

# Global Report on DDD

## Target audience:

- programme managers
- advocates
- NGOs
- Academics

Awareness	Increase awareness of the public health significance of DDD for children and their families.
Data/ Knowledge	Compile data on epidemiology, case studies on policies and care services, and users' perspectives
Guidance for policy	Provide a public health and human rights approach to policy and programme development
Guidance for services	Provide guidance on strengthening health systems and multisectoral actions towards provision of care and enabling environments for children with DD and their families.
Good practices	Document good and innovative practices.
Guidance for HIS	Provide guidance on collection of data through health information systems and population-based monitoring.
Track progress	Discuss and propose strategies to track progress.
Call for action	Call upon partners for international and national advocacy efforts.

# World's Report on DDD

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.1. Introduction

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2. Epidemiology of DDD

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3. Policies, plans and legislation for DD

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4. Care pathways for developmental disabilities

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5. Addressing barriers and promoting participation

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6. Public health monitoring

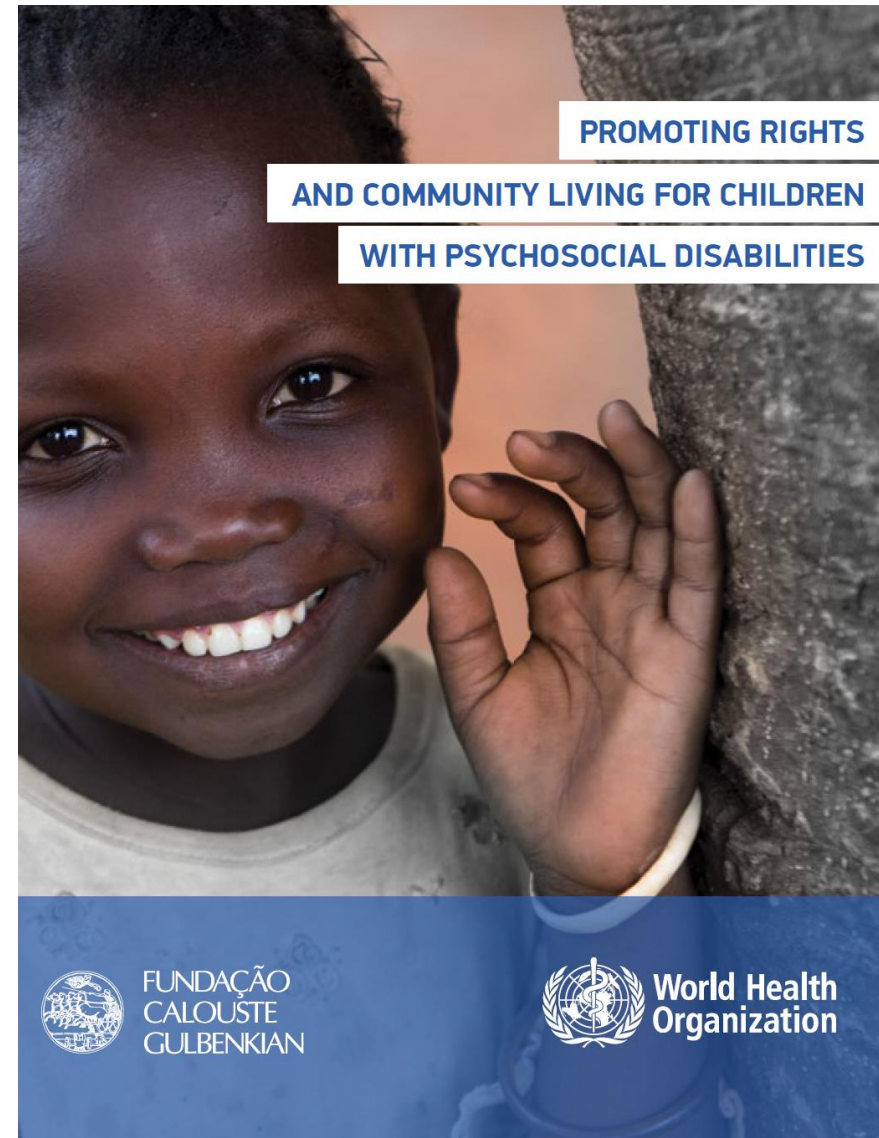
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7. The way forward

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# Human rights framework

- Convention on the Rights of the Child
- Convention on the Rights of Persons with Disabilities



## **WHA resolution 67.8**

### **Comprehensive and coordinate efforts for the management of ASD - 24 May 2014**



Acknowledges **the comprehensive MH action plan 2013-2020** and the policy measures that are recommended in resolution WHA66.9 on disability

Recognizes “the need to create or strengthen, as appropriate, health systems that support all persons with disabilities, mental health and developmental disorders, without discrimination”

Urges Member States:

- **To identify and address disparities in access to services**
- **To improve health information and surveillance systems to capture data on ASD and other developmental disorders**
- To shift systematically the focus of care away from long-stay health facilities towards community-based non-residential services
- To promote sharing of best practices , knowledge and technology

# Sustainable Development Goals



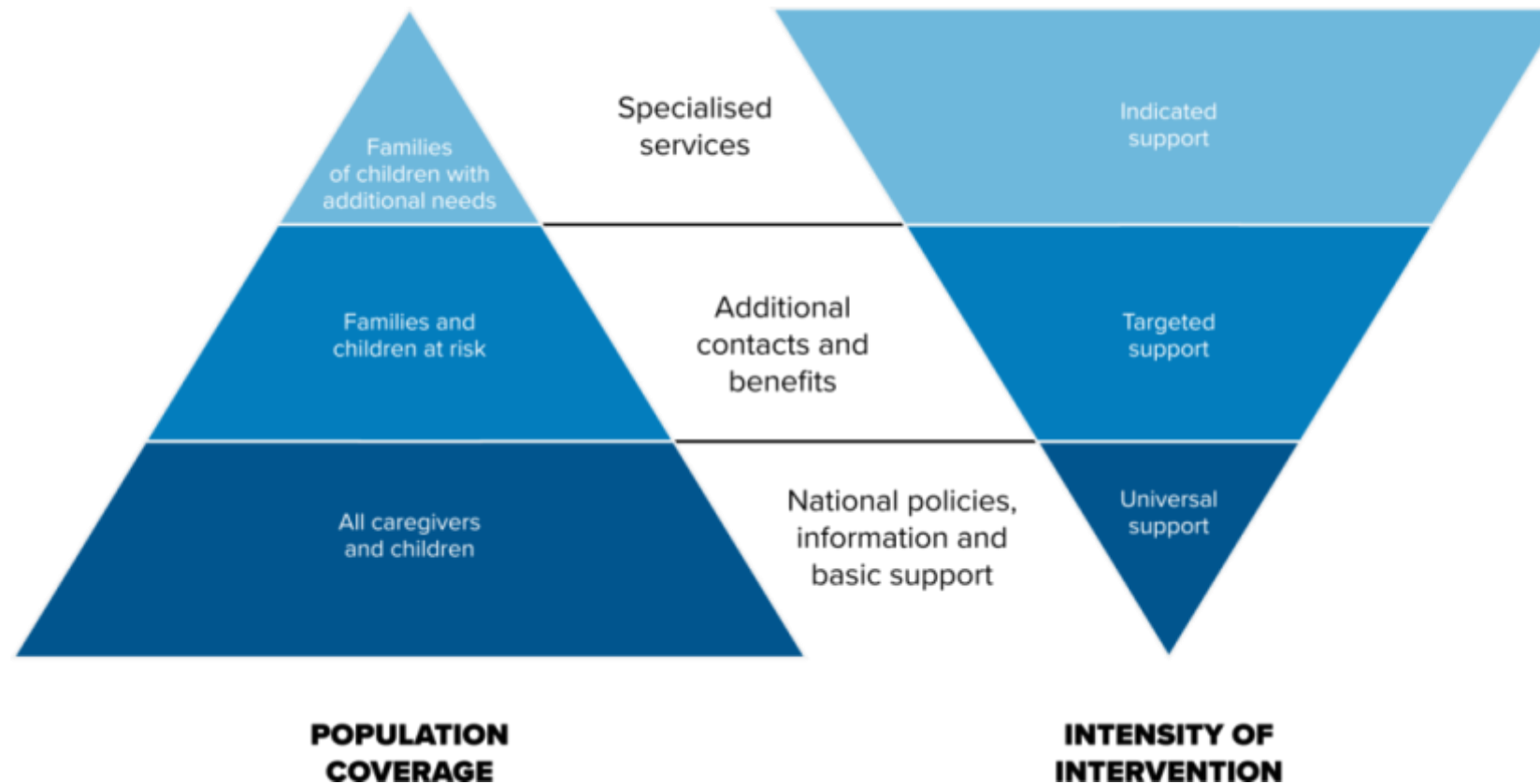
**Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all**

➤ By 2030, ensure that all girls and boys have access to quality early childhood development, care and pre-primary education so that they are ready for primary education

