Our Say in Our Health: A Global Report on Healthcare for People with Intellectual Disabilities

Appendices

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Contents

Appendix A: Additional Methodology Details

Multinomial logistic regression was done to identify particularly vulnerable or disproportionately affected groups, and to make comparisons across key demographic variables such as gender, age, place of residence (rural/urban), disability type, the income level of the country of residence, and government health expenditure as a proportion of GDP (World Bank, 2023; World Bank, 2024).

Statistical weights were applied for the regression analysis to correct for imbalance in the number of responses from certain groups and ensure more representative results. A 1:1 ratio was used to adjust for disability type and place of residence, while country-level weights reflected the global population distribution across four income-level categories.

Multinomial logistic regression, performed in STATA using the *mlogit* command (STATA, 2025a), allows estimation of the likelihood of different demographic groups selecting specific response options, while also accounting for both categorical and numerical predictors. After running the regression, the *margins* command (STATA, 2025b) is used to generate predicted probabilities, i.e. the estimated proportion of each group likely to choose each response option. Graphs made with these results are indicated as ‘regression’ graphs. Hypothesis tests were performed in STATA to assess the reliability of each result. These tests evaluate whether the observed relationships in the data are statistically significant, or if they could have occurred by chance.

Appendix A References

STATA. 2025a. mlogit — Multinomial (polytomous) logistic regression. Retrieved from: https://www.stata.com/manuals/rmlogit.pdf.
STATA. 2025b. mlogit postestimation — Postestimation tools for mlogit. Retrieved from: https://www.stata.com/manuals/rmlogitpostestimation.pdf#rmlogitpostestimationWorld Bank. 2023. The World by Income and Region. Retrieved from: https://datatopics.worldbank.org/world-development-indicators/the-world-by-income-and-region.html.
World Bank. 2024. Current health expenditure (% of GDP). Retrieved from: https://data.worldbank.org/indicator/SH.XPD.CHEX.GD.ZS.

Appendix B: Survey Questions

B.1 Individuals Survey Questions

Questions to all survey respondents at the start of the survey

Respondents were later presented with different questions based on their answer to ‘which option describes you best’.

Question	Answer options
QA1: What country do you live in?	Afghanistan, Albania, Algeria, Andorra, Angola, Antigua and Barbuda, Argentina, Armenia, Australia, Austria, Azerbaijan, Bahamas, Bahrain, Bangladesh, Barbados, Belarus, Belgium, Belize, Benin, Bhutan, Bolivia, Bosnia and Herzegovina, Botswana, Brazil, Brunei, Bulgaria, Burkina Faso, Burundi, Cabo Verde, Cambodia, Cameroon, Canada, Central African Republic, Chad, Chile, China, Colombia, Comoros, Congo (Democratic Republic of the), Congo (Republic of the), Costa Rica, Croatia, Cuba, Cyprus, Czech Republic, Denmark, Djibouti, Dominica, Dominican Republic, East-Timor (Timor Leste), Ecuador, Egypt, El Salvador, Equatorial Guinea, Eritrea, Estonia, Eswatini, Ethiopia, Fiji, Finland, France, Gabon, Gambia, Georgia, Germany, Ghana, Greece, Grenada, Guatemala, Guinea, Guinea-Bissau, Guyana, Haiti, Honduras, Hungary, Iceland, India, Indonesia, Iran, Iraq, Ireland, Israel, Italy, Ivory Coast, Jamaica, Japan, Jordan, Kazakhstan, Kenya, Kiribati, Kosovo, Kuwait, Kyrgyzstan, Laos, Latvia, Lebanon, Lesotho, Liberia, Libya, Liechtenstein, Lithuania, Luxembourg, Madagascar, Malawi, Malaysia, Maldives, Mali, Malta, Marshall Islands, Mauritania, Mauritius, Mexico, Micronesia, Moldova, Monaco, Mongolia, Montenegro, Morocco, Mozambique, Myanmar (Burma), Namibia, Nauru, Nepal, Netherlands, New Zealand, Nicaragua, Niger, Nigeria, North Korea, North Macedonia (formerly Macedonia), Norway, Oman, Pakistan, Palau, Palestine, Panama, Papua New Guinea, Paraguay, Peru, Philippines, Poland, Portugal, Qatar, Romania, Russia, Rwanda, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Samoa, San Marino, Sao Tome and Principe, Saudia Arabia, Senegal, Serbia, Seychelles, Sierra Leone, Singapore, Slovakia, Slovenia, Solomon Islands, Somalia, South Africa, South Kora, South Sudan, Spain, Sri Lanka, Sudan, Suriname, Sweden, Switzerland, Syria, Taiwan,

	Tajikistan, Tanzania, Thailand, Togo, Tonga, Trinidad and Tobago, Tunisia, Turkey, Turkmenistan, Tuvalu, Uganda, Ukraine, United Arab Emirates, United Kingdom, United States, Uruguay, Uzbekistan, Vanuatu, Vatican City, Venezuela, Vietnam, Yemen, Zambia, Zimbabwe						
QA2: What is your gender?	Man	Woman	Non-binary	Prefer not to say			
QA3: How old are you?	Under 18	18-24	25-34	35-44	45-54	55-64	65+
QA4: Do you live in the city or town, or in a rural area / the countryside?	City or town	Rural or countryside					
QA4: Please choose which option describes you best	A family member of a person an intellectual disability (other than Down syndrome)	A family member of a person with Down syndrome	A person with Down syndrome	A person with an intellectual disability (other than Down syndrome)	A support person of a person with an intellectual disability other than Down syndrome (not related to the person)	A support person of a person with Down syndrome (not related to the person)	

Questions to people identifying as ‘a person with Down syndrome’ and ‘a person with an intellectual disability (other than Down syndrome)’

Question	Answer options			
QB1: How healthy do you feel in general?	Not very healthy - I have a lot of health problems	My health feels ok	Very healthy - I feel great!	Not sure
QB2: Do you have to travel a long way to go to the doctor or other health service?	Yes	No	Not sure	
QB3: Are you normally happy with the way you are treated when you go to the doctor or other health service?	Yes - most of the time	Sometimes	Not sure	No - never
QB4: How easy is it to afford to go to the doctor or other health service? If you can access healthcare without paying, then please select 'It is easy - it is affordable'.	It is easy - it is affordable	In the middle - I can afford it but it’s difficult	It is hard - it costs too much	Not sure
QB5: Do doctors and other health workers talk to you in a way you can understand?	Always	Most of the time	Sometimes	Never
QB6: Do you think doctors and other health workers ever treat you unfairly?	Always	Sometimes	No	

For example, are they rude to you or do they treat you differently to other patients?			
QB7: Do you get information about health in ways that you understand?	Yes	Sometimes	No
QB8: Are you able to make your own decisions about your health care? For example, deciding whether you want to have a treatment	No, someone else makes decisions for me	Yes, I make my own decisions	Not sure
QB9: Do you get enough support to get health care? For example, support to attend appointments or to understand information	Yes	Not sure	No
QB10: Can you tell us a time when you had a good healthcare experience? If you have not had a good experience, you don't have to answer.	Free text space		
QB11: Can you tell us a time when you had a bad healthcare experience? If you have not had a bad experience, you don't have to answer.	Free text space		

QB12: Have you done any advocacy or speaking up about your health?	Yes	No	Not sure
QB13: If you said yes, can you tell us more about what you did?	Free text space		
QB14: Have you done any advocacy or speaking up about making health care better in your country?	Yes	No	Not sure
QB15: If you said yes, can you tell us more about what you did?	Free text space		
QB16: Is there anything else you would like to tell us about healthcare where you live or healthcare you have received?	Free text space		

Questions to people identifying as ‘a family member of a person with Down syndrome’ or ‘a family member of a person with an intellectual disability (other than Down syndrome)’

Questions	Answer options							
QF1: How old is your family member with Down syndrome?	Under 12	13-17	18-24	25-34	35-44	45-54	55-64	65+
QF2: What gender is your family member with Down syndrome?	Man/boy	Woman/girl	Non-binary	Prefer not to say				
QF3: At what point did healthcare professionals diagnose your child as having Down syndrome?	Before my child was born	Straight after birth	Between 0 – 6 months	7 – 12 months	1 – 3 years	4+ years		
QF4: When you received the diagnosis that your child has Down syndrome, what advice and information did healthcare professionals give you?	Free text space							
QF5: How do you find information about your family member's health? (Check all that apply)	Down syndrome associations	Healthcare provider recommenddations	Support groups or online forums	Books or publications	Online searches	Free text space		

QF6: How easy is it for you to find accessible and good quality health information about Down syndrome?	Easy	Ok	Hard	Not sure
QF7: How easy is it for you to find good quality health information in accessible formats that your family member with Down syndrome can use and understand?	Easy	Ok	Hard	Not sure
QF8: How easy is it for you to find information about how to access health and support services for people with Down syndrome?	Easy	Ok	Hard	Not sure
QF9: Can you share an example of accessible healthcare information that your family member has accessed? OR where the information has not been accessible.	Free text space			
QF10: This question asked, 'How satisfied are you with the health services available for your family member?' with the prompts:				

