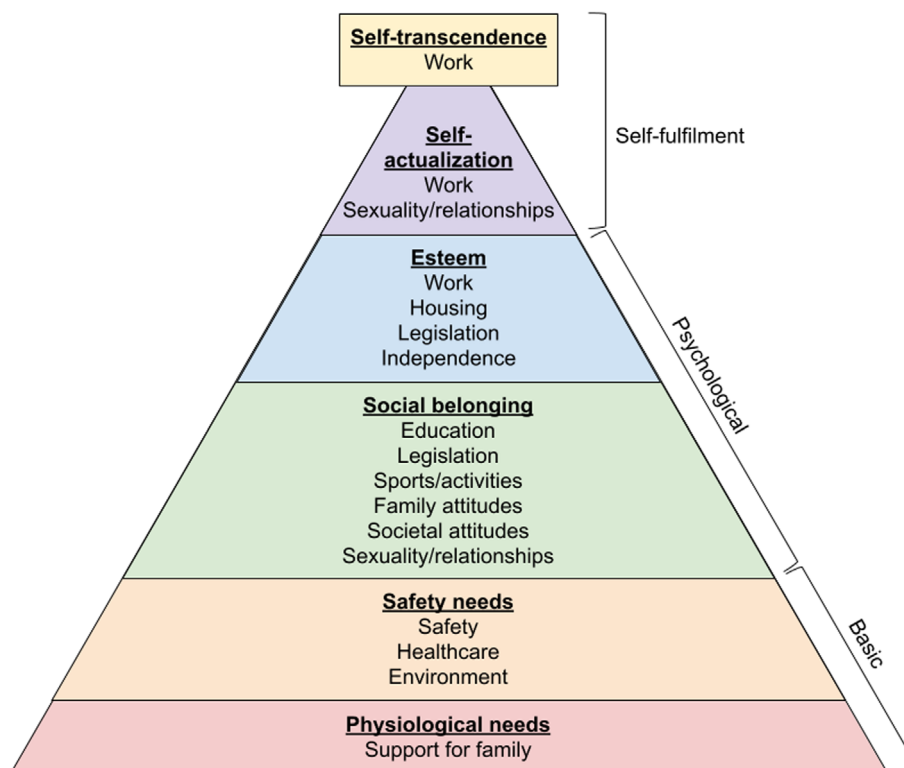
### 2.2 | Questionnaire development

This study was approved by the Mass General Brigham Institutional Review Board (Protocol #2020P002275).

We initially used Abraham Maslow's Hierarchy of Needs as a framework for our discussions of societal services and supports for people with Down syndrome (Maslow, 1943). We used the United Nations' Universal Declaration of Human Rights (United Nations General Assembly, 1948), the United Nations' Convention on the Rights of Persons with Disabilities (United Nations, 2006), and our Working Group's expert opinion to develop additional broad topic areas (which we call ‘domains’) beyond those in Maslow's hierarchy (Figure 1).

To create the DS-4S, the Working Group participated in a modified Delphi method over a period of 18 months (Adler & Ziglio, 1996). Specifically, this meant that the Working Group sought to develop survey items within each domain of societal services and supports that had been created within Maslow's hierarchy.

**FIGURE 1** Maslow's Hierarchy of Needs was used as a framework for our survey's domains (displayed within the hierarchy).



First, previously published indicators, and their composite items, that would be relevant to our work were identified. For each selected domain, approximately 10–20 previously published survey items were initially proposed to the Working Group. Each Working Group member then assessed each survey item with the following questions:

1. Setting aside the specific question wording for this indicator, would this subject matter/content be useful to know?
  - i. Not useful
  - ii. Somewhat useful
  - iii. Useful
  - iv. Very useful
2. How easy would it be for your Down syndrome organisation to answer this question on behalf of your population?
  - i. Very difficult
  - ii. Somewhat difficult
  - iii. Somewhat easy
  - iv. Easy
3. What wording change would have made this question easier to answer? [Open response]

Point values were assigned to each of the ratings according to the Roman numerals above. For each survey item, a mean and standard deviation were calculated for both questions.