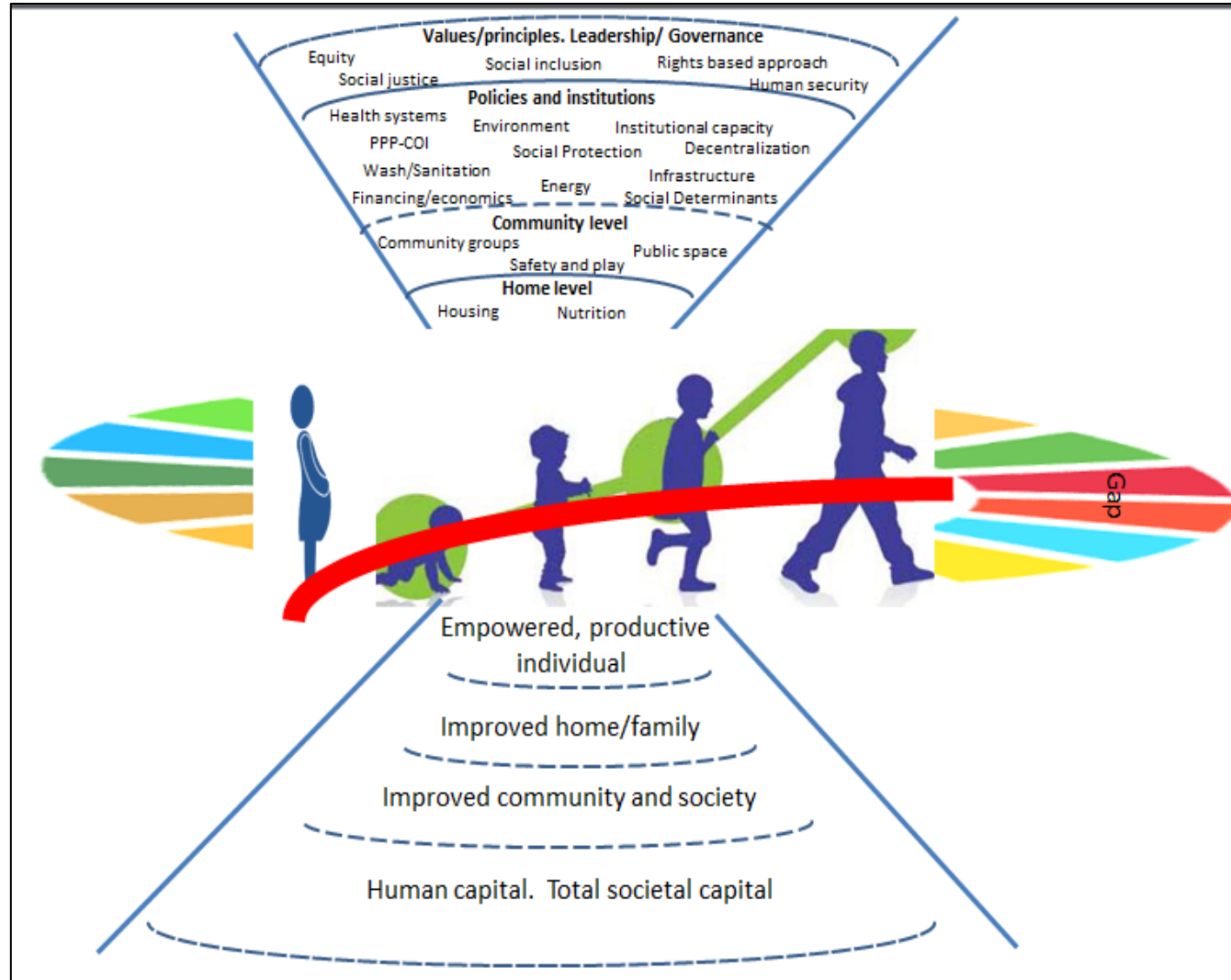
**Ensure healthy lives and promote the wellbeing for all at all ages**

➤ **By 2030, achieve universal health coverage**

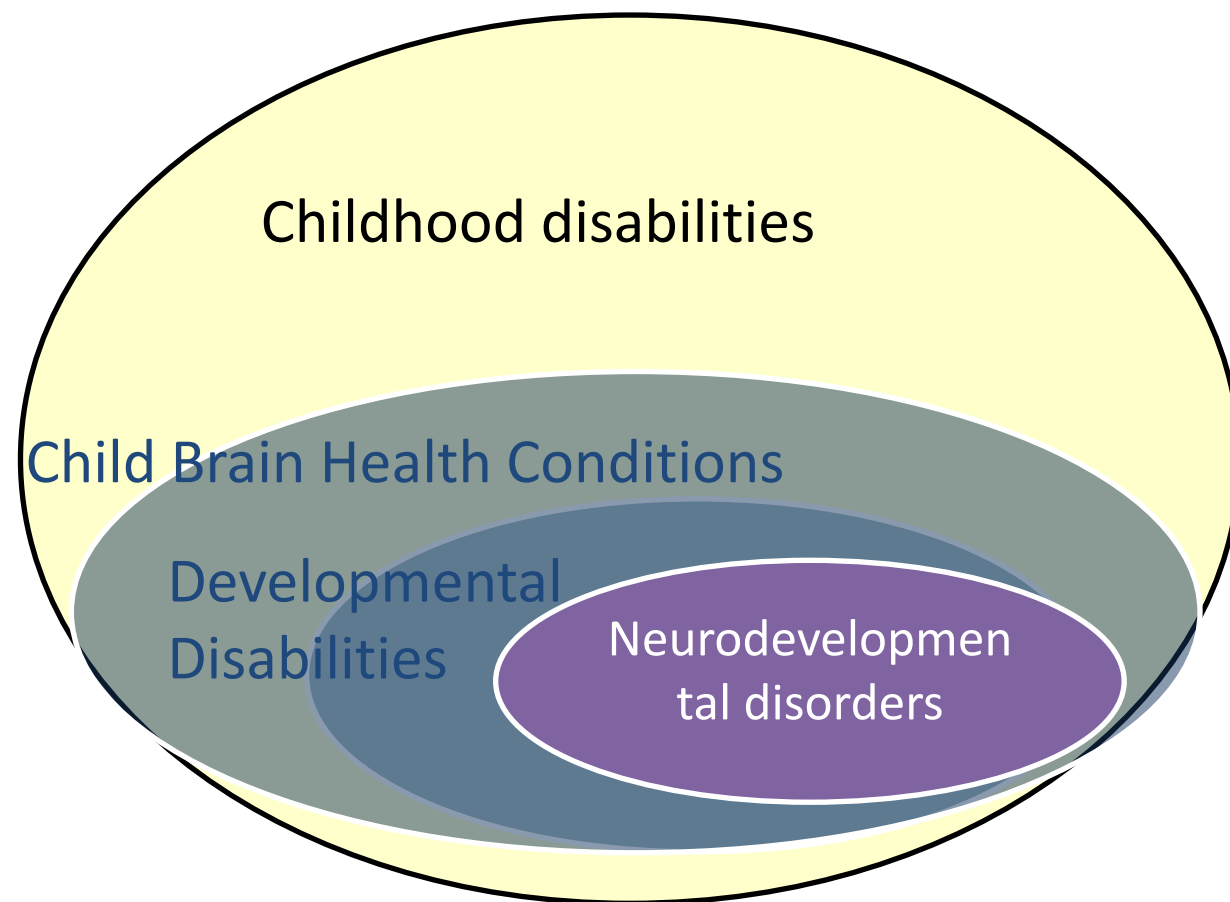
# Proposed implementation model



# Ecologic Model from the UNICEF-WHO-*Lancet* Commission on Realigning Child Health in the SDG Era



Functional domains	Neurodevelopmental disorders
Motor difficulties	Intellectual Disabilities
Language delay	Communication Disorders
Social difficulties	Autism Spectrum Disorder (ASD)
Poor learning in school	Attention Deficit Hyperactivity Disorder (ADHD)
Attention and concentration difficulties	Motor Disorders
Difficult behaviours	Other
Overall slow development	





# Definitions

**Childhood Disabilities** – Impairment/Activity limitation/ Restricted Participation include disabilities related to chronic health conditions such as asthma, diabetes

**Developmental Disabilities:** a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions become apparent during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime.

NDD, Hearing and vision impairments, CP

**Neurodevelopmental Disorders:** behavioural and cognitive disorders that arise during the developmental period that involve significant difficulties in the acquisition and execution of specific intellectual, motor, or social functions.

(1) disorders of intellectual development, (2) developmental speech or language disorders, (3) ASD, (4) developmental learning disorders, (5) developmental motor coordination disorder, (6) ADHD, (7) stereotyped movement disorder, and (8) 'other neurodevelopmental disorders'

**Developmental Delays**

**Developmental Difficulties**

**Brain Health Conditions**

# DDD (dev delays, disorders, disabilities)

- Developmental ‘differences’ (whether they are ‘delays’, ‘disorders’ or ‘disabilities’) are caused by early *disturbances* of the developing brain (or central nervous system) that affect a broad spectrum of motor, sensory, cognitive, learning, communication, and/or behavior functions.
- Common diagnoses include: ASD, ADHD, ID/DID, language disorders, hearing and vision impairment, and developmental learning disorders and CP.
- A ‘non-categorical’ approach because of the overlap among these diagnoses, considerable degree of commonality across these conditions and ‘functional’ rather than diagnosis- or condition-specific approaches to care.

