





## ARTICLE

# Results of inaugural international Down Syndrome Societal Services and Supports survey

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### ABSTRACT

**Purpose:** We previously designed the Down Syndrome Societal Services and Supports Survey (DS-4S) to measure country-specific supports for people with Down syndrome (DS) across multiple life domains (healthcare, education, policy, independence, and community inclusion). We now report and analyze the results.

**Methods:** We partnered with international DS consortia, who distributed the DS-4S to 154 cumulative members representing over 100 countries. Organizations were included if they had a holistic focus on the lives of people with DS and if at least 50% of their members either have DS or are family members of people with DS. Factor analysis was used to analyze the results.

**Results:** We received survey responses from 55 different organizations in 50 countries who met inclusion criteria. Each country had complete data for at least 4 of the 5 domains. The lowest 5 scores were from countries in Africa and Asia; the highest 5 scores were in Europe and North America.

**Conclusion:** The responses to the DS-4S stratified countries within each surveyed domain. The DS-4S can now be used to track countries' progress over time and to determine which countries have best practices that might be replicated. We will publish the results and update them biennially at [www.DownSyndromeQualityOfLife.com](http://www.DownSyndromeQualityOfLife.com).

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## Introduction

An estimated 1.6 to 5.4 million people in the world are living with Down syndrome (DS).<sup>1-4</sup> Life expectancy was approximately only 10 years of age in 1960, but advances in health and community services have increased current life expectancy to 60 years in the last 6 decades in higher-income countries. Although the well-being and quality of life for many populations have been studied on national and global scales,<sup>5-9</sup> the lives of children and adults with DS have not been similarly assessed. People with DS often face multiple health and psychosocial challenges that have led them and their families, as well as medical experts and social services professionals, to emphasize the importance of developing measures that study quality-of-life issues specifically in the context of DS.<sup>10</sup> Some DS-specific issues, such as health-related quality of life and cardiac surgery outcomes, have been studied separately,<sup>10-18</sup> but no single survey has attempted to assess all domains of daily life for people with DS on an international scale, especially not at a country—rather than individual—level.

For example, in the United States, >95% of individuals with DS were happy with their lives and love their families.<sup>14</sup> In Australia, the quality of life of people with DS was associated with their number of friends and comorbid disease burden but was not associated with whether they lived in urban or rural areas.<sup>15</sup> In Spain, the quality of life of people with DS was most strongly associated with their age.<sup>17</sup> Studies have not yet examined country-level outcomes internationally nor explored a broader set of life domains. Because of the interdependence of such domains (eg, the effect of economic status on health and nutrition), a holistic survey would allow policy makers and advocates to identify best practices in population quality of life, as well as areas for improvement.

Our group previously created the Down Syndrome Societal Services and Supports Survey (DS-4S) to address this need.<sup>19</sup> The goal of this study was to analyze the global data collected from the first distribution of the DS-4S.

## Materials and Methods

### Survey development

The development and validation of the DS-4S have been previously described.<sup>19</sup> The survey was developed by a working group (“DS-4S Working Group”) consisting of physicians specializing in DS, parents and siblings of people with DS, and leaders of various DS organizations around the world. The questions were written on topics deemed useful and important with respect to assessing quality of life for people with DS, while also being relatively objective and easy to answer for most organizations. These questions were originally organized by Maslow’s hierarchy of needs and then ultimately condensed into 5 domains by the DS-4S

Working Group: Community Inclusion, Education, Healthcare, Independence, and Social and Policy Issues. For the majority of questions, 1 of 2 response scales was used: Yes/No or None-few/Some/Many/Most-all. The final survey ([Supplemental Methods](#)) consisted of 61 questions.

### Inclusion criteria

The survey included several questions regarding the organization’s characteristics, including 2 questions to identify whether the following inclusion criteria were met:

1. The organization is “holistic in respect of the lives of people with DS—that is, not limited to specific issues, even if [their] current activities may be focused on specific issues.”
2. At least 50% of the organization’s “members are people with DS and/or their family members.”

### Data collection

The DS-4S was distributed to DS organizations through partnerships with global and regional DS consortia: Down Syndrome International emailed their 131 member organizations in 110 countries between January 13, 2021, and January 28, 2021. Federación Iberoamericana de Síndrome de DOWN emailed the survey to their 20 members in 14 countries in South America and Europe between December 1, 2021, and January 4, 2022. The Africa Down Syndrome Network emailed the survey to their 7 members across Africa between March 10, 2022, and April 1, 2022. Then the European Down Syndrome Association emailed the survey to their 44 members in 35 countries across Europe in August 2022. Each organization used the same standardized recruitment message sent to the organization’s primary contact email address, sending up to 3 reminders, all within 1 month. Responses were accepted from all respondents through the end of 2022.

Study data were collected directly using REDCap electronic data capture tools hosted at Mass General Brigham.<sup>20,21</sup> Data were stored and analyzed using Microsoft OneDrive for Business and Microsoft Excel. This study was deemed exempt by the Mass General Brigham Institutional Review Board.