Are they able to access the health services they need? Do the health services they do access meet their needs? Are the services good quality?						
Early childhood development services (for example, monitoring developmental milestones, parental counselling and education, early intervention supports like speech and language therapy)	Satisfied	Ok	Not available	Not satisfied	My family member does not need this service	Have not tried to access
General health services (check-ups with a doctor, nutrition, vaccinations etc)						
Eye health services						
Ear, nose and throat health services						
Oral health services (e.g. dental)						
Sexual and reproductive health and family planning services						
Services for chronic diseases						

(e.g. asthma, diabetes, heart disease)						
Mental health services						
Cardiac (heart) health services						
Specialized health care services (for example, orthopedic specialists, neurologists etc)						
Health services for older people						
QF11: Do you have any other thoughts about the healthcare services available for your family member with Down syndrome?	Free text space					
QF12: Are healthcare services in your area affordable for your family member with Down syndrome?	Yes	In the middle	No	Don’t know		
QF13: Is transport to healthcare services affordable for your family	Yes	In the middle	No	Don’t know		

member with Down syndrome?					
QF14: To what extent do you agree that healthcare is affordable for people with Down syndrome and their families?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
QF15: Are there any financial supports available to help cover the cost of healthcare for people with Down syndrome? For example, through social health insurance, disability allowances, health insurance etc	Yes there are financial supports that fully cover the healthcare costs	Yes there are financial supports, but they do not cover all the healthcare costs	No there are no financial supports available to help cover the healthcare costs	I’m not sure	
QF16: Thinking about where your family member lives, is support provided to help with the cost of transportation to healthcare services for people with Down syndrome? For example, transports subsidies or	Yes there is financial support that fully covers the transport costs	Yes there is financial support, but it does not cover all the transport costs	No there are no financial support available to help cover the transport costs	I'm not sure	

discounted fares; healthcare facilities providing transport to and from their services etc..				
QF16: Can you tell us more about the affordability of healthcare services for your family member with Down syndrome?	Free text space			
QF17: How would you rate the physical accessibility of health facilities for your family member with Down syndrome?	Accessible	Ok	Not accessible	Not sure
QF18: How would you rate communication between health care providers and your family member with Down syndrome?	Good	Ok	Poor	Not sure
QF19: Can you tell us more about how healthcare providers communicate with your family	Free text space			

member with Down syndrome?					
QF20: Do doctors and other health workers ever treat your family member unfairly? For example, are they rude to them or do they treat them differently to other patients?	Yes, all the time	Sometimes	Never	Not sure	
QF21: Is your family member with Down syndrome supported to make free and informed decisions about their healthcare?	No, my family member can't make decisions for themselves, so someone else makes decisions for them	No, the health care system provides no supports to enable my family member to make free and informed decisions about their health	Yes, health care providers have a process and supports in place to enable my family member to make their own informed decisions about their healthcare	Yes, I provide support to my family member to help them to make decisions	Free text space
QF22: Do health facilities provide reasonable accommodations for your family member with Down syndrome?	Yes, reasonable accommodations are provided systematically	Yes, staff do their best to provide reasonable accommodations, but it is not systematic	No, reasonable accommodations are not provided for my family member	Free text space	

Reasonable accommodations are changes or adjustments that a person needs so they can access health services. For example, sending Easy Read appointment letters or giving more time for appointments.			with Down syndrome		
QF23: Are there dedicated patient support persons available in healthcare facilities to assist you and your family member with Down syndrome?	Yes, there are dedicated support persons to assist	No, there are no dedicated support persons, but the medical staff assist us	No, there are no dedicated support persons in health facilities	I'm not sure	Free text space

Questions to people identifying as 'a support person of a person with an intellectual disability other than Down syndrome (not related to the person)' and 'a support person of a person with Down syndrome (not related to the person)'

[...] is used to indicate either *'with Down syndrome'* if the person answering was a support person of a person with Down syndrome, or *'with intellectual disabilities'* if the person answering was a support person of a person with an intellectual disability other than Down syndrome.

Questions	Answer options							
QS1: How old is the person [...] you support?	Under 12	13-17	18-24	25-34	35-44	45-54	55-64	65 +

QS2: What gender is the person [...] you support?	Man/boy	Woman/girl	Non-binary	Prefer not to say		
QS3: How do you find information about the person you support's health? (Check all that apply)	Down syndrome associations	Healthcare provider recommendations	Online searches	Books or publications	Support groups or online forums	Free text space
QS4: How easy is it for you to find accessible and good quality health information about intellectual disabilities/Down syndrome?	Easy	Ok	Hard	Not sure		
QS5: How easy is it for you to find good quality health information in accessible formats that	Easy	Ok	Hard	Not sure		

the person […] you support can use and understand?				
QS6: How easy is it for you to find information about how to access health and support services for people […]?	Easy	Ok	Hard	Not sure
QS7: Can you share an example of accessible healthcare information that the person you support has accessed? OR where the information has not been accessible.	Free text space			
QS8: This question asked, ‘How satisfied are you with the health services available for the person […] you support?’ with the prompts: Are they able to access the health services they need? Do the health services they do access meet their needs?				

Are the services good quality?						
Early childhood development services (for example, monitoring developmental milestones, parental counselling and education, early intervention supports like speech and language therapy)	Satisfied	Ok	Not available	Not satisfied	Have not tried to access	The person I support does not need this service
General health services (check-ups with a doctor, nutrition, vaccinations etc)						
Eye health services						

Ear, nose and throat health services						
Oral health services (e.g. dental)						
Sexual and reproductive health and family planning services						
Services for chronic diseases (e.g. asthma, diabetes, heart disease)						
Mental health services						
Cardiac (heart) health services						
Specialized health care services						

Health services for older people						
QS9: Do you have any other thoughts about the healthcare services available for the person […] you support?	Free text space					
QS10: Are healthcare services in your area affordable for the person […] you support?	Yes	In the middle	No	Don't know		
QS11: Is transport to healthcare services affordable for the person […] you support?	Yes	In the middle	No	Don't know		
QS12: To what extent do you agree	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	

that healthcare is affordable for people […] and their families?					
QS13: Are there any financial supports available to help cover the cost of healthcare for people […]?	Yes there are financial supports that fully cover the healthcare costs	Yes there are financial supports, but they do not cover all the healthcare costs	No there are no financial supports available to help cover the healthcare costs	I’m not sure	
QS14: Thinking about where the person you support lives, is support provided to help with the cost of transportation to healthcare services for people […]? For example, transports subsidies or	Yes there is financial support that fully covers the transport costs	Yes there is financial support, but it does not cover all the transport costs	No there are no financial support available to help cover the transport costs	I'm not sure	

discounted fares; healthcare facilities providing transport to and from their services etc..				
QS15: Can you tell us more about the affordability of healthcare services for the person [...] you support?	Free text space			
QS16: How would you rate the physical accessibility of healthcare facilities for the person [...] you support?	Accessible	Ok	Not accessible	Not sure
QS17: How would you rate communication between	Good	Ok	Poor	Not sure

health care providers and the person [...] you support?					
QS18: Can you tell us more about how healthcare providers communicate with the person [...] you support?	Free text space				
QS19: Do doctors and other health workers ever treat the person you support unfairly? For example, are they rude to them or do they treat them differently to other patients?	Yes, all the time	Sometimes	Never	Not sure	
QS20: Is the person [...]	No, the person I	No, the health	Yes, I provide	Yes, health	Free text space

you support supported to make free and informed decisions about their healthcare?	support can't make decisions for themselves , so someone else makes decisions for them	care system provides no supports to enable the person I support to make free and informed decisions about their health	support to the person I support to help them to make decisions	care providers have a process and supports in place to enable the person I support to make their own informed decisions about their healthcare	
QS21: Do health facilities provide reasonable accommodations for the person [...] you support? Reasonable accommodations are changes or adjustments that a person needs so they can	Yes, reasonable accommodations are provided systematically	Yes, staff do their best to provide reasonable accommodations, but it is not systematic	No, reasonable accommodations are not provided for the person I support	Free text space	

access health services. For example, sending Easy Read appointment letters or giving more time for appointments.						
QS22: Are there dedicated patient support persons available in healthcare facilities to assist you and the person [...] you support?	Yes, there are dedicated support persons to assist	No, there are no dedicated support persons, but the medical staff assist us	No, there are no dedicated support persons in health facilities	I'm not sure	Free text space	

B.2 Organisations Survey Questions

Question	Answer options
QG1: What is the name of your Organization?	Free text space
QG2: What is your role in the Organization?	Free text space