# Addressing barriers and promoting participation

## **Physical, cultural and service environments**

Barriers include:

- negative attitudes and stigma
- limited environmental accommodations and physical inaccessibility
- social isolation
- lack of resources
- communication difficulties
- low expectations
- and low literacy

‘barriers to doing’ or ‘barriers to being’

## **Facilitating access to and participation in health care, education, family and communities, including:**

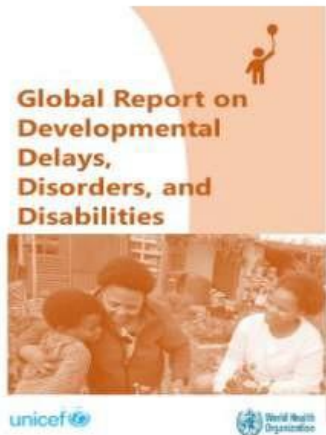
- Awareness of disability, diversity and inclusion
- Competencies and attitudinal changes in professional and communities, including caregivers
- Roles of self-advocates
- Empowerment of caregivers

# Brazilian Research for Global Report

Fátima Minetto, André Choinski, Elyse Matos and Leandro Kruszielski



## WHO UNICEF Global Report on Children with Developmental Delays, Disorders and Disabilities



1. Epidemiology
2. Policies, Plans & Legislation
3. Care Pathways
4. Promote participation
5. Public Health Monitoring

*Users perspective*

A call for action and case for investment in children with developmental disorders and their families

## Brazilian Family Needs Assessment Survey

### Descriptive Summary of Results

2021



Fátima Minetto, André Choinski, Elyse Matos and Leandro Kruszielski

# Method

- Standard FNA questions + two questions regarding living conditions
- September – October/2020
- Dissemination online
  - Sponsored posts on social networks (Facebook and Instagram)
  - Groups of parents
  - Contact with activists and influencers
- Total accesses 5,220
  - Total sample  $n = 4,940$



# Sociodemographic

- Mostly women (91.6%) and mothers (80.3%)
- Ages varying between 26-55 years old (86.9%)
  - Mostly 36-45 years old (45.5%)
- Primary caregivers (87.2%)
- Ethnicity: white (56.6%) or multiracial (33.3%)
- Married or in a stable relationship (72.7%)

# Education and work

- Post graduate degree (34.9%), elementary school (20.1%) and college degree (19.8%)
- Took care of household tasks (30.7%), employed at least 40h/week (25.7%) or less (15%) or unemployed (11.6%)
  - Worked previously (83.7%) and left work because of the child's condition (55.1%)
- Participants' partners
  - Elementary school (21.5%), college degree (19.4%) or post graduate degree (18.2%)
  - Employed 40h/week (51.7%)



# Home condition

- Families' incomes (Brazilian minimum wage is estimated at US\$190)
  - 1 - 3 minimum wages: 55.9%
  - 4 - 6 minimum wages: 20.9%
- Number of people with disabilities in the house
  - One: 79.3%
  - Two: 9.6%
  - Three or more: 1.8%

# Child's diagnosis

Diagnosis	Frequencies	Percentage
ASD	1,776	51.30%
ADHD	405	11.70%
Genetic syndromes	381	11.00%
ID	334	9.70%
Other	271	7.80%
Epilepsy	225	6.50%
No diagnosis	69	2.00%

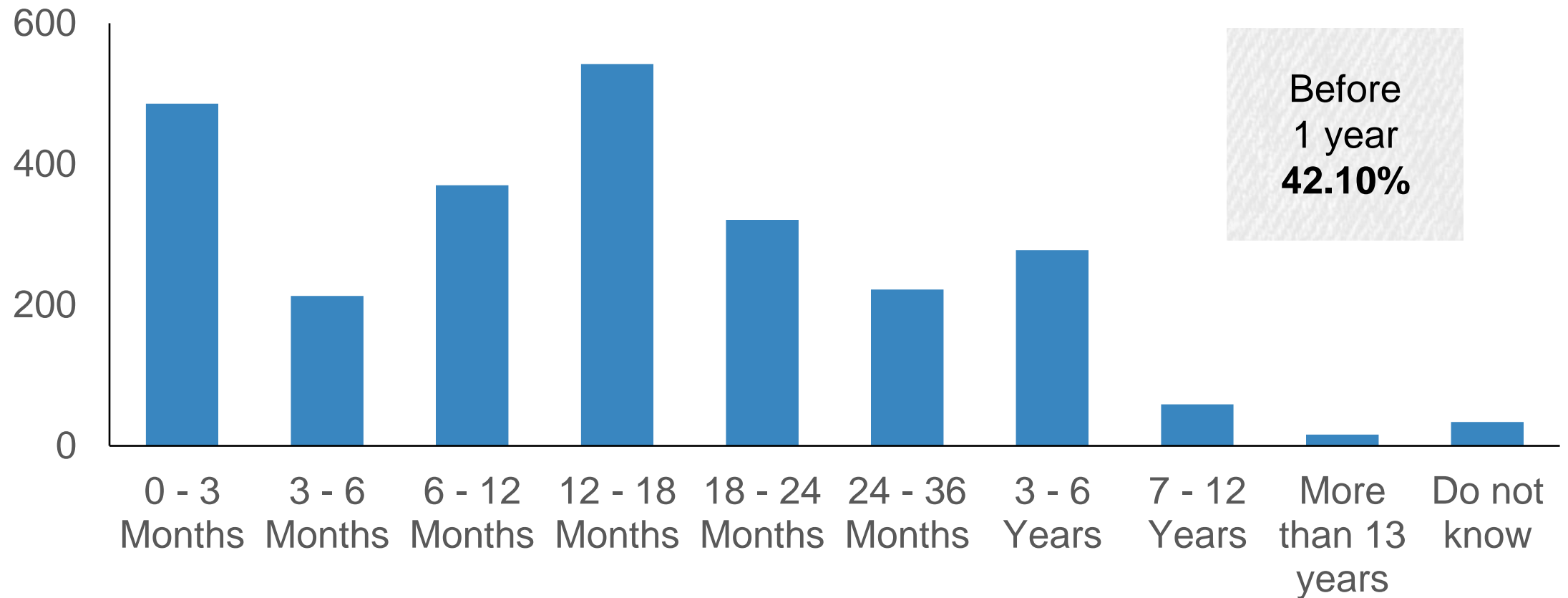
# Assumed causes of the developmental delays

Causes of the developmental delay	Frequencies	Percentage
Genetics or hereditary in some families	1,462	57.20%
Unknown causes	530	20.80%
Act of God or a supreme being	285	11.20%
Traumatic experiences very early in life or in womb	233	9.10%
Vaccinations	27	1.10%
Cold, rejecting parents	15	0.60%
Bad luck or a curse from one's past life	2	0.10%

# First person to notice characteristics of developmental delay in the child

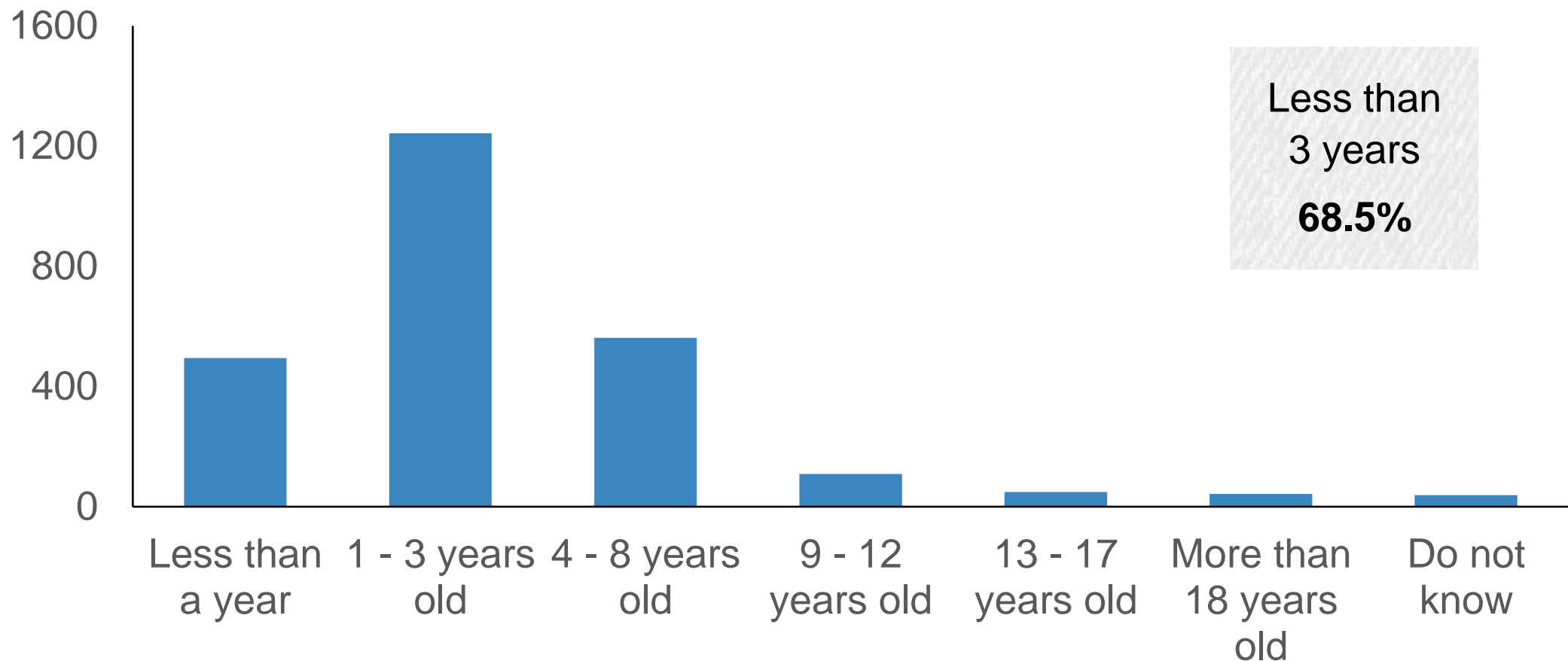
Person to notice	Frequencies	Percentage
Caregiver	1,439	56.70%
Health professionals	367	14.40%
Teacher	245	9.60%
Other family member/relative	230	9.10%
Other	158	6.20%
Spouse / domestic partner	101	4.00%