### Statistical Analysis

Only completed responses (ie, all pages of the survey were answered before submission, although individual questions may have been left blank) were included in the analysis. In cases of multiple responses from one country, the responses of the organization with the largest region (national, regional, or city/town) were used, whereas the smaller organization’s responses were discarded. This was done to obtain the best possible representation of the responding country; we assumed that larger organizations have a

broader network of members that can better represent their countries. Smaller organizations were excluded to avoid overrepresenting smaller and potentially biased responses. If there were multiple responses for organizations of the same size, the scores were averaged.

The indicators across the different survey domains were either binary (Yes/No) or ordered categorical (eg, None-few/Some/Many/Most-all). The frequency and percentage of each response is reported in [Supplemental Table 1](#).

To generate the domain scores and an overall score for each organization, we performed factor analysis in Stata 18. Indicators that had a negative connotation were reverse coded to maintain parity across the responses and ensure that a higher score corresponds to better quality of life. For example, “What proportion of people in your country refer to people with DS using negative language (eg, “retard,” “Mongol,” or “suffering from Down syndrome”)?” had an original coding of “None or Few” = 1, “Some” = 2, “Many” = 3, and “Most or All” = 4 and was reversed to “None or Few” = 4, “Some” = 3, “Many” = 2, “Most or All” = 1. Questions that were reverse coded are noted in the Supplemental Materials. We re-coded the “Do not know” responses to the lowest point value (ie, “No/None” or “Few/None/Less,” as appropriate for the question). As a robustness check, we also recoded “Do not know” responses in 2 alternative ways: (1) choosing the mid-point of the responses (eg, “No” = 1, “Yes” = 2, “Do not know” = 1.5) and (2) categorizing as “missing.” Both of these categorizations yielded similar scorings to the original method of assigning the lowest point value.

Our methodological approach included factor analysis of the indicators for each domain using the following steps<sup>22</sup>:

Step 1: Factor analysis was performed on the indicators within each domain by imposing a single-factor solution for the domain to determine the independent contribution of each indicator to the proportion of variance explained, known as “factor loading.”

Step 2: To ensure that all the indicators within a domain were comparable (because different scales were used to measure responses), each indicator was normalized by creating a *z*-score (ie, subtracting the mean value [across responses] and dividing by the standard deviation [across responses]). The normalized indicators have a mean of 0 and a standard deviation of 1.

Step 3: The domain score was generated for each organization by multiplying the *z*-score of the indicator with the corresponding factor loading of the indicator and then summing across all the indicators in the domain.

Step 4: Each country’s domain score was generated by taking the average of the domain scores across all organizations within the country. Higher scores indicate more favorable responses.

Step 5: To generate the overall score for each country, all the indicators across the 5 domains were considered and the same procedure outlined in steps 1–4 above was followed. Higher scores, again, indicate more favorable responses.