QG3: In which country is your organization located? This survey will ask you to respond to questions about the situation for people with Down syndrome in one specific country. Please select the country that you would like to respond to based on where you are located and have in-depth experience on the issues for people with Down syndrome and intellectual disabilities accessing health care.	Afghanistan, Albania, Algeria, Andorra, Angola, Antigua and Barbuda, Argentina, Armenia, Australia, Austria, Azerbaijan, Bahamas, Bahrain, Bangladesh, Barbados, Belarus, Belgium, Belize, Benin, Bhutan, Bolivia, Bosnia and Herzegovina, Botswana, Brazil, Brunei, Bulgaria, Burkina Faso, Burundi, Cabo Verde, Cambodia, Cameroon, Canada, Central African Republic, Chad, Chile, China, Colombia, Comoros, Congo (Democratic Republic of the), Congo (Republic of the), Costa Rica, Croatia, Cuba, Cyprus, Czech Republic, Denmark, Djibouti, Dominica, Dominican Republic, East-Timor (Timor Leste), Ecuador, Egypt, El Salvador, Equatorial Guinea, Eritrea, Estonia, Eswatini, Ethiopia, Fiji, Finland, France, Gabon, Gambia, Georgia, Germany, Ghana, Greece, Grenada, Guatemala, Guinea, Guinea-Bissau, Guyana, Haiti, Honduras, Hungary, Iceland, India, Indonesia, Iran, Iraq, Ireland, Israel, Italy, Ivory Coast, Jamaica, Japan, Jordan, Kazakhstan, Kenya, Kiribati, Kosovo, Kuwait, Kyrgyzstan, Laos, Latvia, Lebanon, Lesotho, Liberia, Libya, Liechtenstein, Lithuania, Luxembourg, Madagascar, Malawi, Malaysia, Maldives, Mali, Malta, Marshall Islands, Mauritania, Mauritius, Mexico, Micronesia, Moldova, Monaco, Mongolia, Montenegro, Morocco, Mozambique, Myanmar (Burma), Namibia, Nauru, Nepal, Netherlands, New Zealand, Nicaragua, Niger, Nigeria, North Korea, North Macedonia (formerly Macedonia), Norway, Oman, Pakistan, Palau, Palestine, Panama, Papua New Guinea, Paraguay, Peru, Philippines, Poland, Portugal, Qatar, Romania, Russia, Rwanda, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Samoa, San Marino, Sao Tome and Principe, Saudia Arabia, Senegal, Serbia, Seychelles, Sierra Leone, Singapore, Slovakia, Slovenia, Solomon Islands, Somalia, South Africa, South Kora, South Sudan, Spain, Sri Lanka, Sudan, Suriname, Sweden, Switzerland, Syria, Taiwan, Tajikistan, Tanzania, Thailand, Togo, Tonga, Trinidad and Tobago, Tunisia, Turkey, Turkmenistan, Tuvalu, Uganda, Ukraine, United Arab Emirates, United Kingdom, United States, Uruguay, Uzbekistan, Vanuatu, Vatican City, Venezuela, Vietnam, Yemen, Zambia, Zimbabwe

QG4: What level does your Organization work at?	Local - in one part of a country	National - across a whole country	Regional or multi-country	Global or International	
QG5: Which of these is your Organization?	An organization of persons with disabilities (OPD) or representative group.	International Non-Governmental Organization (INGO)	Local NGO	A service provider	UN Agency
QG6: Who does your organization represent or work with?	People with Down syndrome only	People with intellectual disabilities (including people with Down syndrome)	Free text space		

Questions to all respondents

QG7: Are tests available in your country to detect during pregnancy that a child has Down syndrome/an intellectual disability?	Yes	Yes, but they are expensive	Yes, but not everywhere (e.g. only in big cities)	No, not available at all	No, not at all	Free text space	
QG8: On average, how long does it take for healthcare professionals to identify whether a child has Down	Before the baby is born	Straight after birth	Between 0 – 6 months	7 – 12 months	1 – 3 years	4+ years	I don't know

syndrome in your country?							
QG9: Can you tell us what supports and advice health professionals access and share with families to support pre and post-natal diagnosis of Down syndrome/an intellectual disability? For example, are parents directed by healthcare providers to access information and other support?	Free text space						
QG10: Are specialized services for early intervention and early childhood development for children with Down syndrome/intellectual disabilities available in your country?	Yes	No	I don't know	Free text space			
QG11: If available, are specialized early intervention and early childhood development services for children with Down syndrome/	Yes	No	I don't know	Free text space			

intellectual disabilities affordable?				
QG12: If available, are specialized early intervention and early childhood development services for children with Down syndrome/ intellectual disabilities accessible?	Yes	No	I don't know	Free text space
QG13: If available, are specialized early intervention and early childhood development services for children with Down syndrome/ intellectual disabilities good quality?	Yes	No	I don't know	Free text space

QG14: To what extent do you agree that children with Down syndrome/ intellectual disabilities can access the same general health care services as children without Down syndrome/ intellectual disabilities?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
QG15: To what extent do you agree that general healthcare is	Strongly agree	Agree	Neutral	Disagree	Strongly disagree

affordable for children with Down syndrome/intellectual disabilities and their families?					
QG16: To what extent do you agree that children with Down syndrome/an intellectual disability receive good quality health care in your country?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
QG17: Please share more about what are the challenges that children with Down syndrome/ intellectual disabilities might face in accessing good quality, affordable health care, compared to children without Down syndrome/ intellectual disabilities.	Free text space				
QG18: To what extent do you agree that young people with Down syndrome/intellectual disabilities can access the same health care services as young	Strongly agree	Agree	Neutral	Disagree	Strongly disagree

people without Down syndrome/ intellectual disabilities?					
QG19: To what extent do you agree that young people with Down syndrome/intellectual disabilities receive good quality health care in your country?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
QG20: Please share more about what are the challenges that young people with Down syndrome intellectual disabilities might face in accessing good quality health care, compared to young people without Down syndrome/intellectual disabilities.	Free text space				
QG21: Is information and services related to puberty and development made accessible to young people with Down syndrome/intellectual disabilities?	Always	Most of the time	Sometimes	Rarely	Never

QG22: Are young people with Down syndrome/intellectual disabilities encouraged to access sexual and reproductive health services?	Always	Most of the time	Sometimes	Rarely	Never
QG23: Please tell us more about access to sexual and reproductive health information and services for young people with Down syndrome/ intellectual disabilities in your country.	Free text space				
QG24: How easy do perceive the transition from pediatric/child health services to adult health services for people with Down syndrome /intellectual disabilities?	Very easy	Easy	Neither easy or difficult	Difficult	Very challenging
QG25: Please share more about how easy or difficult the transition from child health services into adult healthcare is for people with Down	Free text space				

syndrome/ intellectual disabilities in your country?					
QG26: To what extent do you agree that adults with Down syndrome/ intellectual disabilities can access the same health care services as adults without Down syndrome/intellectual disabilities?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
QG27: To what extent do you agree that adults with Down syndrome/ intellectual disabilities receive good quality health care in your country?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
QG28: To what extent do you agree that healthcare is affordable for adults with Down syndrome/ intellectual disabilities?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
QG29: Please share more about what are the challenges some adults with Down syndrome/ intellectual disabilities might face	Free text space				

in accessing good quality, affordable health care that meets their needs. You can also include an anonymous story here as an example.				
QG30: What care and supports are available for adults and ageing people with Down syndrome/an intellectual disability in your country?	Free text space			
QG31: Are there support services for adults with Down syndrome/ intellectual disabilities who might have a higher risk of developing dementia as they age?	Yes	No	I don’t know	Free text space
QG32: Please share any positive examples of actions to improve access to good quality healthcare that meets the needs of people with Down syndrome/intellectual disabilities in your country.	Free text space			

QG33: If people with Down syndrome/ intellectual disabilities are not happy with the healthcare services they receive, are complaints and feedback mechanisms available to them to report their experiences? If there are complaints and feedback mechanisms available, are processes fully accessible? Are actions taken to address concerns raised?	Free text space

Questions specifically to organizations working with people with intellectual disabilities (including Down syndrome)

QG34: Are tests available in your country to detect that a child has Down syndrome during pregnancy?	Yes	Yes, but not everywhere (e.g. only in big cities)	Yes, but they are expensive	No, not available at all	Not sure	Free text space

QG35: On average, how long does it take for healthcare professionals	Before the	Straight after birth	Between 0 – 6 months	7 – 12 months	1 – 3 years	4+ years	I don't know

to identify whether a child has intellectual disabilities in your country?	baby is born						
QG36: Can you tell us what supports and advice health professionals access and share with families to support pre- and post-natal diagnosis of Down syndrome or intellectual disability? For example, are parents directed by healthcare providers to access information and other support?	Free text space						

These questions were asked to determine the priority level of different health services for the organisations.