# Age that characteristics of developmental delay were noticed in the child

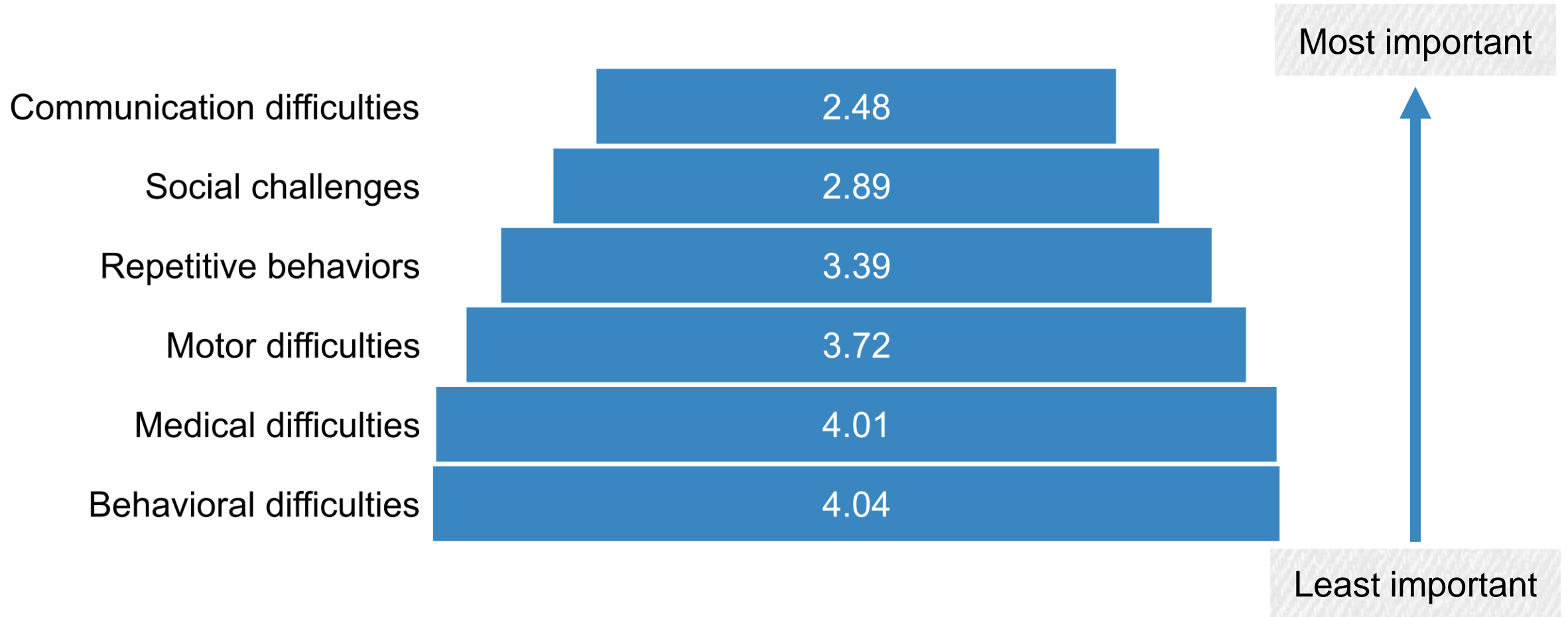




# Age the child was when he/she received the diagnosis



# Ranking of reasons for parents' concerns about their child's development

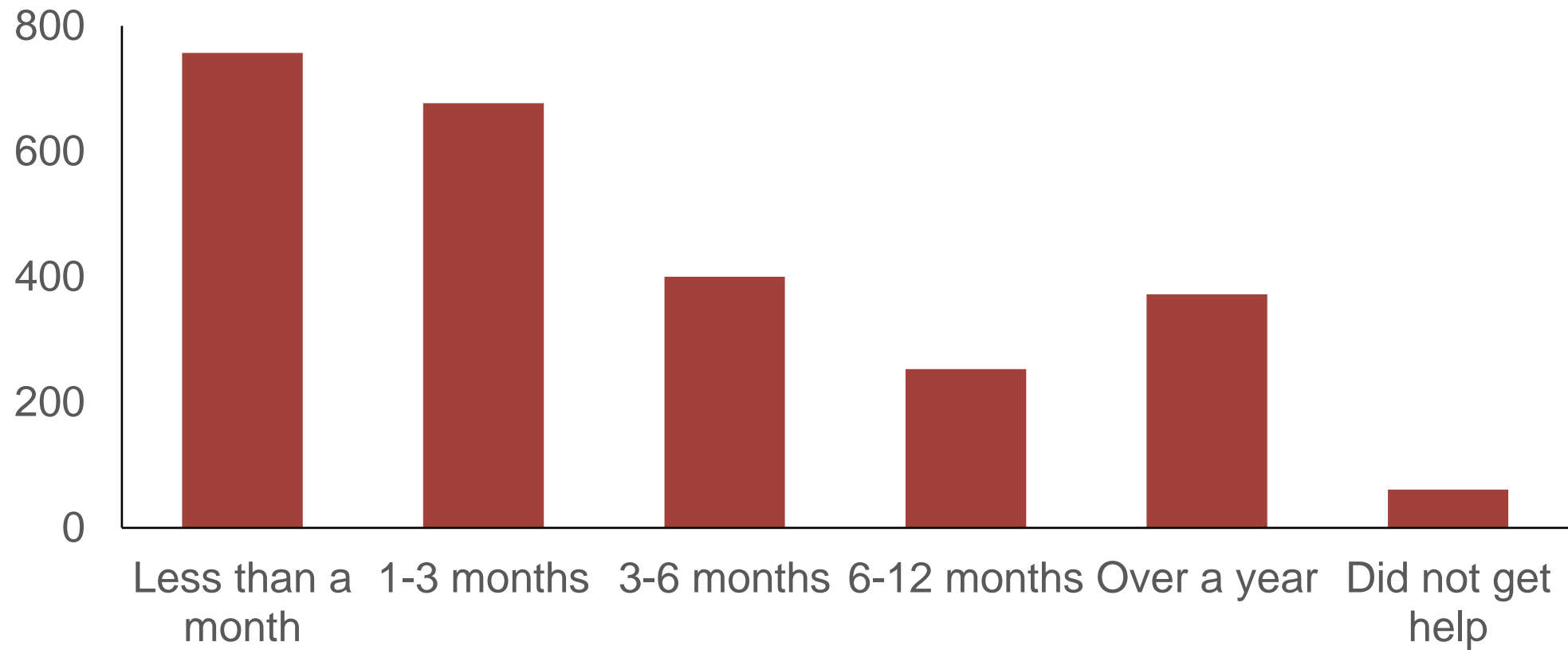


# Travel distance to get support

Distance travelled	Frequencies	Percentage
Within my town	1,467	58.20%
A few towns away	677	26.90%
I had to travel into another state within my country	212	8.40%
Several towns away	142	5.60%
I travelled outside the country	12	0.50%
We have not sought help for our child	10	0.40%



# Time waited to get support



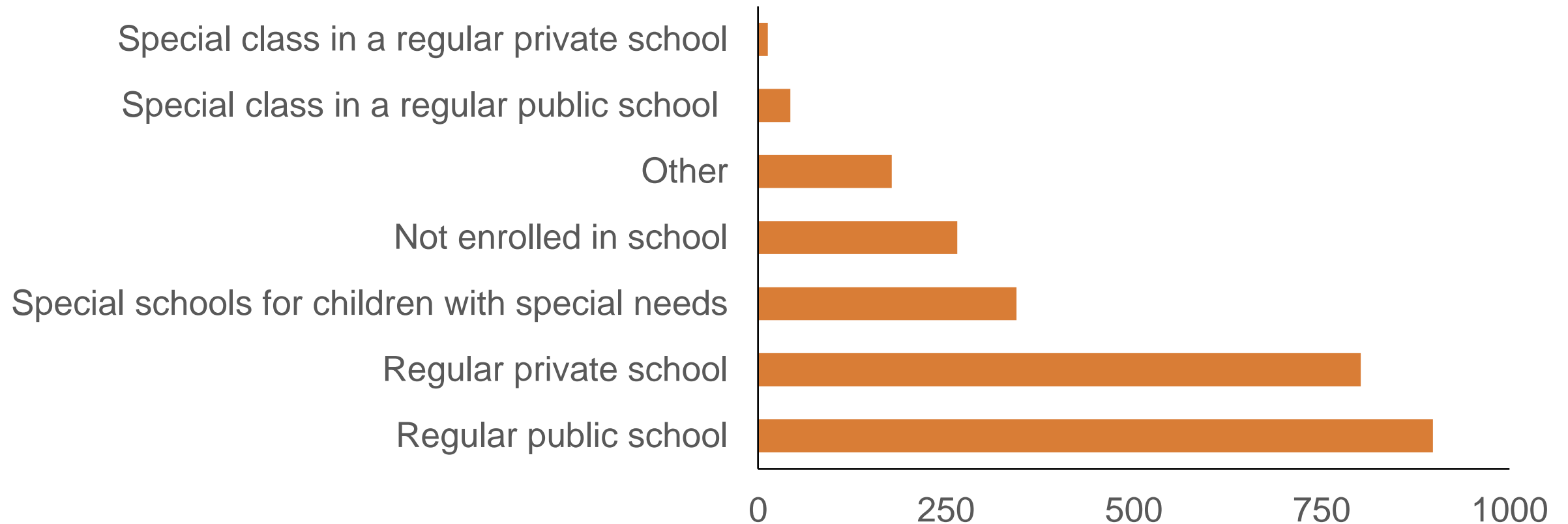
# Difficulties or delays to receive medical attention