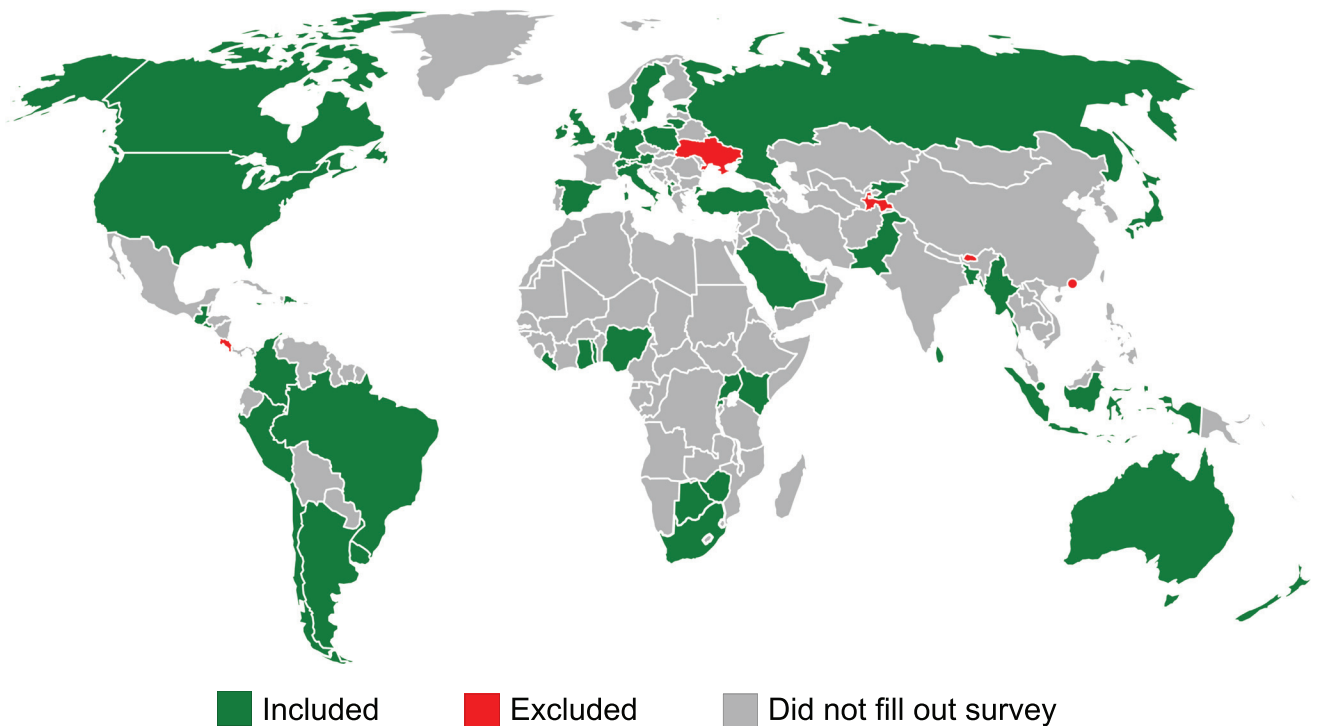
## General well-being indicators

The DS-4S includes some questions comparing life for people with DS with life for people without DS and does not ask questions about the baseline quality of life for people without DS. This was intentional because our respondents were experts on people with DS but not necessarily on the population at large within their country. Instead, we sought to incorporate well-known and publicly available indicators to create a population-based “General Well-being” score for comparison with each of our domains.<sup>23–39</sup> These population-based indicators provide starting points, from which our DS-specific domain scores can be compared. Each General Well-being domain consists of 2 kinds of indicators: (1) “Analogous,” which were selected to be comparable to indicators that are in the DS-4S (eg, “Inequality-adjusted education access”<sup>34</sup> was comparable to our question, “Does your country have a national law ensuring children with Down syndrome have access to a free (publicly funded) education up to the age of 18?” within the Education domain) and (2) “Leading,” which were judged to be important/key indicators for societies but did not necessarily mirror specific questions in the DS-4S (eg, “Life expectancy at birth”<sup>35</sup> for the Health care domain). Domain-specific indicators were then selected based on how closely they matched the DS-4S questions (“Analogous”) and general importance to society (“Leading”) and categorized according to the existing DS-4S domains.

The General Well-being indicators were processed similarly to the DS-4S results as described in the Statistical Analysis section above. A General Well-being score was not able to be calculated for the Independence domain because the selected Analogous and Leading indicators did not have a sufficiently complete data set for enough countries. We also chose not to calculate an overall General Well-being score because we did not want to assume that the domain-specific ones were comprehensive enough to evaluate the backdrop for the countries overall.

## Results

We received complete responses from 75 organizations in 60 countries. Of these, 55 responses from 50 countries met our inclusion criteria and were included in the analyses ([Figure 1](#), [Table 1](#)). These included 10 countries in Africa, 12 countries in the Americas (10 of which are in Latin America), 10 countries in Asia, 16 countries in Europe, and 2 countries in Oceania. Of the 20 responses that were excluded, 12 were from organizations in which <50% of their members either had DS or were family members of people with DS; 5 identified as having a specific focus (1 also met the previous exclusion criterion); 4 were responses either from an organization that had already responded or from an organization in a country that was already represented by a larger organization.



**Figure 1** Countries represented by survey respondents.

Few organizational respondents chose “Do not know” on questions (Supplemental Table 1). Each country had a complete set of responses (ie, no omitted answers) for at least 4 of the 5 domains. There were 45 countries (90%) that had complete responses for all domains (Table 2).

For each set of complete responses, countries received a domain score and associated ranking. If a country had 5 domain scores, they also received an overall score and associated ranking (Figure 2, Table 2). There was significant variation in the domain scores, allowing distinctive separation between countries. The overall rankings also had adequate face validity when presented to the members of the DS-4S Working Group not involved in the analysis.

The overall scores ranged from  $-29.5$  to  $37.1$  (Figure 2, Table 2). The lowest 5 scores were from countries in Africa and Asia, whereas the highest 5 scores were from countries in Europe and North America. The “Community Inclusion” domain score ranged from  $-4.0$  to  $3.5$  (Supplemental Figure 1A, Table 2). The lowest 5 scores were from countries in Africa, Asia, and South America, whereas the highest 5 scores were from countries in Europe and Asia. The “Education” domain score ranged from  $-8.4$  to  $10.6$  (Supplemental Figure 2A, Table 2). The lowest 5 scores were from countries in Africa and Asia, whereas the highest 5 scores were from countries in Europe and North America. The “Healthcare” domain score ranged from  $-11.1$  to  $14.2$  (Supplemental Figure 3A, Table 2). The lowest 5 scores were from countries in Africa and Asia, whereas the highest 5 scores were from countries in Europe and North America. The “Independence” domain score ranged from  $-5.6$  to  $11.6$

(Supplemental Figure 4, Table 2). The lowest 5 scores were from countries in Africa and Asia, whereas the highest 5 scores were from countries in Europe and North America. The “Policy and Law” domain score ranged from  $-7.7$  to  $3.7$  (Supplemental Figure 5A, Table 2). The lowest 5 scores were from countries in Africa and Asia, whereas the highest 5 scores were from countries in Asia, Europe, and North America.