The Working Group's aggregate evaluation of each survey item was then discussed and edited for clarity during a live video conference call. For each domain, approximately five survey items were selected based on which were rated most favourably with respect to

**TABLE 1** Recategorisation of domains. The original domains of Abraham Maslow's Hierarchy of Needs were regrouped for the survey

New groupings	Original domains
1. Education	i. Education
2. Community Inclusion	ii. Support for family iii. Safety iv. Environment v. Family attitudes vi. Sports/activities vii. Societal attitudes
3. Independence	viii. Independence and housing ix. Work
4. Healthcare	x. Healthcare xi. Family attitudes
5. Social and Policy Issues	xii. Sexuality/relationships xiii. Legislation

the first two criteria above. The participants in the conference call were also given the opportunity to present any other novel survey items for discussion prior to finalising the list.

During these 14 meetings, we considered 140 possible items in 13 domains. We knew that this number of survey items would be too lengthy for our eventual survey respondents, so any survey items that could be answered by already existing indicators were set aside. In the end, we chose 61 items to include in our survey. Our original domains (Figure 1) were regrouped to reduce the number of sections from 13 to 5, as well as to more evenly distribute the number of survey items per domain (Table 1).

**TABLE 2** Question scales

Scale	Number of items
Yes	22
No	
Most or All	30
Many	
Some	
None or Few	
Yes, in all regions/states/provinces	6
Yes, in some regions/states/provinces	
No	2
More	
Same	
Less	1
A lot	
Some	
Little	
None	

All questions were written so that one of the scales in Table 2 would apply for the answers.

The top two scales in Table 2 were preferred to simplify data analysis, but the remaining three were necessary for some questions. We used qualitative scales because the Working Group advised that using quantitative scales (e.g., a discrete scale [ $<25\%$ ,  $25\%–49\%$ ,  $50\%–74\%$ ,  $\geq 75\%$ ] or a continuous numeric scale) would be too difficult for many organisations to answer with that precision due to a lack of specific data within their countries. Instead, we asked respondents to use their ‘best guess or estimate’—coupled with data when possible—to answer the survey.

We also included three open-response questions in the survey. These qualitative questions were used, in part, because we wanted to test for issues of particular importance to respondents that our group had excluded or de-emphasised:

1. What are the three most important issues for your country, not necessarily related to Down syndrome?
2. What are the three most important issues for people with Down syndrome in your country?
3. *[At the end of the survey]* Is there any other feedback you would like to give us?

## 2.3 | Piloting and revising the questionnaire

The DS-4S was piloted with Down syndrome organisations in seven world areas: Albania, Argentina, Italy, Pakistan, South Africa, the United Kingdom, and the United States of America. The pilot organisations were selected by Down Syndrome International to be in countries that have more than one member organisation.

We asked all pilot organisations to fill out the survey, and we prompted them with the following questions:

1. Were there any questions, phrases, or words that were hard to understand? If so, please explain.
2. Are there questions where you knew how you wanted to answer, but the answer choices did not seem right? If so, please explain.
3. Are there any other comments you would like to make or issues you would like to mention about the quality of life of people with Down syndrome?
4. Is there any other feedback you would like to give us?

Feedback from the pilot organisations was presented to the Working Group and used to edit the survey for clarity before the final version was distributed by Down Syndrome International to all of their member organisations. The responses of the pilot organisations were not analysed in the final data set, but all pilot organisations were given the opportunity to respond to the final version of the DS-4S.

## 2.4 | Survey validity

Traditional psychometric analysis was not performed, as such analysis depends on a large sample size. This was not available for our international survey in which the respondents are country-level organisations.

To assess the content validity of the DS-4S, we instead used a modified Delphi method and pilot testing, as described above.