Reasons of delays or difficulties	Frequencies	Percentage
There were no difficulties or delays	1,061	27.50%
Unreasonable costs	628	16.20%
Long wait times	600	15.50%
Lack of services in the area	539	13.90%
No services are available	446	11.50%
Lack of information about services	236	6.10%
Other reasons	206	5.30%
Ineligibility	149	3.90%

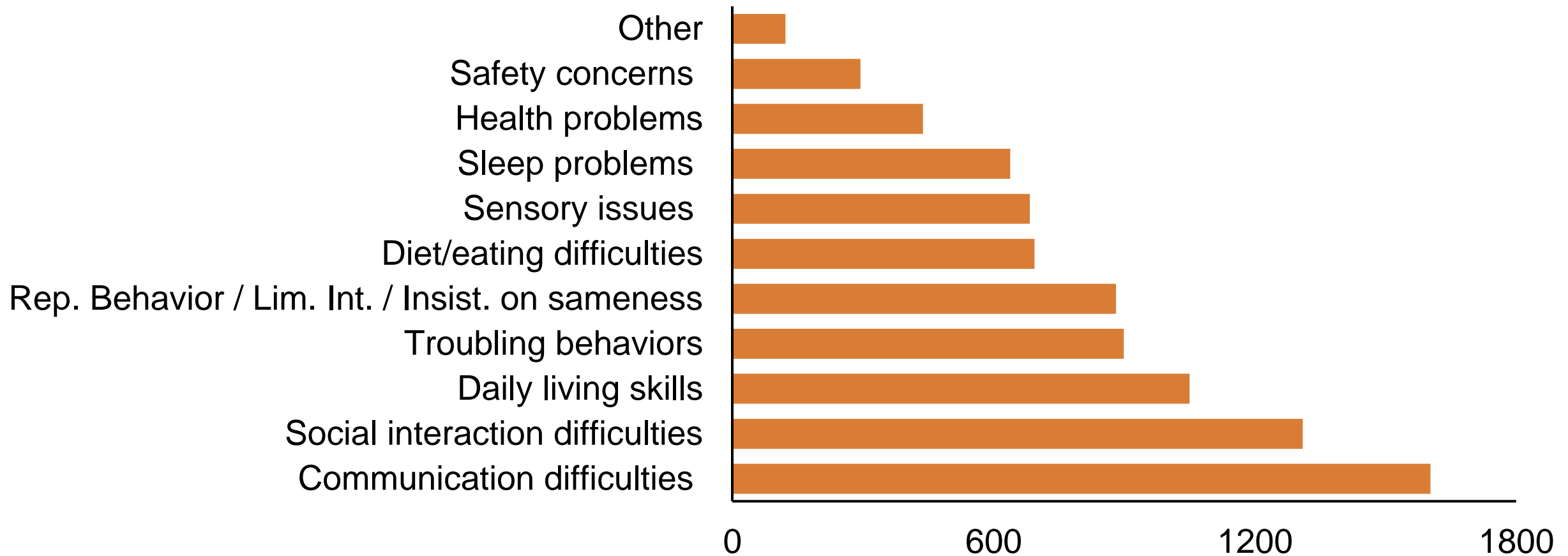
# Difficulties or delays to access education

Reasons of delays or difficulties	Frequencies	Percentage
There were no difficulties or delays	1,242	44.90%
No services are available	376	13.60%
Lack of services in the area	323	11.70%
Unreasonable costs	293	10.60%
Lack of information about services	261	9.40%
Long wait times	204	7.40%
Ineligibility	70	2.50%