The General Well-being indicators (Supplemental Table 2) were culled from the Central Intelligence Agency,<sup>35</sup> United Nations,<sup>26,30</sup> World Bank,<sup>36-38</sup> World Economic Forum,<sup>34</sup> and World Health Organization.<sup>39</sup> The final Index consists of 3 indicators within Community Inclusion, 3 indicators within Education, 4 indicators within Health care, and 3 indicators within Policy and Law. The “Community Inclusion” domain score ranged from  $-7.0$  to  $1.6$  (Supplemental Table 2, Supplemental Figure 1B). The lowest 5 scores were from countries in Africa, whereas the highest 5 scores were from countries in Asia, Oceania, and Europe. The “Education” domain score ranged from  $-4.8$  to  $4.0$  (Supplemental Table 2, Supplemental Figure 2B). The lowest 5 scores were from countries in Asia and Africa, whereas the highest 5 scores were from countries in Oceania, North America, and Europe. The “Healthcare” domain score ranged from  $-8.8$  to  $3.3$  (Supplemental Table 2, Supplemental Figure 3B). The lowest 5 scores were from countries in Africa, whereas the highest 5 scores were from countries in Asia and Europe. The “Policy and Law” domain score ranged from  $-4.6$  to  $2.8$  (Supplemental Table 2, Supplemental Figure 5B). The lowest 5 scores were from



**Table 1** Characteristics of included responses/organizations

Country	Reach of Organization	Number of Members	Percentage of Members With Down Syndrome and/or their Family Members	Respondent's Role at the Organization
Albania	National	101–500	50%–74%	Founder and CEO
Argentina	National	501–1000	75% or more	President
Argentina	National	>1000	75% or more	Executive Director
Australia	National	>1000	75% or more	CEO
Austria	National	501–1000	75% or more	Board Member
Bangladesh	National	101–500	50%–74%	Founder and Chairman
Botswana	National	101–500	75% or more	Chairperson
Brazil	National	>1000	75% or more	Board Member
Canada	National	101–500	75% or more	Interim Executive Director
Chile	National	21–100	75% or more	Founder and President
Colombia	Single city or town	101–500	75% or more	Board President
Colombia	Single city or town	101–500	75% or more	Founder and Board Member
Dominican Republic	Single city or town	101–500	50%–74%	Executive Director
El Salvador	National	101–500	75% or more	Academic Director
Estonia	National	101–500	75% or more	Board Member
Germany	National	>1000	75% or more	Managing Director
Ghana	National	21–100	50%–74%	Director
Guatemala	National	101–500	50%–74%	Founder and Fundraiser
Guatemala	National	501–1000	75% or more	Director of Programs
Indonesia	Single city or town	21–100	75% or more	Board Member
Italy	National	>1000	75% or more	President
Jamaica	National	501–1000	75% or more	Founder and Director
Japan	National	>1000	75% or more	Director
Saudi Arabia	Single city or town	0–20	75% or more	Team Leader
Kenya	National	101–500	75% or more	Chairperson
Kosovo	National	101–500	75% or more	Responsible for Therapeutic Services
Kyrgyzstan	National	21–100	75% or more	(Not Provided)
Liberia	National	21–100	50%–74%	Founder and CEO
Lithuania	National	21–100	75% or more	Regional Coordinator and International Relations
Malta	National	101–500	75% or more	President
Myanmar		501–1000	75% or more	Chairperson
Netherlands	National	>1000	75% or more	Educational and Scientific Officer
New Zealand	National	>1000	75% or more	National Executive Officer
Nigeria	National	101–500	50%–74%	President
Pakistan	National	101–500	75% or more	President
Peru	National	>1000	75% or more	Self-advocate Program Coordinator/ Citizenship and Rights Coordinator
Poland	Single city or town	21–100	75% or more	Organizer of Education and Health Care
Republic of Ireland	National	>1000	75% or more	Head of Member Support Team
Russia	National	>1000	75% or more	Head of the Analytical Group
Rwanda	National	101–500	75% or more	Executive Secretary
Singapore	National	>1000	75% or more	Executive Director
South Africa	National	>1000	75% or more	National Director
Spain	A large region within one country (multiple states, provinces, or counties)	>1000	50%–74%	Steering Committee Member
Sri Lanka	A large region within 1 country (multiple states, provinces, or counties)	101–500	50%–74%	Director General

(continued)

**Table 1** Continued

Country	Reach of Organization	Number of Members	Percentage of Members With Down Syndrome and/or their Family Members	Respondent's Role at the Organization
Sweden	National	>1000	75% or more	(Not Provided)
Switzerland	A large region within 1 country (multiple states, provinces, or counties)	501–1000	75% or more	International Contact
Togo	National	501–1000	50%–74%	Program Director
Turkey	National	>1000	75% or more	President
Uganda	National	501–1000	75% or more	Overall Policy, Oversight, and National/International Relations Management / Strategic Planning
Uganda	National	>1000	75% or more	Director for Overall Policy Oversight and Relations Management
United Kingdom	National	>1000	75% or more	Services Development Manager
United States	National		50%–74%	President and CEO
Uruguay	Single city or town	101–500	75% or more	Member of the Board of Directors
Zimbabwe	National	101–500	50%–74%	Director
Zimbabwe	National	21–100	50%–74%	Director

countries in Asia, South America, and Africa, whereas the highest 5 scores were from countries in Europe and Oceania.

## Discussion

Our study measured societal supports for people with DS in 50 nations. Most of the high-ranking countries were relatively wealthy countries in Europe. However, on some domains, there were some smaller countries (in terms of population and economy) that had higher scores, including Estonia, Lithuania, Malta, Pakistan, and Peru. This suggests that strong advocacy efforts for people with DS exist in many regions of the world and do not necessarily depend on geographic and socioeconomic status.