## 2.5 | Population/eligibility criteria

Respondents were included based on the following criteria to ensure that survey respondents would accurately represent the interests of people with Down syndrome in their country:

1. The organisation has a holistic focus on the lives of people with Down syndrome, that is, not limited to specific issues, such as a dance or comedy group.
2. At least 50% of the organisation's members either have Down syndrome or are family members of people with Down syndrome.

Umbrella organisations that represent several countries were excluded from recruitment, because our goal was to obtain country-level data.

## 2.6 | Data collection

The final survey was distributed by Down Syndrome International via e-mail to 131 member organisations in 110 countries between 13 January 2021, and 28 January 2021. Three weekly reminders were sent prior to the survey closing at the end of March. The collected

**TABLE 3** The Working Group's ratings of each accepted indicator

Education	How useful is the indicator? <sup>a</sup>		How easy is the indicator to answer? <sup>b</sup>	
	Mean	SD	Mean	SD
Are daycares/childcare centres required by national law/policy to accept children with Down syndrome?	3.3	0.63	2.9	0.79
Are there daycares/childcare centres where children with Down syndrome are together with children without Down syndrome?	3.5	0.78	3.0	0.77
Is there a national law/policy requiring all publicly funded schools to adapt their curriculum to meet the needs of students with Down syndrome?	3.5	0.52	3.3	0.79
Is there a national law/policy which enables students with Down syndrome to be in classrooms together with children without Down syndrome?	3.7	0.47	3.5	0.69
Is there a national law/policy enabling adults with Down syndrome to have access to a free (publicly funded) post-secondary education?	3.2	0.87	3.2	0.92
What proportion of children with Down syndrome have access to daycare/childcare services, if desired by their parents?	3.1	0.76	3.4	0.52
What proportion of children with Down syndrome are enrolled in school?	3.3	0.65	3.2	0.79
What proportion of students with Down syndrome who are enrolled in school, ages 6–13, are being educated in inclusive school classrooms (i.e., educated alongside their neurotypical peers)?	3.6	0.50	2.3	0.79
What proportion of students with Down syndrome who are enrolled in school, ages 14–21, are being educated in inclusive school classrooms (i.e., educated alongside their neurotypical peers)?	3.6	0.50	2.3	0.79
What proportion of students with Down syndrome who are enrolled in publicly-funded school have an adapted curriculum to meet their needs?	3.2	0.60	2.1	0.88
What proportion of teachers have access to training on how best to educate students with Down syndrome?	*	*	*	*
Community inclusion	How useful is the indicator? <sup>a</sup>		How easy is the indicator to answer? <sup>b</sup>	
	Mean	SD	Mean	SD
Are there sports activities specifically for people with Down syndrome and for people with other intellectual disabilities in your country?	2.4	1.13	3.3	0.96
Are there organisations that offer sports where people with and without disabilities play together?	3.1	0.69	2.5	0.84
What proportion of family members of people with Down syndrome have opportunities to meet and learn from other family members of people with Down syndrome?	3.3	0.76	3.0	0.63
What proportion of people in your country refer to people with Down syndrome using negative language (e.g., 'retard', 'Mongol', or 'suffering from Down syndrome')?	*	*	*	*
How much of the news media in your country refers to people with Down syndrome using negative language (e.g., 'retard', 'Mongol', or 'suffering from Down syndrome')?	*	*	*	*
What proportion of live-born babies diagnosed with Down syndrome are kept by their families (opposed to being given up for adoption or abandoned)?	3.1	1.19	3.0	0.71