# Type of school the child attends

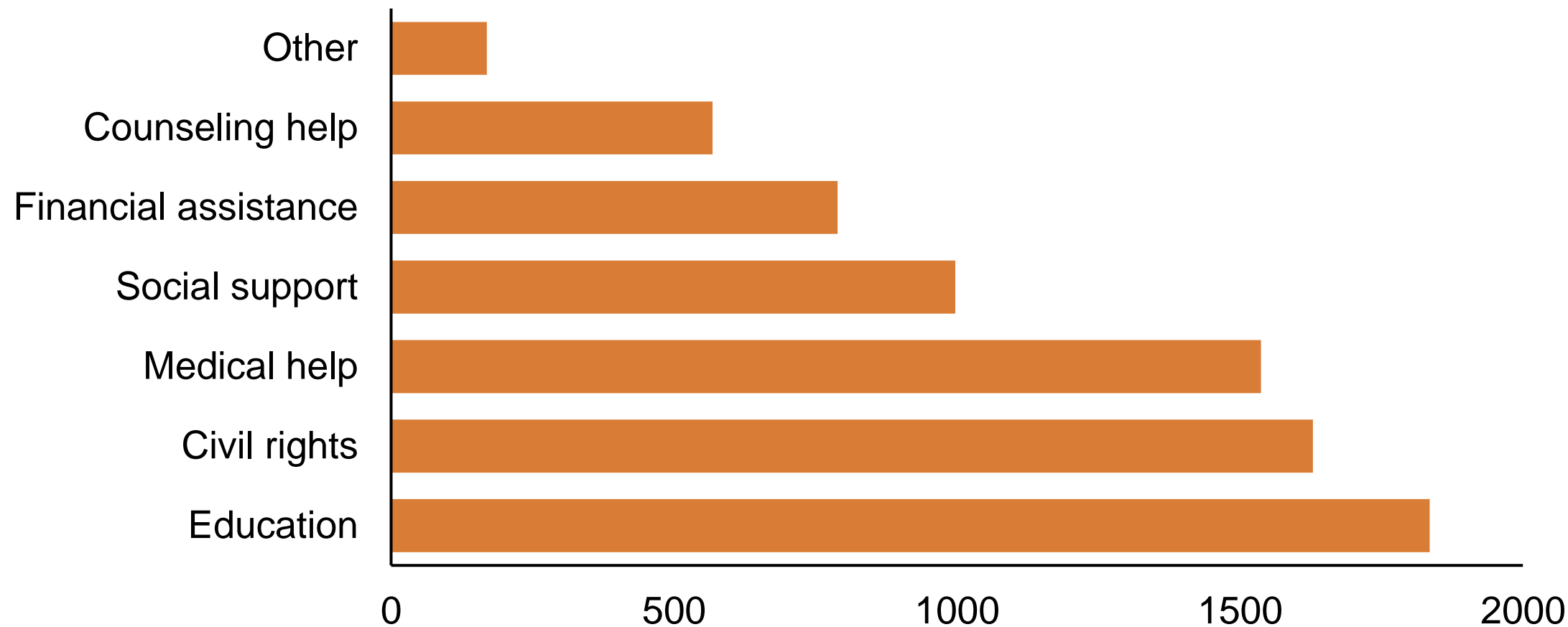


# Greatest challenges taking care of a child with developmental delay

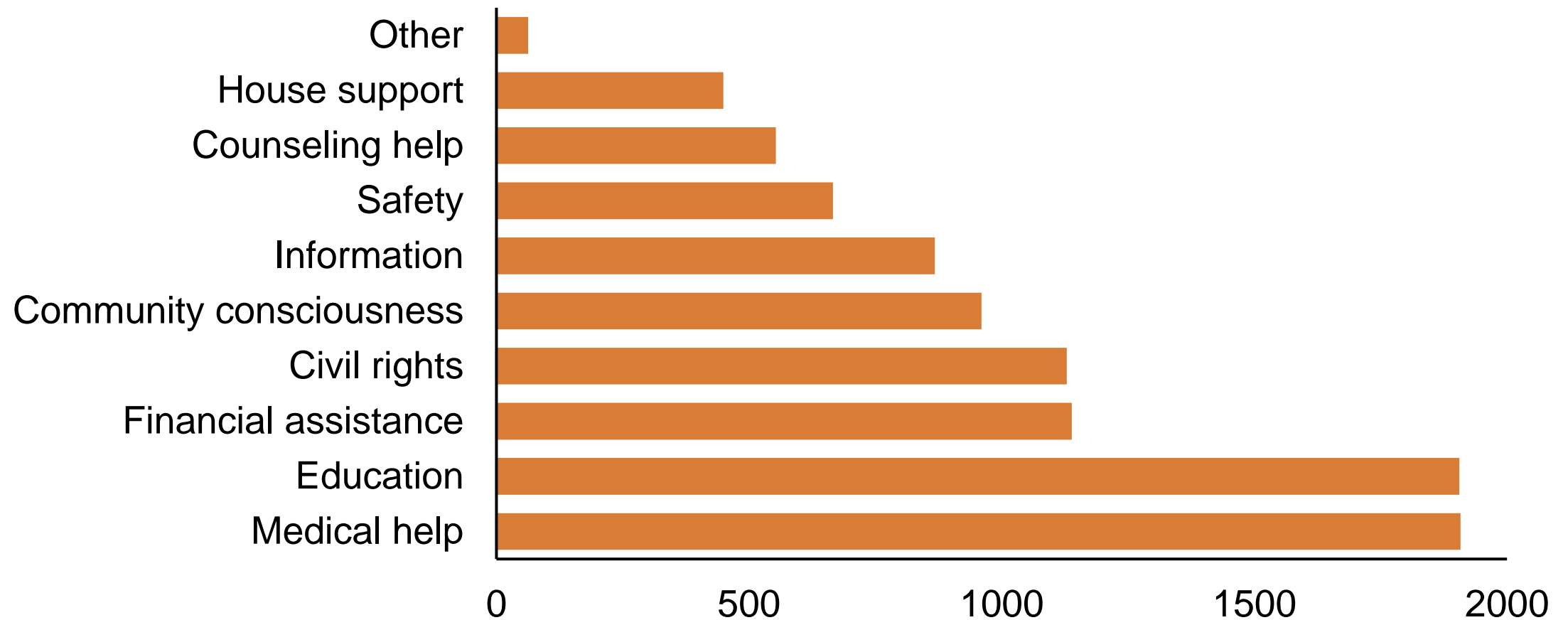




# Greatest challenges getting help to take care of a child with developmental delay



# Greatest challenges of families with people with developmental delays in Brazil



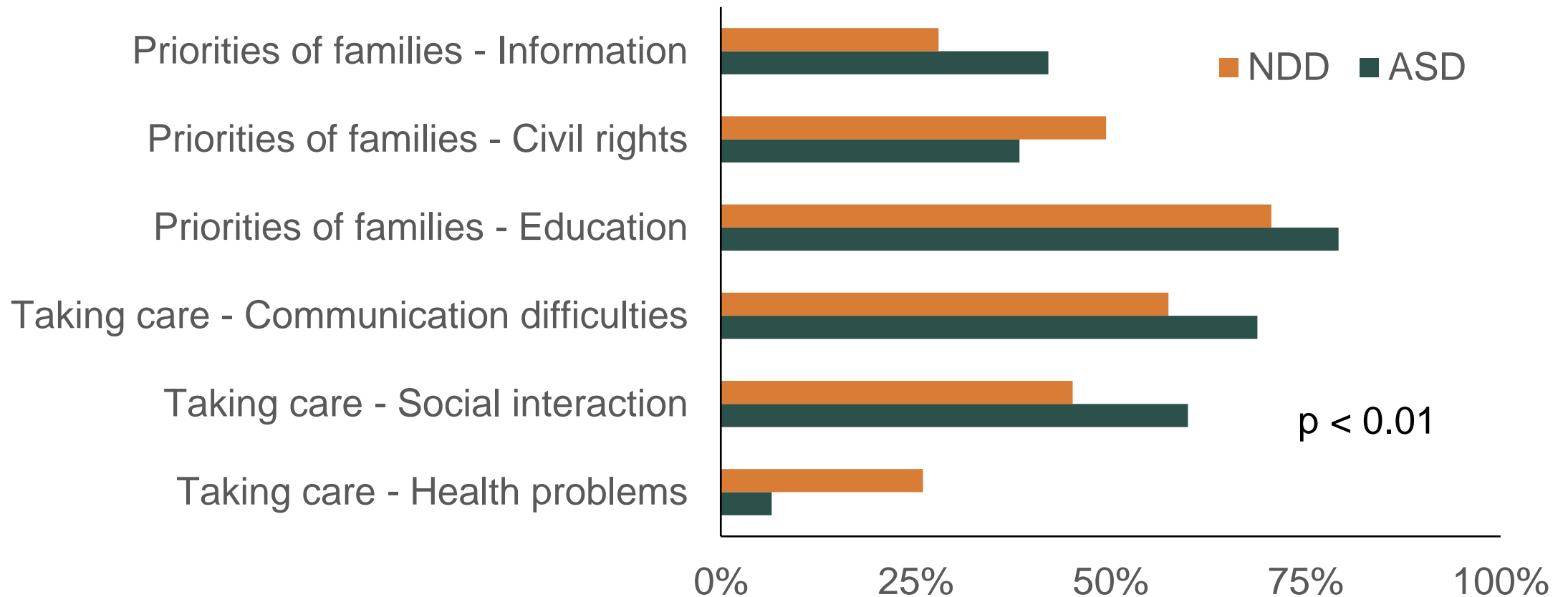
# Inferential Analysis

Diagnosis	Frequencies
ASD	1,776
ADHD	405
Genetic syndromes	381
ID	334
Other	271
Epilepsy	225
No diagnosis	69

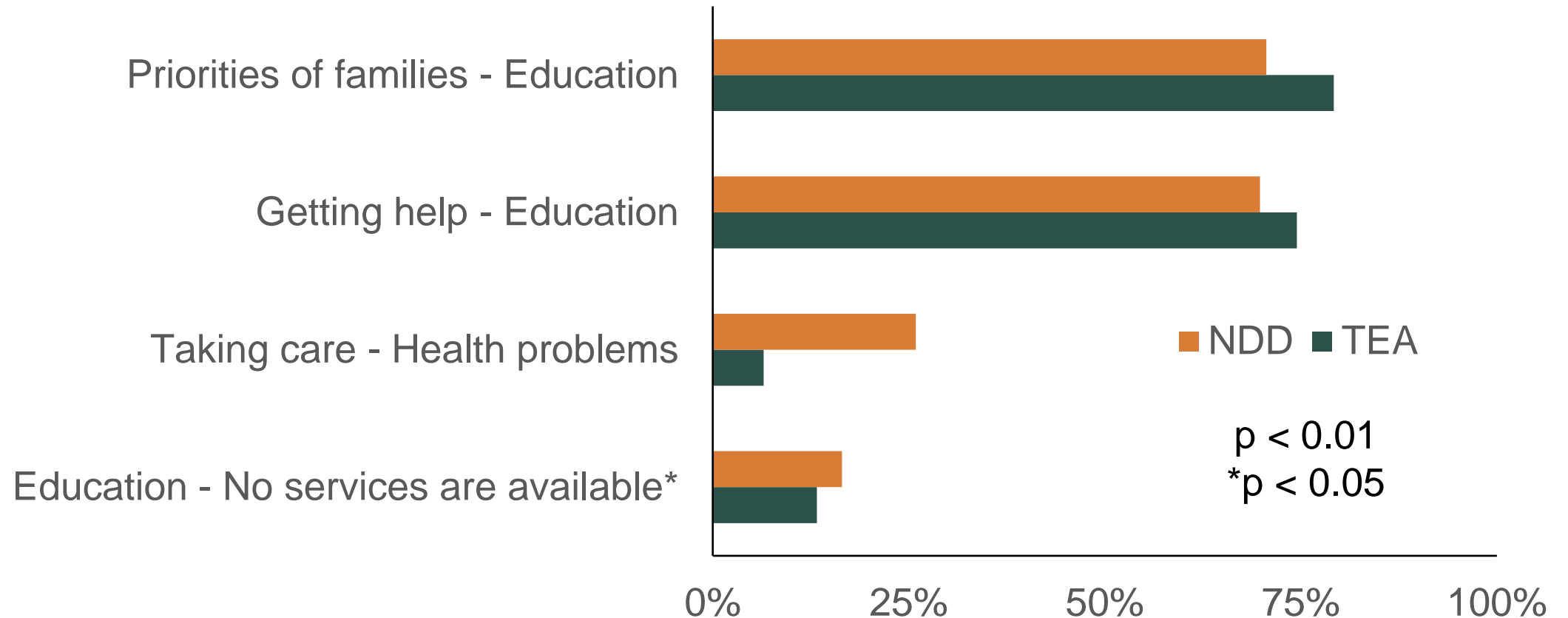
NDD  
(n = 1,616)



# Greatest differences between groups



# Highest and lowest values



Thank you!