Crucially, we demonstrated that the questions on the DS-4S generated sufficiently varied responses so that high- and low-achieving countries could be identified within each surveyed domain. As such, the DS-4S can be used to identify countries that are in high need of advocacy efforts and resources. The DS-4S can also be used as a barometer to track progress over time, similar to many of the non-DS-specific surveys.<sup>5-9,16</sup> For example, the National Core Indicators, established in the United States in 1997, have shown that a large proportion of people with intellectual and developmental disabilities would like to have jobs but do not.<sup>7</sup> As a result, these data have been used to support legislation that promoted hiring workers with intellectual and developmental disabilities. Our survey extends this, and our results show that the United States ranks behind many countries in Europe within the Independence domain.

We have now generated lists of high-achieving countries by each domain, which should allow researchers, advocates, and policymakers to emulate organizations' and countries' best practices. For example, Ireland ranked as a leader in the Community Inclusion domain. Their campaign, "The UpSide," features murals around the country that are created by local artists to celebrate key aspects of life for individuals with DS. The murals publicly show the positive contributions of individuals with DS to Irish society, emphasizing the value that people with DS bring to their communities. Future implementation and dissemination research could study how best to adapt and distribute such best practices to resource-poor countries.

Our study is not without limitations. Because a global individual-based survey is not yet feasible, our respondents were DS organizational leaders. The survey was also distributed electronically, which might not have reached organizational leaders in rural parts of some countries. To this extent, it is possible that the responses from the organizational leaders are not representative and generalizable to all people with DS within their country. To address this potential source of bias and inaccuracy, we plan to readminister this survey biennially—and, if possible, to different organizations within countries—to develop a more robust sample of responses within each country.

The data did not easily separate into clear quantiles; therefore, we have reported exact ranking numbers. Because some countries only had 1 organizational respondent, there might be some imprecision in these rankings (ie, it might be imprecise to conclude that "ranking 4 is better than ranking 5"; however, it is likely to be more precise to conclude that "ranking 4 would, indeed, be better than ranking 15").