Independence	How useful is the indicator? <sup>a</sup>		How easy is the indicator to answer? <sup>b</sup>	
	Mean	SD	Mean	SD
Are there government-financed programmes to support people with Down syndrome to transition between school and work?	3.0	0.63	2.6	0.55
Are there government-financed services to make public transportation accessible to people with intellectual disabilities?	2.9	0.99	2.5	1.05
For most adolescents and adults with Down syndrome, are books and educational materials on the subject of romantic and sexual relationships available?	3.5	0.84	2.2	0.84
Are employers required to make reasonable accommodations for people with Down syndrome/intellectual disabilities by national law/policy?	3.0	0.63	3.2	0.84
What proportion of adults with Down syndrome are able to receive financial assistance (any amount) from the government solely because of their disability alone?	3.2	0.45	3.2	0.84
What proportion of adults with Down syndrome have a volunteer (unpaid) job* for at least 10 h a week? *This does not include organised day programs/daycares	2.5	0.84	1.8	0.96
What proportion of adults with Down syndrome have a paid job?	3.7	0.52	2.5	0.55
What proportion of adults with Down syndrome who are working have jobs where they are paid at least minimum wage?	3.2	0.41	2.2	0.75
Out of people with Down syndrome who have a paid job, what proportion work 20 or more hours/week?	3.0	0.00	2.5	0.84
Out of people with Down syndrome who have a paid job, what proportion work alongside people without disabilities?	3.5	0.84	2.8	0.45
Out of people with Down syndrome who have a paid job, what proportion receive the same employment benefits (not wages; e.g., insurance or retirement savings) as people without Down syndrome?	3.0	0.00	2.5	0.55
Out of adults with Down syndrome who desire to live outside of the parental home, what proportion receive financial support from the government to cover their basic living expenses?	2.9	1.25	3.3	0.82
What proportion of adults with Down syndrome are excluded when making decisions about their lives?	*	*	*	*
Healthcare	How useful is the indicator? <sup>a</sup>		How easy is the indicator to answer? <sup>b</sup>	
	Mean	SD	Mean	SD
Is prenatal screening for Down syndrome available in your country?	*	*	*	*
Does your country have an established set of national medical guidelines, written by the medical community, for children with Down syndrome?	2.9	1.10	3.3	0.52
Do people with Down syndrome experience worse access to healthcare than the general population?	*	*	*	*
Do people with Down syndrome experience lower quality healthcare than the general population?	*	*	*	*
Has your government developed a plan to address access to healthcare for people with intellectual disabilities during the COVID-19 crisis?	*	*	*	*
Do people with Down syndrome who have COVID-19 experience worse access to healthcare than the general population?	*	*	*	*

TABLE 3 (Continued)

Healthcare	How useful is the indicator? <sup>a</sup>		How easy is the indicator to answer? <sup>b</sup>	
	Mean	SD	Mean	SD
Is cell-free DNA noninvasive prenatal screening (NIPT/NIPS) available in your country?	3.4	0.53	3.1	1.05
What proportion of babies with Down syndrome receive speech therapy services by 2 years of age?	2.9	1.10	3.0	0.63
What proportion of babies with Down syndrome, who need heart surgery, have access to it?	3.1	1.20	3.5	0.53
What proportion of people with Down syndrome have access to hearing tests?	3.0	0.94	3.3	0.71
What proportion of people with Down syndrome, who need medical or surgical treatment for hearing loss (hearing aids or tympanostomy tubes), have access to it?	*	*	*	*
What proportion of people with Down syndrome have access to mental health/behavioural services, if needed?	*	*	*	*
What proportion of people with Down syndrome whose families cannot afford healthcare have access to free (publicly-financed) healthcare?	3.4	0.84	3.3	0.71
What proportion of women with Down syndrome have access to birth control*, if supported by the family?	3.3	0.52	3.0	1.26
*We do NOT consider forced sterilisation to be a form of birth control				
What proportion of expectant couples have prenatal screening* other than NIPT/NIPS paid for at least partially by insurance and/or government resources?	*	*	*	*
*Amniocentesis, chorionic villus sampling (CVS), screening blood tests				
What proportion of parents feel pressured to terminate pregnancies prenatally diagnosed with Down syndrome?	3.2	1.09	2.0	1.00
What proportion of expectant parents receive prenatal information about Down syndrome from their healthcare professional that is accurate, balanced, and up-to-date?	3.1	1.05	2.6	0.79
What proportion of expectant couples have NIPT/NIPS paid for at least partially insurance and/or government resources?	2.9	1.05	2.8	0.98
Social and policy issues	How useful is the indicator? <sup>a</sup>		How easy is the indicator to answer? <sup>b</sup>	
	Mean	SD	Mean	SD
Does your country have a national law/policy ensuring children with Down syndrome to have access to a free (publicly funded) education up to the age of 18?	3.6	0.67	3.7	0.48
Do adults with Down syndrome have the right to vote in national elections?	3.3	1.04	3.7	0.49
Is there a national non-discrimination law/policy that protects people with Down syndrome?	3.4	0.52	3.4	1.06
Are there national laws/policies in place to prevent people with Down syndrome from marrying?	3.5	0.84	2.4	0.89
Does your country have a legal process for investigating suspected cases of physical and sexual abuse/assault for people with Down syndrome?	2.8	1.01	3.1	0.93
Are there national laws/policies in place to prevent the sterilisation of people with Down syndrome against their will?	3.3	0.52	2.5	1.05
Are babies with Down syndrome UNDER 2 years old more likely to be killed, abandoned, or left to die in your country on an annual basis than the typical population?	*	*	*	*