QG37: Diagnostic services for Down syndrome and/or intellectual disabilities	Low Priority	Medium Priority	High Priority	Not sure
QG38: Early Childhood Development	Low Priority	Medium Priority	High Priority	Not sure
QG39: General health care (check-ups, nutrition, vaccinations etc)	Low Priority	Medium Priority	High Priority	Not sure

QG40: Eye & hearing health	Low Priority	Medium Priority	High Priority	Not sure
QG41: Oral health services (e.g. Dental care)	Low Priority	Medium Priority	High Priority	Not sure
QG42: Adolescent, youth friendly services	Low Priority	Medium Priority	High Priority	Not sure
QG43: Sexual and reproductive health and family planning services	Low Priority	Medium Priority	High Priority	Not sure
QG44: Services for chronic diseases (e.g. asthma, diabetes, heart disease)	Low Priority	Medium Priority	High Priority	Not sure
QG45: Mental health services	Low Priority	Medium Priority	High Priority	Not sure
QG46: Specialized health care services	Low Priority	Medium Priority	High Priority	Not sure
QG47: Older age health care	Low Priority	Medium Priority	High Priority	Not sure
QG48: Legal policy environment for legal capacity and/or supported decision making in your country	Low Priority	Medium Priority	High Priority	Not sure
QG49: Affordability of health care for people with Down syndrome	Low Priority	Medium Priority	High Priority	Not sure

and intellectual disabilities				
QG50: Training healthcare workforce to provide equitable healthcare to people with Down syndrome and intellectual disabilities	Low Priority	Medium Priority	High Priority	Not sure
QG51: Is there another health issue that is an advocacy priority for your organization?	Free text space			
QG52: Does your organization have experience running campaigns to advocate on health?	Yes, we have experience advocating on health topics	No, but I would be interested to learn more	No, this is not currently a priority for my organization	Free text space
QG53: If yes, please tell us more information about the health campaigns you have run in your country	Free text space			
QG54: Does your organization have experience training or supporting people with Down syndrome and/or intellectual disabilities to advocate for their right to health?	Yes	No, but I would be interested to learn more	No, this is not currently a priority for me/my organization	Free text space

QG56: If yes, please tell us more information about the training or support you gave.	Free text space			
QG57: Has your organization done research to understand the specific challenges that people with Down syndrome and/or intellectual disabilities face in accessing health care?	Yes	No, but I would be interested to learn more	No, this is not currently a priority for me/my organization	Free text space
QG58: If yes, please tell us more information about the research on health challenges for people with Down syndrome and/or intellectual disabilities?	Free text space			
QG59: Does your Organization do any other work on health?	Free text space			

Questions asked only to organisations other than those working only with Down syndrome

QG60: On average, how long does it take for healthcare professionals to identify whether a child has an intellectual disability in your country?	Yes	No	Not sure
QG61: Is access, quality or affordability of healthcare different for children with Down syndrome?	Yes	No	Not sure
QG62: If yes, please explain how it is different for children with Down syndrome?	Free text space		
QG63: Is access to sexual and reproductive health information and services different for young people with Down syndrome compared to other young people with intellectual disabilities?	Yes	No	Not sure
QG64: If yes, please explain how it is different for young	Free text space		

people with Down syndrome?			
QG65: Is access, quality or affordability of healthcare different for adults with Down syndrome?	Yes	No	Not sure
QG65: If yes, please explain how it is different for adults with Down syndrome?	Free text space		
QG66: Please share any positive examples of actions to improve access to good quality healthcare that meets the needs of people with intellectual disabilities in your country.	Free text space		

Appendix C: Affordability Challenges In High-income Countries: United States And United Kingdom Case Study

As a result of the high number of survey respondents from the United States and the United Kingdom, many people mentioned their experience with Medicaid, Medicare, and the National Health Service. A few respondents in each country also mentioned receiving money from the government.

C1. Medicaid, Medicare, and Social Security Disability Insurance (United States)

Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities (from Medicaid website). Medicare is health insurance for people 65 or older, but some people are eligible to get Medicare earlier if they have a disability, End-Stage Renal Disease (ESRD), or ALS (also called Lou Gehrig's disease). Medicaid and Medicare were mentioned multiple times – 27 and 10, respectively. Social Security Disability Insurance (SSDI), mentioned by two people, is a separate monthly payment to people who have a disability that stops or limits their ability to work.

Of the 27 people who mentioned Medicaid, only seven said it covered all their medical costs. Ten said it covered all costs when combined with Medicare or private insurance. One person even mentioned using Medicare, Medicaid, and private insurance to cover all costs. Three people said that although it helps, it does not cover their preferred medications and therapies. Wait times and providers not taking Medicaid patients were also mentioned as problems, each by one person.

Additionally, eight people say that they can't access Medicaid due to being above the required income level, which leaves them with unbearable costs. Although it is possible to apply for a waiver to access Medicaid regardless of income, it is mentioned as difficult to obtain. Understanding how to apply for and use Medicaid was also cited as challenging by two people, especially cross-culturally. Lastly, two people mentioned Social Security Disability Insurance, which was cited as a source of frustration. One person was told their daughter wasn’t “special needs enough” (ID 313) while another person said you’d have to be “basically destitute to qualify it” (ID 335).

> “My husband and I make too much to qualify for Medicaid anymore. But the cost of sleep studies, speech therapies, occupational therapies, surgeries, etc is more than someone can genuinley afford without going into serious debt. Yet my daughter "isnt special needs enough" to be on disability as she doesnt have a major heart problem or something "severe" in the eyes of the social security and disability office. And I have no idea who else to ask for help on assistance when paying for medical bills for my daughter.” – Female family member of a girl under 12 with Down syndrome from the United States (ID 313)

> “In the United States, if a person doesn't have health insurance, then a person with Down syndrome would be eligible for Medicaid, although this can be a complicated process for an already challenged person with or without Ds to navigate. My understanding is that Medicaid dictates which meds can be prescribed etc., even thought that med may not be best for the person with Ds.” – Female family member of boy aged 13-17 with Down syndrome from the United States (ID 506)– Female family member of a boy aged 13-17 with Down syndrome from the United States (ID 506)

Two people mentioned the Social Security Disability Insurance (SSDI), stating they made too much income to qualify.

“My husband and I make too much to qualify for medicaid anymore. But the cost of sleep studies, speech therapies, occupational therapies, surgeries, etc is more than someone can genuinley afford without going into serious debt. Yet my daughter "isnt special needs enough" to be on disability as she doesnt have a major heart problem or something "severe" in the eyes of the social security and disability office. And I have no idea who else to ask for help on assistance when paying for medical bills for my daughter.” – Female family member of a girl under 12 with Down syndrome from the United States (ID 313)

C2. National Health Service and the Disability Living Allowance (United Kingdom)

> Of the 27 family members and support persons who mentioned the National Health Service (NHS), seven mentioned a lack of services, four mentioned long wait lists, and two mentioned poor quality of service. Eleven people said they needed to access private healthcare services in addition to the NHS to meet their needs. Three of the 11 said that while private services are necessary, they are not able to afford them. "The NHS services are available for free, but don't cover a lot of the everyday costs of care and do not cover any therapies/early interventions that are scarcely offered on the NHS (Speech and language, physio therapy, OT) these are very expensive and unaffordable." – Female family member of a boy under 12 with Down syndrome from the United Kingdom (ID 545)

The Disability Living Allowance (DLA) was mentioned twice but was said to be insufficient.

> 'The NHS services are available for free, but don't cover a lot of the everyday costs of care and do not cover any therapies/early interventions that are scarcely offered on the NHS (Speech and language, physiotherapy, OT) these are very expensive and unaffordable. Our DLA does not cover these.'—Female family member of a girl under 12 with Down syndrome from the United Kingdom (ID 537)

Appendix D: Additional Quotes

D1. Accessibility

D1a. Lack of training by healthcare providers (in response to QF9/QS7)

"Currently most importantly are therapies which are not adequate and too generic. In general I can't accept the saying from a doctor to treat my son the same as he isn't the same. So that has to be appreciated but it isn't and just highlights ignorance." – Female family member of a boy under 12 with Down syndrome from the United Kingdom (ID 136)

"A lot of information is out of date and many health professionals lack knowledge due to lack of training and so generalise and stereotype which has caused me anxiety." – Female family member of a girl under 12 with Down syndrome from the United Kingdom (ID 306)

"Our local NHS services are pretty good, though I don't know how much we aren't told about Downs, because nobody is a specific expert in Downs." – Male family member of a boy under 12 with Down syndrome from the United Kingdom (ID 185)

"In Pakistan unlike Developed Countries there no care of Down Syndrome peoples there are no specific institute to guide them or treat their health issues." – Male family member of a boy under 12 with Down syndrome from Pakistan (ID 265)

"The issue we run across most frequently is that we are limited because we are in a rural setting... We would have to inform THEM on what we knew, and this still happens quite frequently today." – Female family member of a boy under 12 with Down syndrome from Canada (ID 610)

"We are in a private clinic to ensure that my son has access to a health professional... I have to do the research and follow up with the doctor to ensure he follows certain guidelines for my son's health." – Female family member of a man aged 25–34 with Down syndrome from Canada (ID 150)

"Our healthcare system generally does not have much information on Down Syndrome." – Female family member of a girl under 12 with Down syndrome from Kenya (ID 394)

"Not every medical professional have the know how in dealing with different abilities... understanding levels and etc." – Female family member of a girl under 12 with Down syndrome from Malaysia (ID 410)

"Generally speaking, most providers are nice, but don't have much experience or knowledge about DS-specific care." – Female family member of a woman aged 18–24 with Down syndrome from the United States (ID 515)

"In Estonia, there is an online health portal where everyone can view their health history... this information is not written anywhere, and doctors (and also family members) do not know how to keep an eye on certain symptoms." – Female family member of a woman aged 18–24 with Down syndrome from Estonia (ID 554)

"We have really struggled with the Paediatrician as it feels like he goes through a tick list and then doesn't signpost us to things that would be useful or needed." – Female family member of a boy under 12 with Down syndrome from the United Kingdom (ID 172)

“In government hospitals it's so difficult to access health facilities for persons with Down syndrome. Even health workers themselves are less informed about persons with Down syndrome.” – Female family member of a woman aged 25–34 with Down syndrome from Zimbabwe (ID 455)