**Table 2** Scores and rankings, overall and for each domain, by country

Country	Overall		Community Inclusion		Education		Health Care		Independence		Policy and Law	
	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank
Albania	−2.5	24	−1.8	40	1.6	21	−4.1	33	1.0	21	1.2	22
			1.5	12	−0.6	30	0.5	29	<i>b</i>	<i>b</i>	0.8	21
Argentina	6.1	18	1.2	18	1.4	22	1.7	21	1.2	19	1.3	19
			1.4	22	1.2	19	1.7	19	<i>b</i>	<i>b</i>	0.6	22
Australia	26.0	6	2.1	9	8.1	6	9.2	9	6.9	6	0.9	25
			1.6	1	4.0	1	2.8	6	<i>b</i>	<i>b</i>	2.3	2
Austria	<i>a</i>	<i>a</i>	1.3	15	3.5	13	3.8	18	<i>a</i>	<i>a</i>	2.4	7
			1.6	1	1.5	16	2.8	6	<i>b</i>	<i>b</i>	2.0	9
Bangladesh	−21.1	41	−1.7	38	−5.2	41	−8.8	45	−3.8	40	−4.1	47
			−1.6	40	−2.5	39	−2.0	39	<i>b</i>	<i>b</i>	−4.0	36
Botswana	−13.5	36	−0.3	29	−6.4	44	−1.9	29	−2.8	31	−1.1	37
			−1.5	39	−0.8	33	−1.6	38	<i>b</i>	<i>b</i>	<i>a</i>	<i>a</i>
Brazil	1.8	20	−2.4	45	3.0	15	0.3	24	0.7	23	−0.2	31
			1.1	31	−0.6	30	0.8	27	<i>b</i>	<i>b</i>	−1.1	29
Canada	34.5	2	2.7	6	9.4	5	12.9	2	9.3	2	2.5	4
			1.5	12	3.7	3	2.7	9	<i>b</i>	<i>b</i>	2.2	5
Chile	−5.1	30	−0.9	32	1.3	24	−4.1	34	−2.6	29	1.6	15
			1.6	1	0.7	21	2.2	16	<i>b</i>	<i>b</i>	0.9	20
Colombia	−4.3	29	−2.1	44	2.6	19	−1.5	28	−3.2	38	1.8	13
			1.2	29	−0.7	32	1.2	21	<i>b</i>	<i>b</i>	−1.2	30
Dominican Republic	−3.8	27	0.5	21	1.3	23	−6.5	38	−0.4	25	1.1	23
			0.9	34	<i>a</i>	<i>a</i>	−0.1	32	<i>b</i>	<i>b</i>	<i>a</i>	<i>a</i>
El Salvador	−2.2	23	−1.6	37	−2.3	32	2.0	20	1.2	20	−2.3	40
			1.0	33	−2.7	40	0.9	26	<i>b</i>	<i>b</i>	−1.6	32
Estonia	5.3	19	1.2	17	−5.0	38	10.0	6	−2.9	32	2.9	2
			1.5	12	2.5	10	2.1	17	<i>b</i>	<i>b</i>	1.9	11
Germany	23.0	7	2.7	6	3.8	11	7.4	11	7.4	5	2.7	3
			1.5	12	2.5	10	2.7	9	<i>b</i>	<i>b</i>	2.3	2
Ghana	−26.0	43	−3.2	47	−3.5	35	−8.3	41	−5.6	46	−7.7	50
			−3.2	43	−1.7	37	−3.6	41	<i>b</i>	<i>b</i>	−2.6	34
Guatemala	−12.1	34	−0.2	26	−3.3	34	−5.7	37	−2.8	30	−0.4	34
			−0.2	37	−3.8	43	−1.3	35	<i>b</i>	<i>b</i>	−3.7	35
Indonesia	−25.7	42	−4.0	49	−7.7	48	−8.4	42	−5.6	46	−0.7	35
			0.2	36	−1.8	38	−1.3	35	<i>b</i>	<i>b</i>	−1.4	31
Italy	33.2	3	2.0	11	10.5	1	12.6	3	7.5	4	2.5	4
			1.5	12	−0.1	26	2.9	3	<i>b</i>	<i>b</i>	1.4	16
Jamaica	−2.1	22	1.2	19	−0.7	29	0.5	23	−3.0	34	−0.1	30
			1.1	31	−1.1	34	−0.3	33	<i>b</i>	<i>b</i>	<i>a</i>	<i>a</i>
Japan	6.8	17	−0.1	22	4.6	10	0.1	26	1.2	17	1.7	14
			1.6	1	1.4	17	3.3	1	<i>b</i>	<i>b</i>	1.9	11
Kenya	−16.5	39	−0.3	27	−4.0	36	−8.6	43	−3.0	35	−3.0	43
			−5.1	46	−3.0	41	−5.0	46	<i>b</i>	<i>b</i>	<i>a</i>	<i>a</i>
Kosovo	1.4	21	−0.2	25	3.6	12	−3.7	32	1.7	15	1.5	16
			<i>a</i>	<i>a</i>	<i>a</i>	<i>a</i>	<i>a</i>	<i>a</i>	<i>b</i>	<i>b</i>	<i>a</i>	<i>a</i>
Kyrgyzstan	<i>a</i>	<i>a</i>	<i>a</i>	<i>a</i>	−6.4	44	−7.1	40	−3.0	36	−3.7	46
			1.4	22	0.4	22	−1.5	37	<i>b</i>	<i>b</i>	<i>a</i>	<i>a</i>
Liberia	−29.5	45	−3.2	46	−8.4	49	−9.1	46	−4.8	43	−7.4	49
			−7.0	50	−4.5	47	−7.0	48	<i>b</i>	<i>b</i>	<i>a</i>	<i>a</i>