(Continues)

TABLE 3 (Continued)

Social and policy issues	How useful is the indicator? <sup>a</sup>		How easy is the indicator to answer? <sup>b</sup>	
	Mean	SD	Mean	SD
Are people with Down syndrome OVER 2 years old more likely to be killed, abandoned, or left to die in your country on an annual basis than the typical population?	*	*	*	*
Are people with Down syndrome physically or sexually abused/assaulted more than the general population?	1.7	0.75	3.0	0.00
Is your national government open to your organisation's input into the development of government policy or services?	3.3	0.49	3.1	0.38
Compared to the general population, how much access do people with Down syndrome have to electricity?	3.0	0.53	2.7	1.38
Compared to the general population, how much access do people with Down syndrome have to sanitation in their homes?	2.9	0.64	2.3	1.37
Overall, as an organisation, how much influence do you feel you have with your government?	3.1	0.69	3.0	0.63

<sup>a</sup>The full wording of the question was: Setting aside the specific question wording for this indicator, would this subject matter/content be useful to know? Point values were assigned as follows: Not useful—1 point; Somewhat useful—2 points; Useful—3 points; Very useful—4 points.

<sup>b</sup>The full wording of the question was: How easy would it be for your Down syndrome organisation to answer this question on behalf of your population? Point values were assigned as follows: Very difficult—1 point; Somewhat difficult—2 points; Somewhat easy—3 points; Very easy—4 points.

\*Data not available, because this question was added after the initial surveys or is a combination of more than one of the initially proposed indicators.

data were only accessible to the researchers directly involved with their analysis.

Study data were collected directly using REDCap electronic data capture tools hosted at Mass General Brigham (Boston, MA, USA) (Harris et al., 2009, 2019). Data were stored and analysed using Microsoft OneDrive for Business and Microsoft Excel (Redmond, WA, USA).

### 3 | RESULTS

For all quantitative questions, our Working Group independently rated each potential survey indicator with respect to the utility of the indicator and the ease for organisational leaders to answer it.

During the multi-step construction, validation, and piloting of the DS-4S, we assessed the usefulness and practicality of 162 indicators. The Supplementary Table in Data S1 shows the outcome of each tested indicator and at which point the rejected ones were discarded. In the end, we included 11 Education questions, 6 Community Inclusion questions, 13 Independence questions, 18 Healthcare questions, and 13 Social and Policy questions (Table 3).