“Some healthcare workers do not know the syndrome and therefore do not know how to take care of it.” – Male family member of a girl aged 13–17 with Down syndrome from Burkina Faso (ID C10)

“It's not easy to get the access information when we continue going to the hospital… care providers continue to give us information on how the disability can be cured and the medicines to take.” – Female family member of a girl under 12 with an intellectual disability from Ghana (ID 396)

“Health workers including doctors not awair about ID.” – Male family member of a woman aged 25–34 with an intellectual disability from Nepal (ID 602)

“At first, doctors recommended contacting early intervention institutions… We also had to explore for a long time before we knew where to find help.” – Female family member of a woman aged 18–24 with an intellectual disability from the United States (ID B33)

“My child was diagnosed at the age of 10, but the doctor did not tell me any information about rehabilitation training… we didn't know what policy support we could enjoy.” – Male family member of a boy aged 13–17 with an intellectual disability from China (ID B30)

“Dr. who told us the result didn't know very well about the people with disabilities and Down Syndrome… It was very hard for us to see how timidly he treated my child.” – Female family member of a woman aged 35–44 with Down syndrome from Japan (ID 139)

“Very little knowledge about DS by nurses and doctors in our town.” – Female family member of a woman aged 45–54 with Down syndrome from Sweden (ID 3)

“Medical staff have insufficient understanding of Down syndrome and lack the knowledge that parents have.” – Female family member of a man aged 18–24 with Down syndrome from China (ID B5)

“Back in 2008 since my baby born with Down syndrome, we did not find any accessible information for special healthcare… the doctor has a limited information on healthcare about children with Down syndrome." – Male family member of a boy aged 13–17 with Down syndrome from Bangladesh (ID 682)

D1b. More lack of training by healthcare providers (in response to QF11/QS9)

"It's a challenge to find what is best for them and often people's views and opinions are outdated." - Female support person for a boy under 12 with Down syndrome from the United Kingdom (ID 172)

"Healthcare workers should be trained on how to communicate properly with person with down Syndrome." – Male support person for a man aged 18-24 with Down syndrome from Nigeria (ID 376)

"Persons with down syndrome in Zimbabwe are not provided good health services, their special needs are not considered and just general treatment granted to any person is what they receive. Our health services leaves a lot to be mentioned." - Female support person for a woman aged 25-34 with Down syndrome from Zimbabwe (ID 455)

"National healthcare services need more focus in this area . Cost for therapy is very high. Free care has long list. No speciality care for DS. Health care professionals are not up to date on DS." - Female support person for a man aged 25-34 with Down syndrome from Trinidad and Tobago (ID 621)

"in my country, there is no special care and medical checkup system for people with [Down syndrome]. From the moment they are born, they experience discrimination, even from medical doctors and nurses." - Female support person for a boy aged 13-17 with Down syndrome from Mongolia (ID 683)

"Actually they are not really focus on Down Syndrome like, I'm just fighting to continue advocating for them, but we will support to do a campaign and information government about Down Syndrome/disabilities needs to be well taking care off." - Female support person for a girl aged 13-17 with Down syndrome from Liberia (ID 47)

D1c. Accessible information (in response to QF9/QS7)

"My son with DS knows how to take his medications, but there is no reading material that is easily accessible through simple reading for people with DS. This is essential since, in general, their memory and ability to acquire VISUAL information is more developed. The professionals who care for them, for example, should give them instructions on their health care in written, simple, graphic brochures.” – Female family member of a man aged 25-34 with Down syndrome from Argentina (ID A1)

“In the Down syndrome health program at the Valencia clinical hospital, the information is provided in an accessible way. The pediatrician also provides the necessary information. In the rest of the institutions it is Hard to access accessible information at a cognitive level (neither in medical leaflets, nor in recommendations, nor in healthy diets...)” – Female family member of a girl aged 13-17 with Down syndrome from Spain (ID A10)

“I have never seen accessible healthcare information. Some doctors are good at explaining in simple language, but many are not. When diagnosed with and treated for a malignant melanoma, there was no accessible information offered.” – Female family member of a girl aged 13-17 with Down syndrome from the United Kingdom (ID 645)

D1d. Location as a barrier to access (in response to QF9/QS7)

“Now that we live in a rural area of France, rather than a suburb in the UK, access to support groups has been difficult. We find that the attitude towards disability is very different to that in the UK.” – Female family member of a boy aged 13–17 with Down syndrome from France (ID C3)

“Our first exposure was to a woman… who was our daughters first teacher. She believed that children with Down Syndrome learn differently than children with other developmental disabilities. She was the most knowledgeable person that we dealt with. She also had a rolodex of MD’s that she recommended. We then connected with the MGH/BW Hospital in Boston which has offered the most comprehensive informational team that we have experienced. We also lived outside of Atlanta accessing information and resources in the south was extremely difficult.” – Female family member of a woman aged 25–34 with Down syndrome from the United States (ID 179)

“We live in a fairly small town but there are a lot of specialized clinics available not more than 1-2 hours away.” – Female family member of a woman aged 25–34 with Down syndrome from Germany (ID 188)

“We lived for a year in Detroit, Michigan (where I am from) before moving to Denmark. In Denmark, Down syndrome isn't really known by medical professionals especially the newer doctors as the older ones are retiring. I usually find the information on an American site and share it with them.” – Female family member of a boy under 12 with Down syndrome from Denmark (ID 200)

“Support through a DS association was easy to find, but not as easy to access. We live over an hour away so a lot of the services are not accessible for working parents.” – Female family member of a boy under 12 with Down syndrome from the United States (ID 326)

“The area in which we live does not have accessible healthcare in general. We have had several different primary care physicians, as they do not stay here long. We travel to Baltimore for all specialty care.” – Woman from the United States with a male family member with Down syndrome under 12 (ID 361)

“Our child lives in Indonesia but is monitored for his health in France, on a regular basis. The reliable information comes from France, mainly from the healthcare professionals and also from Down syndrome organisations/groups.” – Male family member of a man aged 25–34 with Down syndrome from France (ID 428)

“He lives in a city, there fore health care service is accessible.” - Male family member of a boy under 18 with Down syndrome from Nigeria (ID 376)

D2. Affordability

D2a. Inadequate public healthcare services and the need to access private services (in response to QF16/QS15)

“The NHS services are available for free, but don’t cover a lot of the everyday costs of care and do not cover any therapies/early interventions that are scarcely offered on the NHS (Speech and language, physiotherapy, OT) these are very expensive and unaffordable. Our DLA does not cover these.” – Female family member of a girl under 12 with Down syndrome from the United Kingdom (ID 537)

“In the UK everything available on NHS for free, but these are generalised services. For example, speech and language therapy is inadequate, but I cannot afford for private provision.” – Female family member of a boy under 12 with Down syndrome from the United Kingdom (ID 39)

“The Government healthcare facilities accept the National Health Insurance. This kind of insurance is woefully inadequate for the many healthcare challenges for persons with Down Syndrome. Most children with DS here in Ghana die of Cardiac issues, pneumonia etc.” – Female family member of a girl aged 13–17 with Down syndrome from Ghana (ID 76)

“Our healthcare is covered for our son, except when it comes to expensive equipment. When he needed orthotic devices for clubfoot, we had to pay out of pocket for that ($2000) and when he needed a hearing aid, ADL (Alberta Daily Living) could only pay a fraction of that (we paid $1500). That stings. His dentistry bills are also only partially covered. I worry about the future, because we don't know what he'll need, and if it will fall out of the typical parameters of what is covered.” - Female family member of a boy under 12 with Down syndrome from Canada (ID 610)

“The state services are of poor quality and very limited. Only 1 speech therapist for the whole country. Private services are very expensive.” – Female family member of a boy under 12 with Down syndrome from Namibia (ID 465)

“Everthing cost more for our children. Eye glasses only cover the basic, but their need for prescription is always more expensive (lighter frames, lighter weight lenses because the rx is so strong). As with anyone who has special needs.” – Female family member of a man aged 18–24 with Down syndrome from the United States (ID 225)

“Optical, dental and consultant medical care has to be paid for. Speech therapy, OT and physiotherapy has to be paid for. As a single parent, working full time, I have to take time off work to attend appointments with my daughter. She had knee surgery twice. I had to hire a wheelchair from a private company and pay for follow up physiotherapy.” – Female family member of a woman aged 18–24 with Down syndrome from Ireland (ID 566)

“We have no alternative but to pay privately for all healthcare for our daughter because that which is offered publicly is either not available or erratic or major staff competence issues.” – Female family member of a girl under 12 with Down syndrome from Ireland (ID 591)

"Can access all as a medical card holder but waiting lists can take years, having private medical insurance is essential to access care in timely fashion but it is very expensive." – Female family member of a girl aged 13–17 with Down syndrome from Ireland (ID 158)

"We have our son included in our private cover the cost to us is $5000.00 per year so he can have quick access to health services instead of going on a waiting list which could be up to 12 months." – Female family member of a man aged 35–44 with Down syndrome from Australia (ID 149)