(continued)

Table 2 Continued

Country	Overall		Community Inclusion		Education		Health Care		Independence		Policy and Law	
	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank
Lithuania	20.8	10	1.9 1.3	14 26	4.9 3.1	8 5	9.6 0.7	7 28	3.8 <i>b</i>	12 <i>b</i>	0.4 1.8	29 13
Malta	22.1	8	2.0 1.6	10 1	9.7 2.1	2 14	6.6 1.6	13 20	4.4 <i>b</i>	11 <i>b</i>	1.1 1.1	23 19
Myanmar	<i>a</i>	<i>a</i>	-1.0 -1.9	33 41	-4.4 -4.4	37 46	<i>a</i> <i>a</i>	<i>a</i> <i>a</i>	-4.4 <i>b</i>	42 <i>b</i>	1.4 <i>a</i>	17 <i>a</i>
Netherlands	28.3	4	2.7 1.5	6 12	2.9 2.5	17 10	14.2 2.7	1 9	6.7 <i>b</i>	7 <i>b</i>	2.5 2.2	4 5
New Zealand	13.3	14	-0.2 1.6	24 1	1.1 4.0	28 1	6.1 2.7	15 9	5.3 <i>b</i>	8 <i>b</i>	0.9 2.2	25 5
Nigeria	-28.3	44	-3.2 -6.5	48 49	-8.4 <i>a</i>	49 <i>a</i>	-11.1 -8.8	48 49	-5.6 <i>b</i>	46 <i>b</i>	-2.8 <i>a</i>	42 <i>a</i>
Pakistan	-3.9	28	1.2 -2.3	16 42	1.2 -4.8	26 48	-3.4 -3.8	31 43	-4.8 <i>b</i>	43 <i>b</i>	3.7 -4.6	1 37
Peru	<i>a</i>	<i>a</i>	2.0 0.4	13 35	1.3 -0.3	24 28	<i>a</i> -0.6	<i>a</i> 34	-1.2 <i>b</i>	26 <i>b</i>	2.0 -0.8	9 27
Poland	-3.2	26	-1.0 1.5	35 12	-2.0 1.6	31 15	1.1 1.0	22 24	1.4 <i>b</i>	16 <i>b</i>	-3.0 1.7	44 14
Republic of Ireland	20.8	9	3.5 1.3	1 26	3.2 2.7	14 7	9.4 2.7	8 9	3.2 <i>b</i>	13 <i>b</i>	2.0 2.2	10 5
Russia	-5.9	32	-1.1 1.2	36 29	1.2 0.3	27 23	-2.3 1.2	30 21	-4.2 <i>b</i>	41 <i>b</i>	1.2 1.2	20 17
Rwanda	-16.1	38	-0.3 -3.6	28 44	-3.1 -4.2	33 45	-4.7 -3.6	36 41	-5.1 <i>b</i>	45 <i>b</i>	-2.5 <i>a</i>	41 <i>a</i>
Saudi Arabia	-15.8	37	-1.8 1.6	40 1	-5.7 1.2	43 19	-4.5 0.2	35 31	-1.5 <i>b</i>	27 <i>b</i>	-3.2 0.2	45 25
Singapore	-2.8	25	2.8 1.6	5 1	-7.1 2.3	47 13	2.6 3.3	19 1	-0.3 <i>b</i>	24 <i>b</i>	-1.1 0.4	38 23
South Africa	-5.9	31	-1.0 -0.5	33 38	-1.7 -0.1	30 26	-0.2 -3.0	27 40	-3.5 <i>b</i>	39 <i>b</i>	0.7 -0.8	28 27
Spain	27.4	5	-0.9 1.6	31 1	9.7 1.3	2 18	8.5 2.8	10 6	8.1 <i>b</i>	3 <i>b</i>	2.4 1.2	7 17
Sri Lanka	-10.1	33	-0.2 1.3	23 26	-5.7 0	42 25	0.2 0.5	25 29	-2.0 <i>b</i>	28 <i>b</i>	-2.0 -1.7	39 33
Sweden	20.5	11	3.5 1.5	1 12	4.7 3.5	9 4	7.0 2.9	12 3	4.6 <i>b</i>	9 <i>b</i>	0.7 2.3	27 2
Switzerland	20.0	12	3.5 1.6	1 1	2.7 2.6	18 9	11.3 2.9	5 3	2.8 <i>b</i>	14 <i>b</i>	1.2 2.4	21 1
Togo	<i>a</i>	<i>a</i>	-1.7 -6.0	39 48	-6.9 -3.1	46 42	-6.6 -4.5	39 44	<i>a</i> <i>b</i>	<i>a</i> <i>b</i>	-5.1 <i>a</i>	48 <i>a</i>
Turkey	9.2	16	0.6 1.5	20 12	2.2 0.1	20 24	5.2 1.1	16 23	0.7 <i>b</i>	22 <i>b</i>	1.4 -0.2	18 26
Uganda	-18.5	40	-2.0 -5.7	43 47	-5.1 -4.1	39 44	-8.7 -6.4	44 47	-3.1 <i>b</i>	37 <i>b</i>	-0.3 <i>a</i>	32 <i>a</i>
United Kingdom	37.1	1	3.5 1.5	1 12	9.7 3.0	2 6	12.5 2.6	4 14	11.6 <i>b</i>	1 <i>b</i>	2.0 2.0	10 9
United States	15.7	13	2.0 1.6	11 1	5.3 2.7	7 7	4.1 2.4	17 15	4.6 <i>b</i>	10 <i>b</i>	-0.7 1.5	36 15

(continued)



**Table 2** Continued

Country	Overall		Community Inclusion		Education		Health Care		Independence		Policy and Law	
	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank
Uruguay	10.4	15	−1.8	42	2.9	16	6.3	14	1.2	18	1.9	12
			<i>1.4</i>	<i>22</i>	<i>−0.5</i>	<i>29</i>	<i>1.9</i>	<i>18</i>	<i><sup>b</sup></i>	<i><sup>b</sup></i>	<i>0.4</i>	<i>23</i>
Zimbabwe	−12.5	35	−0.6	30	−5.1	40	−9.2	47	−3.0	33	−0.3	33
			<i>−4.7</i>	<i>45</i>	<i>−1.1</i>	<i>34</i>	<i>−4.9</i>	<i>45</i>	<i><sup>b</sup></i>	<i><sup>b</sup></i>	<i><sup>a</sup></i>	<i><sup>a</sup></i>

Higher scores are more favorable. The top (upright) numbers in each row represent scores and rankings for the domains measured in the DS-4S. Overall scores ranged from −29.5 to 37.1, Community Inclusion scores ranged from −4.0 to 3.5, Education scores ranged from −8.4 to 10.6, Health care scores ranged from −11.1 to 14.2, Independence scores ranged from −5.6 to 11.6, and Policy scores ranged from −7.7 to 3.7. The bottom (italics) numbers in each row represent scores and rankings for the General Well-being indicators. The Education domain of the General Well-being indicators was also recalculated excluding education expenditures (% GDP) removed, because different countries have vastly different strategies for allocating their gross domestic product (Supplemental Table 3), with the resulting scores and rankings shown in Supplemental Table 4. Community Inclusion scores ranged from −7.0 to 1.6, Education scores ranged from −4.8 to 4.0, Health care scores ranged from −8.8 to 3.3, and Policy scores ranged from −4.6 to 2.8.

<sup>a</sup>Domain scores were calculated only if data were available (not null) for all the indicators within the domain (ie, all questions were answered). Overall scores were calculated only if scores for every domain were computed.

<sup>b</sup>General Well-being scores were not calculated for the Independence domain because of the high amount of missing data in the selected indicators.