The pilot DS-4S began with two open-response questions that asked for main issues affecting quality of life for people with and without Down syndrome (before any other questions were visible). All replies generally fit into our five domains, and there were not any significant omissions discovered, reassuring us that the DS-4S is a holistic measure of societal services and supports. Furthermore, while developed independently, our domains are conceptually identical to those in previously published similar surveys (Epstein et al., 2019; Gómez et al., 2020; Human Services Research Institute & The National Association of State Directors of Developmental Disabilities Services, 2018).

The last question of the survey allowed for open-ended feedback. Most organisations used this space to elaborate on their reasoning for specific answers. No one identified any critiques of the survey in terms of content or their ability to understand/interpret the questions.

The Working Group then edited each question to make it easier to answer; the complete final DS-4S is included in the Supplementary Materials.

The specific results of the DS-4S will be reported in forthcoming publications.

### 4 | DISCUSSION

Over a two-year period that included guidance from key stakeholders, we developed a new measure of societal services and supports for people with Down syndrome around the globe. In the end, we selected a relatively consistent number of indicators for each domain. Some indicators measure resources and supports relative to a society's general population (e.g., 'Compared to the general population, how much access do people with Down syndrome have to electricity?' and 'Compared to the general population, how much access do people with Down syndrome have to sanitation in their homes?'). Other indicators measured laws and supports specific to people with Down syndrome (e.g., 'Are there national laws/policies in place to prevent people with Down syndrome from marrying?').

Our next goal will be to combine the results of this survey with previously published indicators concerning societal services and supports, as well as quality of life, for the general population to stratify countries.

These data could then be used to focus advocacy efforts on the specific supports that are most lacking. For example, if we discover that a country has worse access to cardiac surgeries than other countries in the same region, the countries with better access could develop targeted partnerships to help improve access for people in the lower-performing country. Similarly, if there are significant discrepancies among countries with respect to laws relevant to people with Down syndrome, organisations could use that data to better advocate for their members.

Our long-term goal is to administer the DS-4S on an annual or biennial basis to reassess global progress with respect to the societal services and supports for people with Down syndrome. Specifically, we hope to develop relationships with other Down syndrome umbrella organisations to recruit a larger number of participants. We also aim to secure funding to translate the DS-4S into other languages to improve its accessibility and reduce bias.

Our survey could also serve as a blueprint for other disability groups or health conditions (with revisions from the relevant stakeholders). In particular, the DS-4S could be adapted to other developmental or intellectual disabilities with relative ease (the Healthcare questions are the most specific to Down syndrome and would need the most adjustment). We hope that this survey will enable other organisations to conduct similar research into societal services and supports for other disadvantaged or underserved populations.

Equally important to future goals will be the development of an individual-specific questionnaire. While the DS-4S gathers important information from the perspective of global leaders, not all people with Down syndrome and their families participate in these non-profit organisations. An ultimate goal will be to have a composite survey informed by people with Down syndrome, family members, and organisational leaders.

## 5 | CONCLUSION

We successfully developed a novel survey, the DS-4S, to measure the societal services and supports of people with Down syndrome, as perceived by global organisational leaders. This will help target and measure the effectiveness of future initiatives directed at improving societal services and supports. We also developed a method that can be applied to other populations of people with disabilities.

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## FUNDING INFORMATION

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## CONFLICT OF INTEREST

Dr. Skotko serves in a non-paid 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 receives compensation for consulting on Down syndrome through Gerson Lehrman Group and annual book royalties from Woodbine House, Inc. Within the past 2 years, Dr. Skotko 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. He receives speaking stipends with various Down syndrome non-profit organisations. Dr. Skotko has a sister with Down syndrome. Gert de Graaf works for the Dutch Down Syndrome Foundation, a non-profit organisation. He had a daughter with Down syndrome, who passed away in 2005 at the age of 15. Dr. Skladzien previously worked for Down Syndrome Australia, a non-profit peak organisation representing people with Down syndrome and their families in Australia. The remaining authors do not have any conflicts of interest to disclose.

## 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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## SUPPORTING INFORMATION

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

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