"Everything is covered at almost no cost within the public system, however waitlists have exploded since covid began which means we now use expensive private insurance to access specialists privately. However this still costs $100's on top of our insurance payments. The cost of parking, petrol, and time off work is also significant." – Female family member of a boy under 12 with Down syndrome from Australia (ID 154)

"I was attending a free government hospital because here in my country public hospital are for free. The service was poor but I could not manage private hospitals." – Female family member of a girl under 12 with Down syndrome from Malawi (ID 58)

"In Pakistan the Family has to afford all expenses regarding the treatment and other learning of down syndrome person there is no any support from government." – Male family member of a boy under 12 with Down syndrome from Pakistan (ID 74)

"The specialist of speech therapist is expensive from the private agenda. Public service is fully booked." – Female family member of a woman aged 18–24 with Down syndrome from Japan (ID 585)

"If they are private they are expensive, if they are public they are slow." – Female family member of a girl under 12 with Down syndrome from Spain (ID A13)

"The services that the public sector provides are free for children. The services we parent fell are lacking, and that we have to buy in the private sector are not covered in any way." – Female family member of a boy under 12 with Down syndrome from Norway (ID 415)

D3. Availability

D3a. Wait times for public healthcare (more can be seen above within quotes about inadequate public health care) (in response to QF11/QS9)

“If you have monitoring of health conditions that public hospital (government) take care of it which is free to get service but you have to wait for waiting list.” - Female family member of a boy aged 13-17 with Down syndrome from New Zealand (ID 490)

“My family member is on Medicaid. It covers most things, but there are waiting periods for other services. For example, my daughter had to go nearly a year without hearing aids while we navigated appointments out of state as well as coverage.” - Female family member of a girl aged 13-17 with Down syndrome from the United States (ID 231)

“In Ireland free healthcare is offered to individuals with DS but waitlist are way too long so we often go private which is not covered at all.” – Female family member of a woman aged 18-24 with Down syndrome from Ireland (ID 287)

“Medical services are covered under the provincial health care plan, but services such as speech and occupational therapy are usually accessed privately, as waitlists for funded services of this type are very long.” – Female family member of a woman aged 35-44 with Down syndrome from Canada (ID 561)

D3b. Unavailability of speech therapy (in response to QF11/QS9)

“Basic services like speech and language are hard to reach and don't properly start until later and only run for 6 sessions, at which point we are discharged and need to wait to be accepted for another 6 sessions.” – Female family member of a girl under 12 with Down syndrome from the United Kingdom (ID 26)

“Services for speech therapy is almost not existent.” – Female family member of a boy aged 13–17 with Down syndrome from Rwanda (ID 95)

“The area in which I think NHS is lacking especially for people with Down’s Syndrome is speech therapy.” – Female family member of a boy aged 13–17 with Down syndrome from the United Kingdom (ID 195)

"Speech and language is usually not available to anyone that has Down's syndrome unless they have an unsafe swallow. It's borderline discriminatory." – Female family member of a boy aged 13–17 with Down syndrome from the United Kingdom (ID 588)

D3c. Unavailability of mental health care (in response to QF11/QS9)

"Finding a mental health specialist who also understood developmental disabilities was impossible. After 3 years, I gave up." – Female family member of a man aged 25–34 with Down syndrome from the United States (ID 216)

"There are insufficient professionals who specialise in Downs syndrome and other neurodivergent disabilities. I have been looking for the past four years for a psychiatrist who has experience in Downs Syndrome as well as mental health issues." – Female family member of a woman aged 25–34 with Down syndrome from the United Kingdom (ID 399)

"We live in a large city and have been able to access medical specialists and health services as needed, with the exception of mental health, which was more challenging to access." – Female family member of a woman aged 35–44 with Down syndrome from Canada (ID 561)

D3d. Unavailability of dentistry/oral health care (in response to QF11/QS9)

"We had to search hard to find a dentist willing to take on our son and currently still drive over two hours for service. Absolutely no local care." – Female family member of a boy under 12 with Down syndrome from Canada (ID 125)

"Easier to get access through children's hospitals, however dental care and healthcare specializing in young adult care is significantly harder and dentistry with sleep apnea is extremely difficult and i will have to travel 800 miles to get basic cavities taken care of after jumping through hoops and [getting] every specialist to sign off while waiting for referrals for months. Same with Psychiatry for Down syndrome and Autism dual diagnosis" – Female family member of a man aged 18–24 with Down syndrome from the United States (ID 266)

D3e. Want for separate Down syndrome clinics (in response to QF11/QS9)

“There should be special healthcare center for the people with Down syndrome or who takes more time than other people, but Doctors or practitioners do not have sufficient time for them (very commercialize).” – Female family member of a woman aged 25–34 with Down syndrome from Nepal (ID 148)

‘It would be valuable to have a Down syndrome clinic with specialists that understand the health challenges of this population and they could recommend solutions that parents could follow-up.’ – Female family member of a man aged 25–34 with Down syndrome from Canada (ID 150)

‘We need DS clinics where doctor are familiar with Down syndrome and everything that comes with it. We heard way too often symptoms ‘blamed’ on Down syndrome. That’s the easy answer when the doctor hasn’t got a clue.’ – Female family member of a woman aged 18–24 with Down syndrome from Ireland (ID 287)

D3f. Sources of *information* (in response to QF9/QS7)

‘Most of the information was through google, and e-books I was able to purchase. And through my local Down syndrome school.’ – Female family member of a boy under 12 with Down syndrome from Malaysia (ID 71)

“She hasnt been able to access anything but I find it hard on her behalf.” – Female family member of a woman aged 25–34 with Down syndrome from Australia (ID 372)

“Information about cancer or sex. Education even the easy read is too hard.” – Female family member of a man aged 25–34 with Down syndrome from the United Kingdom (ID 28)

“Looking for early onset Alzheimer's information regarding D.S. hard to find.” – Female family member of a woman aged 35–44 with Down syndrome from Canada (ID 240)

D4. Acceptability and Quality of Care

D4a. Healthcare providers not communicating directly to people with Down syndrome or intellectual disability (in response to QF19/QS18)

“They never speak to her unless I force it. They always address me about her, in front of her.” – Female family member of a girl under 12 with Down syndrome from the United States (ID 43)

“They ignore completely him & speak to family members who tell him what’s going on & ask if it’s ok to proceed.” – Female family member of a man aged 25–34 with Down syndrome from Australia (ID 112)

“They talk to us and not him, or treat him like he can’t speak for himself.” – Female family member of a man aged 25–34 with Down syndrome from the United States (ID 133)

“Most healthcare providers talk to me and not my child. They are 17 and can answer most questions. Healthcare providers should talk to my family member with Down syndrome.” – Female family member of a girl aged 13–17 with Down syndrome from the United States (ID 178)

“They generally talk about her, not TO her. If they talk to her, the tone is condescending. They usually operate on an assumption of incompetence until she speaks to them.” – Female family member of a girl under 12 with Down syndrome from the United States (ID 248)

“Most of the time doctors would treat my aunt like she was a child and then direct any medical questions towards her care provider (another family member).” – Female family member of a woman aged 65+ with Down syndrome from the United States (ID 304)

“I have found that most do not communicate with him. They rely on me. My son is non-verbal but uses an assistive device to communicate. They talk over him and straight to me never asking him first.” – Female family member of a man aged 25–34 with Down syndrome from the United States (ID 324)

“it varries a lot but most talk primarily to us as parents and not to our son. Sometimes it feels like a waste of his time that he came since they, sometimes, for example the astma / c-pap responcible team only talk to us and do not even listen to his lungs." – Female family member of a boy aged 13–17 with Down syndrome from Sweden (ID 385)

"Doctors should let people with DS speak first but they do not get that opportunity." – Female family member of a man aged 18–24 with Down syndrome from Rwanda (ID 460)

"It's ok because I attend every appointment and help her understand what is being discussed. I don't know what will happen when I die." – Female family member of a woman aged 35–44 with Down syndrome from Ireland (ID 557)

"Sometimes talk to me rather than him. He can't answer everything but please give him the opportunity and I can chip in as appropriate." – Female family member of a man aged 55–64 with an intellectual disability from the United Kingdom (ID 623)

'My daughter has excellent communication skills so can be treated like any other person. She hates being spoken to like a child or a pet. I usually go with her and sit in the background in case I am needed and to monitor things.' – Female family member of a woman aged 18–24 with Down syndrome from Australia (ID 59)

D4b. Indirect communication from the perspective of people with Down syndrome and intellectual disabilities (in response to QB11)

"Most of the time, because the professionals do not talk to me or explain to me what I have and what treatment to do." – Man aged 25-34 with Down syndrome from Brazil (ID A9)

"They don't talk to me about my health." – Man aged 25-34 with Down syndrome from Brazil (ID 141)

"Sometimes the specialist doctors don't talk to me, only my mom." – Woman aged 25-34 with Down syndrome from Canada (ID 235)

"The consultant was not really interested in what I said and listened to my parent only. He wasn't interested in how psoriasis affected me." – Man aged 18-24 with Down syndrome from Ireland (ID 487)

"I don't like it when people talk to my mother instead of talking to me." – Woman aged 25-34 with Down syndrome from Portugal (ID 62)