We intend to re-distribute our survey at least biennially, posting our results at [www.DownSyndromeQualityOfLife.com](http://www.DownSyndromeQualityOfLife.com). In the future, we hope to distribute our survey in other languages, rather than solely in English, to improve the diversity of the respondents. We also hope to partner with more umbrella consortia to improve the reach of the survey. On our website, we also intend to post best practices from organizations in high-scoring countries.

The DS-4S might also serve as a blueprint for global assessments of other populations, particularly those with rare diseases or genetic conditions. Although some questions (particularly those in the healthcare section) would need to be customized based on the target population, the majority of the questions should be applicable to other groups.

## Data Availability

Data are publicly and freely available on this project's website, [www.DownSyndromeQualityOfLife.com](http://www.DownSyndromeQualityOfLife.com).

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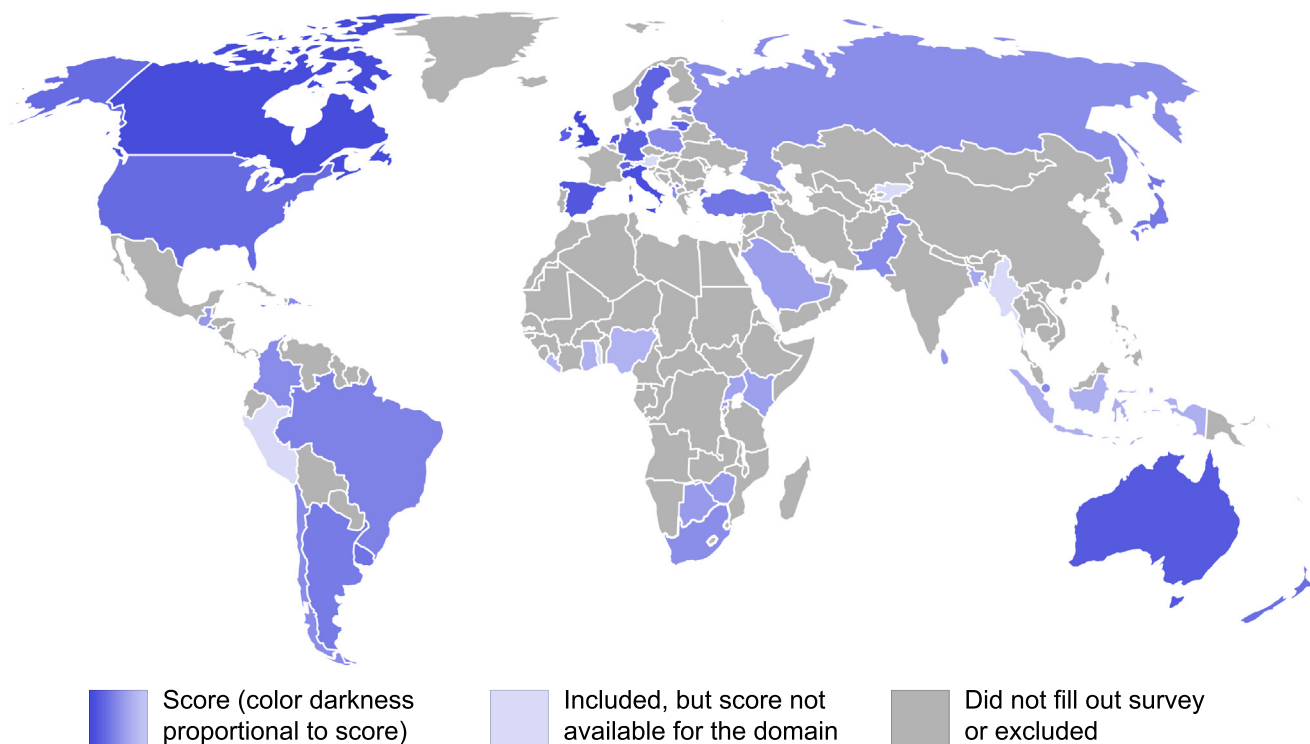
This research was unfunded.

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## Ethics Declaration

This study was deemed exempt by the Mass General Brigham Institutional Review Board. Informed consent was obtained from all participants as required by the IRB.



**Figure 2** Map of overall scores using the DS-4S.

## Conflict of Interest

Dr de Graaf works for the Dutch Down Syndrome Foundation, a non-profit organization. He had a daughter with Down syndrome, who passed away in 2005 at the age of 15. Dr Santoro receives research funding from the LuMind IDSC Down Syndrome Foundation to conduct clinical trials for people with DS and serves on the Executive Board for the Massachusetts Down Syndrome Congress, the Board of the Down Syndrome Medical Interest Group, and the Executive Board of the American Academy of Pediatrics Council on Genetics. Dr Skladzien worked for Down Syndrome Australia, a non-profit peak organization representing people with Down syndrome and their families in Australia. 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. Within the past 2 years, Dr Skotko has received annual book royalties from Woodbine House, Inc, and research funding from 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 organizations. Dr Skotko has a

sister with Down syndrome. Mr Buckley works for Down Syndrome Education International, a nonprofit that supports young people with Down syndrome and their families. He had a sister with Down syndrome who passed away in 2020, aged 51. All other authors declare no conflicts of interest.

## Additional Information

The online version of this article (<https://doi.org/10.1016/j.gim.2024.101114>) contains supplemental material, which is available to authorized users.

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