“I have gone to different doctors and the sometimes direct all questions to my mom. My mom turns around and tells them my daughter is right there and they then talk to me. My mom only adds to the conversation when needed or when I do not know the answer.” – Woman aged 25-34 with Down syndrome from the United States (ID 301)

“Yes I met a doctor who talked to me like a baby in a loud voice.” – Man aged 25-34 with Down syndrome from the United States (ID 34)

D4c. Being ignored, dismissed, or misunderstood from the perspective of people with Down syndrome and intellectual disabilities (in response to QB11)

“When i went to the hospital the receptionist and theatre nurse ignored me and dismissed my anxiety.” – Woman from Australia with Down syndrome aged 25-34 (ID 151)

“An optometrist was dismissive and bored with my eye exam.” – Man aged 25-34 with Down syndrome from the United States (ID 56)

“I had gout and the emergency doctor explained everything very quickly and I didn't understand anything.” – Man aged 35-44 with Down syndrome from Belgium (ID C25)

“When I was little, I felt unwell when I was sick. Once I went to a doctor I didn't know, he wasn't very nice because I was sick and he didn't understand what I wanted to say.” – Man aged 25-34 with Down syndrome from France (ID C4)

“I was confused at the gyne. I did not understand what was going on. I wanted to know about birth control. The staff was nice, but I did not get the birth control and still dont understand what i need.” – Woman aged 18-24 with Down syndrome from the United States (ID 514)

“One time when i was younger because he was dismissive,because of my disability.” – Woman aged 35-44 with an intellectual disability from the United States (ID 212)

“They don’t listen.” – Woman aged 45-54 with an intellectual disability from the United States (ID B26)

D4d. Healthcare providers being rough from the perspective of people with Down syndrome and intellectual disabilities (in response to QB11)

“The blood nurse hurt me.” – Man aged 18-24 with Down syndrome from Australia (ID 252)

“Sometimes the doctors become rough in their engagement with the patients.” – Man aged 18-24 with Down syndrome from Bangladesh (ID 101)

“When I went to get a blood test, I said that I was scared to do it. the lady called in 3 other people to hold me down. My mother said no way and they left. When they are nice and talk with me, then I'm not scared.” – Woman aged 55-64 with Down syndrome from the United States (ID 85)

“Exam for sleep apnea. I don't like to be dressed as a robot and they are angry because i don't sleep good and enough in the hospital. I don't want to have a mask on my nose.” – Girl under 18 with Down syndrome from France (ID 380)

“I have had many many bad experiences. The worst is when doctors don't listen to me or my support person, they just go ahead and try to do things, or they make assumptions that I will not cooperate and then they try to restrain me, or they don't give me pain medication or anaesthetic because they say people who have Down syndrome don't feel pain. It took eight years to get my health to improve mostly because people didn't listen or believe me.” – Woman aged 25-34 with Down syndrome from Canada (ID 13)

D4e. Misdiagnosis, mixed up healthcare results, or lack of understanding of disability from the perspective of people with Down syndrome and intellectual disabilities (in response to QB11)

“Doctors in Hong Kong don't know about Down syndrome at all.” – Man aged 25-34 with Down syndrome from China (ID 369)

“When clinicians don't get that my autism affects my capacity in some areas and not others. They assume I can understand and do everything or nothing, they don't get that it is more complex than that.” – Person aged 18-24 with Down syndrome from the United Kingdom (ID 520)

“I had fever repeatedly but no hospital would take me. We went to several hospitals but no one would take us.” – Woman aged 35-44 with Down syndrome from China (ID B13)

“The hospital didn't take me, I have to sign disclaimers.” – Woman aged 35-44 with Down syndrome from China (ID B34)

“Yes, when I went to the emergency room, I was injected with insulin without being informed or asked about whether I wanted it.” – Woman aged 18-24 with Down syndrome from Switzerland (ID 418)

“When I had to have an operation on my ear the surgeon wouldn’t let me sign the approval, even though I was over 21, he wouldn’t let my mum sign either and he signed himself.” – Woman aged 25-34 with Down syndrome from United Kingdom (ID 592)

“An optician mixed up the prescriptions for both eyes. To this day I'm still suffering the effects of this mistake.” – Man aged 18-24 with Down syndrome from Morocco (ID C31)

D4f. Healthcare providers communicating directly to people with Down syndrome or intellectual disability (in response to QF19/QS18)

“They tell what they are about to do…they take time, ask questions at her and if she doesn't know it they will ask us.” – Female family member of a girl under 12 with Down syndrome from the Netherlands (ID 120)

“They speak directly to her in plain English. They stop and check her understanding. The offer leaflets for backup.” – Female family member of a woman aged 25–34 with Down syndrome from the United Kingdom (ID 121)

“Our pediatrician is wonderful. Enjoys chatting with our boy and asks him most questions directly!” – Female family member of a boy under 12 with Down syndrome from Canada (ID 125)

“Our pediatrician and pediatric specialists are really wonderful about including our child in healthcare conversations and previewing what will happen next for him.” – Female family member of a boy under 12 with Down syndrome from the United States (ID 138)

“I was once scolded for answering for my daugher! i thought that was pretty cool.” – Female family member of a woman aged 25–34 with Down syndrome from Germany (ID 188)

“They usually talk to her instead of talking about her to us. She is verbal and doesn’t like when she is not involved in the conversation.” – Female family member of a woman aged 18–24 with Down syndrome from Ireland (ID 287)

“Generally respectful and speak to her, ask her questions. Some are very good at explaining the steps of the procedure as it is about to happen.” – Female family member of a woman aged 35–44 with Down syndrome from Canada (ID 339)

“Good communication, they speak to him at his level of understanding and always explain situations to him.” – Female family member of a man aged 35–44 with Down syndrome from Ireland (ID 590)

‘There have been providers whose communication has been poor, demeaning or who appear very nervous. Fortunately we can shop around and find alternatives.’ – Female family member of a woman aged 18–24 with Down syndrome from Australia (ID 59)

D4g. Quality examples of communication (in response to QF19/QS18)

“They were very delicate and at the same time useful to make you feel confident.” – Male family member of a girl aged 13–17 with Down syndrome from Italy (ID 97)

“Health care providers take extra care in communicating and making the person comfortable during treatment, The communication is mostly warm and friendly.” – Male family member of a girl under 12 with Down syndrome from India (ID 416)

“Despite her siutation and age, I have always had the feeling that health professionals treated my daughter like any other child, with great kindness and respect.” – Female family member of a girl under 12 with Down syndrome from Germany (ID C29)

“They communicate gently. Are not nervous. They are smiling.” – Male support person for a girl under 12 with an intellectual disability from Burkina Faso (ID C22)

D4h. Direct communication from the perspective of people with Down syndrome and intellectual disabilities (in response to QB10)

“When I visit our family doctor, He speaks to me and not my mum, He explains everything and make sure i understand.” – Woman aged 25-34 with Down syndrome from Australia (ID 151)

“My GP surgery are excellent - all the doctors talk to me and not just my mum. They explain things in a way I can understand and always give me the time I need to tell them things. They are very supportive.” – Man aged 18-24 with Down syndrome from the United Kingdom (ID 193)

“Lovely dentist who spoke to me and explained things.” – Girl under 18 with Down syndrome from Ireland (ID 478)

“The consultant & nurse spoke to me and was very kind and concerned.” – Man aged 18-24 with Down syndrome from Ireland (ID 487)

“When I had my hip operation. I was treated fairly and given all of the information and spoke to me as a patient.” – Woman aged 35-44 with Down syndrome from the United Kingdom (ID 556)

“Recently went to the doctor and all the questions were directed to me instead of my mom.” – Woman aged 25-34 with Down syndrome from the United States (ID 301)

“When I visit my GP (family doctor) she always talks to me and asks me questions. She treats me nice.” – Woman aged 25-34 with Down syndrome from Canada (ID 235)

“My yearly healthcare checks are great, the nurse talks to me and not just my mum and always asks if there is anything else I’d like to discuss.” – Woman aged 25-34 with Down syndrome from the United Kingdom (ID 592)

“When clinicians tell me when they are going to touch me and make sure I know what will happen. When they don't guess about what I can and can't do but ask me or my carer directly. When they get my pronouns right in all the letters and in person.” – Person aged 18-24 with an intellectual disability from the United Kingdom (ID 520)

D4i. Doctors explaining and understanding from the perspective of people with Down syndrome and intellectual disabilities (in response to QB10)

“When my doctor helps me understand what blood tests are for.” – Woman aged 25-34 with Down syndrome from Australia (ID 191)

“Visiting my GP is always a good experience, she understands me, explains what she’s doing and makes I understand.” – Woman aged 25-34 with Down syndrome from Australia (ID 598)

“When I go to my doctor, it goes well, because she knows me well. I know how to explain why I came and where I have pain. The doctor speaks to me with simple words so I can understand. When I go to the dentist, it also goes well because he goes slowly and gently when treating me and I trust him.” – Man aged 25-34 with Down syndrome from France (ID C4)

“With the Diabetes nurse - she spoke in a way that I could understand.” – Woman aged 18-24 with Down syndrome from Switzerland (ID 418)

“At my yearly health check I see the same nurse who asks me questions in a way that I understand and explains everything clearly.” – Woman aged 25-34 with Down syndrome from the United Kingdom (ID 293)

“I rarely go to the doctor but when I go the staffs treat me well by talking nicely, cracking jokes and the take time to explain my situation.” – Man aged 45-54 with an intellectual disability from Seychelles (ID 474)

D4j. More positive healthcare experiences from the perspective of people with Down syndrome and intellectual disabilities (in response to QB10)

“Getting my bloods taken. The nurse was very polite and told me the step by step procedure so I would not be scared. She was very kind and it did not hurt. She said I was amazing.” – Boy under 18 with Down syndrome from Ireland (ID 483)

“My doctor when I was younger, was nice and patient. When I go to the adult down syndrome center, everyone is nice and addresses me.” – Woman aged 18-24 with Down syndrome from the United States (ID 514)

“The doctor is kind to me and gave me my flu injection. He likes to see me happy and healthy.” – Man aged 18-24 with Down syndrome from Australia (ID 580)

“I had a good doctor for my thyroid problem, he took good care of me and explained how he would treat my problem. He was kind and did not rush me.” – Woman aged 25-34 with Down syndrome from Australia (ID 653)

“I had an operation on my jaw and the peope treated me so well. They were kind and supportive.” – Woman aged 35-44 with Down syndrome from South Africa (ID 73)

“Yes - I need to have bloods checked, hearing tests as well. They like and are kind. I don’t like the needle jab.” – Man aged 18-24 with Down syndrome from the United Kingdom (ID 335)

“I met a doctor recently. She was kind. She asked me questions. She is going to help me feel better.” – Man aged 25-34 with Down syndrome from the United States (ID 34)

D4k. Transition to adult services (in response to QF11/QS9)

“Health services were easy to access as a child, but some services are very hard to access for my now adult child.” – Female family member of a man aged 18–24 with Down syndrome from the United States (ID 17)

“We found as soon as she turned 18 there are no services available it's disgraceful.” – Female family member of a woman aged 18–24 with Down syndrome from Ireland (ID 267)

“Fantastic service up until 18; then no specialist services - everything through GP who had never met her. Has an annual health check and that is all.” - Female family member of a woman aged 25–34 with Down syndrome from the United Kingdom (ID 160)

“Now that [he] has transitioned to adult care the struggle is a bit more difficult. Even though he is 19 years old, cognitively he is not and when he is in facilities for adults the care and attention is different... not sure how to explain that. In a perfect world, all healthcare and educational institutes would be well versed in the needs of people with Down syndrome -but in the meantime we must continue to educate others at each appointment and educational encounter. Thanks for asking for input!" – Female family member of a man aged 18–24 with Down syndrome from Canada (ID 219)

"Until eighteen, my daughter went to the big children's hospital, but after she became of age, we have to look for private clinics for each category. It's really difficult and anxious." – Female family member of a woman aged 18–24 with Down syndrome from Japan (ID 284)

"There is a great lack of information and appropriate healthcare services available for adults with Down syndrome and their families. Specifically, in the areas of healthy aging, menopause, hormone health, alternative medicine." – Female family member of a woman aged 45–54 with Down syndrome from Canada (ID 153)

"It is difficult to plan for future support/dementia care for our family member as there is little information out there." – Male family member of a man aged 35–44 with Down syndrome from the Netherlands (ID 373)

D4l. Negative experiences at point of diagnosis – given little information (in response to QF4)

"Oh nothing really, just looked sad at myself and my wife and gave us a leaflet." – Male family member of a boy aged 13–17 with Down syndrome from the United Kingdom (ID 42)

"They did nothing for us." – Male family member of a girl under 12 with Down syndrome from Iran (ID 23)

"Nothing much was provided until he had grown up to 10 year old." – Male family member of a girl aged 13–17 with Down syndrome from Fiji (ID 256)

"None, except that he would know nothing when he grows up." – Female family member of a boy aged 13–17 with Down syndrome from China (ID B3)

"None. The diagnosis was communicated negatively. We received very little support and no one gave us information. We were told we would be referred to a disability service and they would be in contact." – Female family member of a boy under 12 with Down syndrome from Ireland (ID 19)

"Almost none. All professionals were very badly prepared." – Male family member of a woman aged 35–44 with Down syndrome from Brazil (ID 132)

“None. Only that I should forget about breastfeeding and that I had to get used to pumping my milk (which was obviously false and I'm still breastfeeding my daughter who is nearly 2 years old). I acquired all the information on my own through internet research.” – Female family member of a girl under 12 with Down syndrome from Germany (ID C29)

“Not much at all. My paediatric shoved a couple of printed out pages at me, and that was it. Was devastating.” – Female family member of a girl aged 13–17 with Down syndrome from South Africa (ID 215)

“Not much, just to not read about it on the internet, which we of course did.” – Female family member of a boy aged 13–17 with Down syndrome from Sweden (ID 385)

“Not much, the doctor walked into the room, measured up my son's ears, said he had Down syndrome and walked out. We had just had an emergency C-section and he was born 1 month premature, so it was a shock and the staff had no clue how to best support us.” – Female family member of a man aged 18–24 with Down syndrome from the United Kingdom (ID 618)

“No advice or information. He just said, ‘Sorry, she has Down syndrome.’” – Female family member of a boy aged 13–17 with Down syndrome from the United States (ID 178)

“They did not give me any advice or explanation of what Down syndrome is.” – Female family member of a girl aged 13–17 with Down syndrome from Ghana (ID 76)

“They referred me to a specialist but did not give any information on what needs to be done. The specialist was too expensive considering genetic related conditions are not covered by local insurance firms.” – Female family member of a boy under 12 with Down syndrome from Kenya (ID 110)

“20 days after birth, doctors gave me some brochures. I think they did not give enough information.” – Female family member of a boy under 12 with Down syndrome from Mongolia (ID 594)

“After the news, they did not give me any advice. When I went to the following consultations, they started talking to me (because of questions that I asked). It is worth saying that the consultation was private (paid).” – Female family member of a woman aged 18–24 with Down syndrome from Costa Rica (ID A8)

“There was no information given. On the whole people were ignorant themselves.” – Female family member of a woman aged 35–44 with Down syndrome from India (ID 96)

“No information was given. At time of birth once I brought up some facial features I noticed on my daughter I was told she didn’t have Down syndrome. Two days later a nurse came in and my mom brought it up to her. The nurse went for a doctor and they began testing. One day later she was diagnosed with trisomy 21. We were told she wouldn’t eat, she wouldn’t walk, talk, hear, and she has a heart murmur. All of which were not true.” – Male family member of a girl under 12 with Down syndrome from the United States (ID 129)

“Not enough. The midwife told us the news. No information given from the hospital after that.” – Female family member of a girl aged 13–17 with Down syndrome from Ireland (ID 197)

“No real advice. Basically scared me, explained a social worker would come see me.” – Male family member of a man aged 35–44 with Down syndrome from the United States (ID 597)

D4m. Negative experiences at point of diagnosis – termination (in response to QF4)

“I was advised to terminate and try again.” – Female family member of a girl under 12 with Down syndrome from the United States (ID 43)

“Abortion is an option I should seriously consider.” – Female family member of a girl under 12 with Down syndrome from Ecuador (ID 66)

“The doctor said he would schedule an abortion without even asking. I said no.he refused to be my doctor and told me get a peadiatrician.” – Female family member of a woman aged 18-24 with Down syndrome from Canada (ID 560)

“I was advised to terminate. I was told that she would have vision, hearing, heart, skeletal problems. I was told it would take a toll on our marriage and the siblings would suffer if we chose to continue.” – Female family member of a girl under 12 with Down syndrome from the United States (ID 248) “termination was legal in canada up to 24 weeks gestation, and as I was at about 20 weeks pregnant, i needed to make my decision quickly. This was reiterated to me a total of six times by different health professionals EVEN AFTER they read in my file that termination of my pregnancy simply because of a Down Syndrome diagnosis, was not an option.” – Female family member of a boy under 12 with Down syndrome from Canada (ID 378)

“I was told by the Maternal Fetal Medicine doctor that my daughter would be mentally retarded and to decide if I wanted to continue the pregnancy. It was framed as a very "unfortunate" thing to be happening to me. The doctor shared information that my child wouldn't live a full live like a "normal" person.” – Female family member of a girl under 12 with Down syndrome from Canada (ID 313)

“I was asked immediately if abortion might be best. Was asked a number of times throughout my pregnancy.” – Female family member of a boy under 12 with Down syndrome from Canada (ID 125)

“They kept asking if we wanted to abort the pregnancy. It was not until we told them it does not matter if he lives 5 min, 5 days, 5 years, or dies on the way out that is our son and we are not aborting.” – Male family member of a boy under 12 with Down syndrome from the United States (ID 388)

D4n. Positive experiences at point of diagnosis

‘[After diagnosis] I was encouraged to reach out to local organizations that support families with children with Down syndrome.’ – Female family member of a girl under 12 with Down syndrome from the United States (ID 297)

‘[Upon diagnosis] they referred me to a bigger [hospital] so that I would get proper care for the rest of my pregnancy. And a [geneticist] was introduced to me after [baby] was born.’ – Female family member of a boy under 12 with Down syndrome from the United States (ID 16)