# WHO-UNICEF World Report on Developmental Delay, Disorders and Disabilities

## Family Needs Assessment Country Highlights Argentina

Sebastian Cukier, Giselle Vetere & Daniel Valdez



**Advocacy Leadership Network 4th Biennial  
Conference**

**April 27 - 28, 2021**

# Family Needs Assessment Country Highlights - Argentina

	Current sample (2020)		REAL sample (2015)	
<i>Distribution of diagnoses and total number of dx in the sample</i>	N	% out of 453	N	% out of 786 -all ASD related
<b>Diagnosis</b> (could choose more than one)				
Autism	35	7,6	55	7
Pervasive Developmental Disorder (PDD)	65	14,2	128	16.3
Autism Spectrum Disorder (ASD)	252	55	322*	41
Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)	73	15,9	256	32.6
Global Developmental Delay	23	5	312	39.7
Intellectual Disability	30	6,6		
ADHD	15	3,3		
Cerebral Palsy	8	1,7	-	-
Epilepsy	20	4.4	52	6.6
<b>Distribution of Diagnoses</b>				
Autism, ASD, PDD, PDD-NOS, DD, Asperger, Childhood Autism or other ASD related dx	425	92,7	786	100
<b>Number of Diagnoses</b>				
1	119	26.3	-	-
2	147	41.6	-	-
3	64	14.1	-	-
4	58	12.8	-	-
5 or +	64	14.1	-	-

# Family Needs Assessment Country Highlights - Argentina

	Current sample (2020)		REAL sample (2015)	
	N	% out of 453	N	% out of 786 -all ASD related
<b>Child's Age when First Concern was Noticed</b>				
0 – 3 months	1	0.2	24	3.1
3 – 6 months	23	5.1	21	2.6
6 – 12 months	29	6.4	68	8.6
12 – 18 months	45	9.9	88	11.2
18 – 24 months	129	28.5	147	18.7
24 months – 3 years	101	22.3	257	32.7
3 – 6 years	79	17.4	161	20.5
7 – 12 years	40	8.8	7	0.9
>13 years	3	0.7	2	0.1
<b>Child's Age at diagnosis</b>				
< 1year old	11	2.5	8	1
1 – 3 years	315	70.5	508	64.6
4 – 8 years	97	21.7	208	26.5
9 – 12 years	14	3.1	35	4.4
13 – 17 years	3	0.7	14	1.8
> 18 years	4	0.9	5	0.6
Don't know	3	0.7	-	-
No answer	6	1.4	-	-

# Family Needs Assessment Country Highlights - Argentina

Age of diagnosis of child correlated with highest educational level of respondent	N 453	
	Dx at 1-3 years old	Dx later than 3
<b>Primary</b>	<b>55.6 %</b>	<b>33.3 %</b>
<b>Secondary</b>	59.7 %	37.7 %
<b>University incomplete</b>	68.8 %	26.6 %
<b>University complete</b>	70-8 %	23.7 %
<b>Higher than university</b>	<b>89.7 %</b>	<b>7.7 %</b>

# Family Needs Assessment Country Highlights - Argentina

	Current sample (2020)		REAL sample (2015)	
	N	% out of 453	N	% out of 786 - all ASD related
<b>How far did you have to travel to obtain a diagnosis?</b> <b>41% out of town</b>				
Within my town/village	261	58.3	431^	54.8
In a neighborhood nearby	78	17.4		
A few towns/villages away	49	10.7		
Had to travel into another province	55	12.3	155*	19.7
I traveled outside the country	5	1.1	6	0.8
<b>Stopped working because of condition of child: 35%</b>				
Yes	159	35.1	269	34.3
No	204	45%	505	64.2
No answer			9	-



# Family Needs Assessment Country Highlights - Argentina

How long did you have to <i>wait between your initial pursuit of a dx &amp; the ultimate confirmation</i> of a clinical dx for your child?	N	% out of 453
Less than a month	119	26.5
1 – 3 months	132	29.4
3 – 6 months	73	16.3
6 – 12 months	63	14
Over a year	52	11.6
We still have not received a diagnosis	10	2.2

**25.6% had to wait more than 6 months**

# Family Needs Assessment Country Highlights - Argentina

<b>55 %</b> <i>had difficulties or delays in getting <b>medical</b> services for child during the past year for the following reasons:</i>	N	% out of 453
Delayed because of ineligibility	51	11.1
Delayed because of lack of information about services	24	5.2
Delayed because of lack of services in our area	63	13.8
Delayed because of long wait times	77	16.8
Delayed because of unreasonable costs	62	13.5
No services available	55	12
Other	65	14.2

<b>56%</b> <i>had difficulties or delays in getting <b>psychosocial care</b> services for child during the past year for the following reasons:</i>	N	%
Delayed because of ineligibility	44	9.6
Delayed because of lack of information about services	22	4.8
Delayed because of lack of services in our area	65	14.2
Delayed because of long wait times	81	17.7
Delayed because of unreasonable costs	58	12.7
No services available	47	10.3
Other	68	14.8

# Family Needs Assessment Country Highlights - Argentina

*Does child's school offer any **additional academic support** for children with developmental disabilities (such as **tutors**)*

Yes	159	37
<b>No</b>	233	<b>54.2</b>
I do not know	38	8.8
Did not respond	23	

***35%** had difficulties or delays in getting **educational services** for child during the past year for the following reasons:*

Delayed because of ineligibility	32	7.2
Delayed because of lack of information about services	10	2.2
Delayed because of lack of services in our area	12	2.7
Delayed because of long wait times	14	3.1
Delayed because of unreasonable costs	3	0.7
No answer	8	
Other	88	19.8

# Family Needs Assessment Country Highlights - Argentina

## Unmet needs: *significant associations:*

- ☞ Respondents with level ***lower than university*** AND those ***unemployed*** had significantly **higher probability of not receiving adequate psychosocial care** and of experiencing delays and/or difficulties accessing **medical care**
- ☞ Having a ***monthly income lower than \$40000*** was significantly associated to not receiving specific ***caregiver's services*** to take care of their children and to difficulties in access to **medical care**
- ☞ Having to ***travel out of town/ city*** to receive a diagnosis was significantly correlated to difficulties in access to **most services**
- ☞ Reporting **difficulties to access medical care** was significantly correlated to many demographic characteristics: **younger parents, respondent's and partner's educational level (lower than university), unemployment, lower monthly income**

# Family Needs Assessment Country Highlights - Argentina

## Unmet needs: *significant associations:*

- ✎ Having **difficulties to access medical care** was also significantly correlated to other unmet needs such as
  - ✎ having to ***travel outside of town*** for assessment
  - ✎ having to ***wait more than a year for diagnosis***
  - ✎ having ***delays or difficulties to get psychosocial therapies, school and services for parent training***
- ✎ CG who believed **that the cause** (of child condition) **was an act of God** were more likely to not receiving (or finding difficulties in access to) **psychosocial care, services for CG's training, medical care**, and were also more likely to report that their children were not attending to any type of **school**

# WHO-UNICEF World Report on Developmental Delay, Disorders and Disabilities

## Family Needs Assessment Country Highlights Argentina

Sebastian Cukier, Giselle Vetere & Daniel Valdez



Thank you!



Advocacy Leadership Network 4th Biennial  
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# Family Needs Assessment Survey in Bulgaria

*Team:*

*Mihaela (Mia) Barokova, Ana Andreeva-Sapundzhieva,*

*Elena Andonova, Galina Marokova*

# BULGARIA

- According to the World Bank:
  - Upper Middle Income Country
  - GDP per capita: \$21,363  
(US = \$62,794)
- Country Population: 6 951 482
- Children <19yrs: 1 253 874
- No publicly available statistics on the number of children with developmental disabilities in the country
- Ministry of Education and Science data (2019-2020):
  - 25,000 children with special education needs enrolled in kindergarten or school
  - Additional 10,000 children not enrolled



# METHODS

- In addition to the standard set of FNA questions, we added a comment box at the end of the survey
- Dissemination of the survey online, word of mouth, media
- Data collection April – June 2020
- Final sample N = 305



## Family Needs Assessment

A tool developed by researchers at Autism Speaks to evaluate the needs of children with autism or developmental delay and the resulting demands these needs create for caregivers and family members.





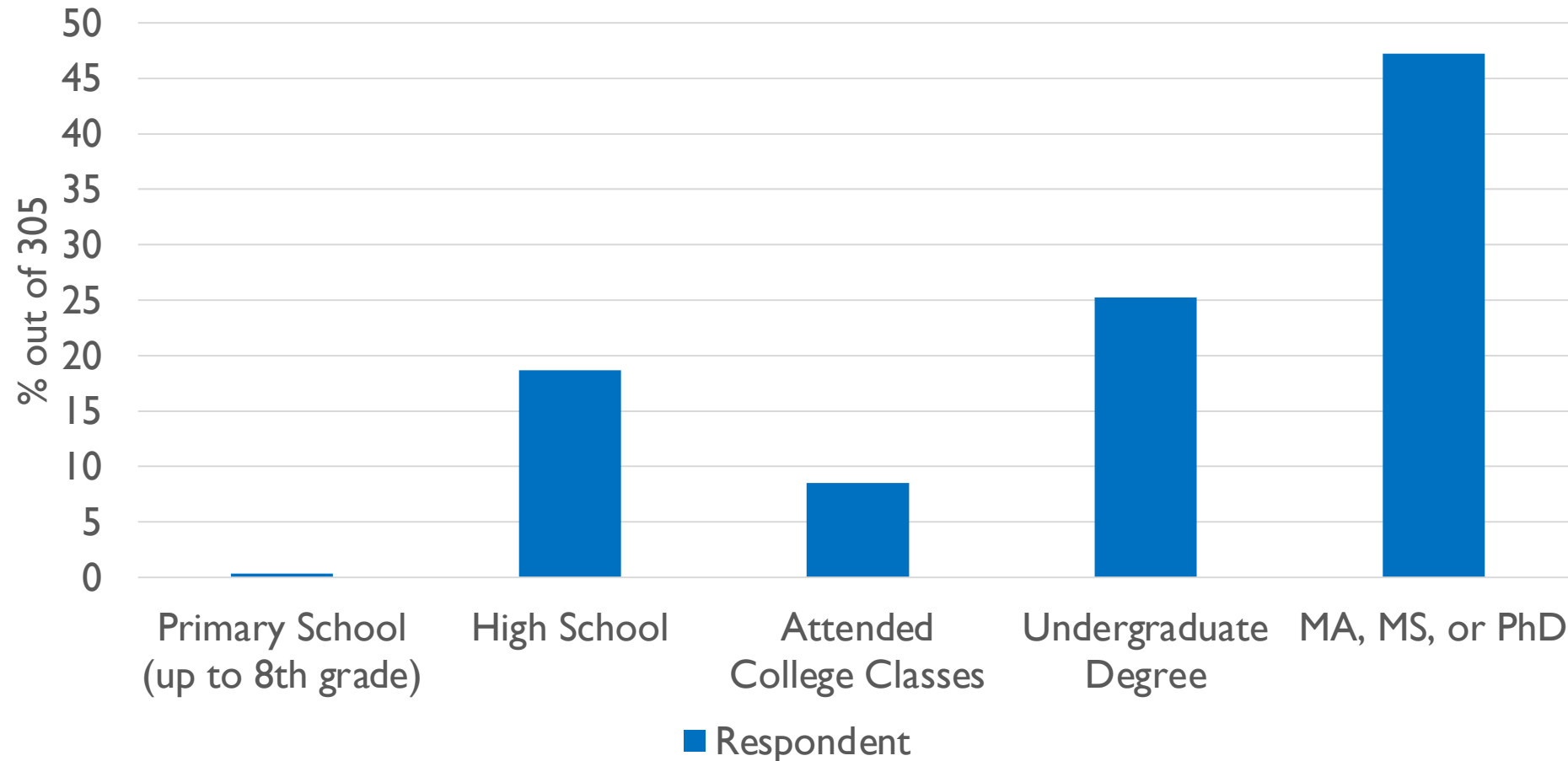
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METHOD:		TIME START:	TIME END:

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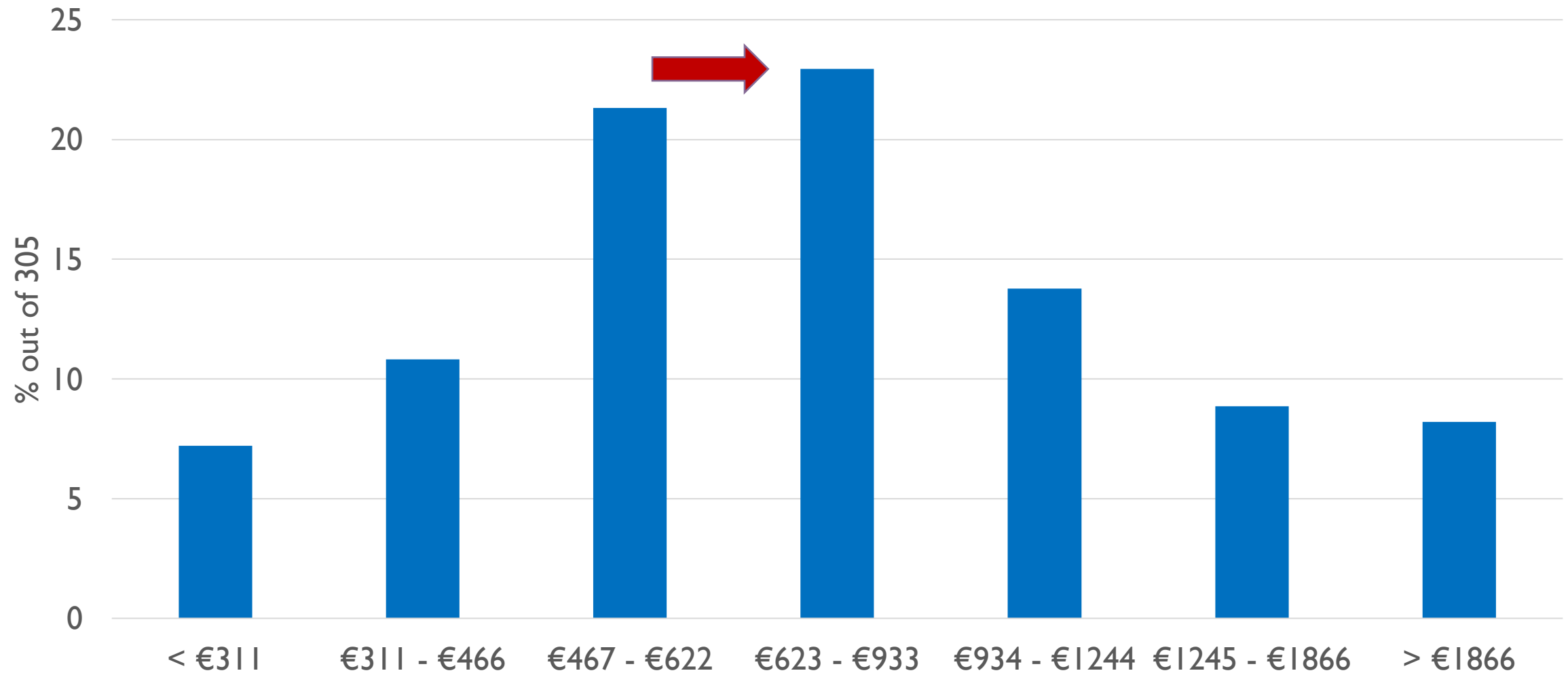
# RESPONDENTS:

## Respondent Education

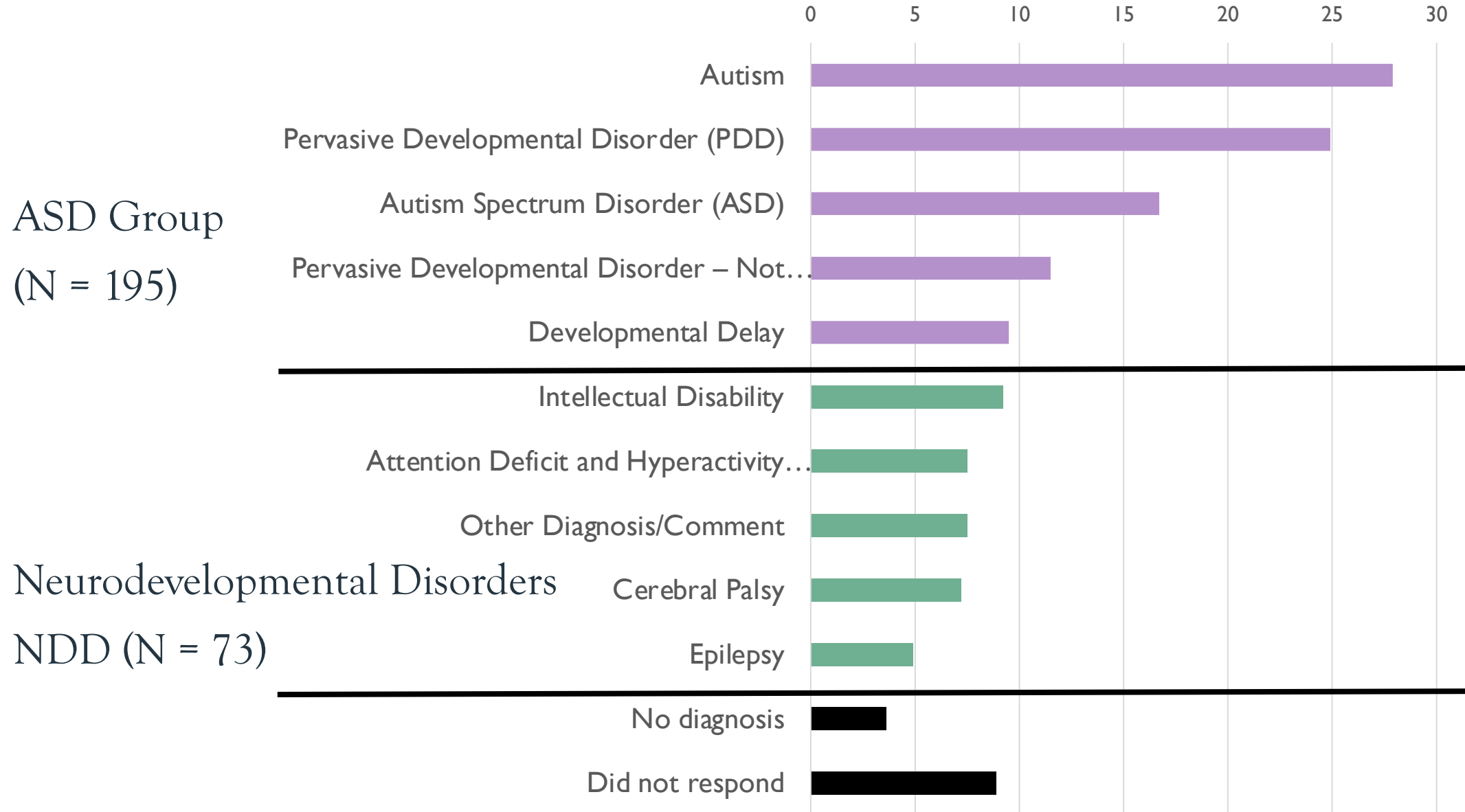


# RESPONDENTS:

## Monthly Income in EURO

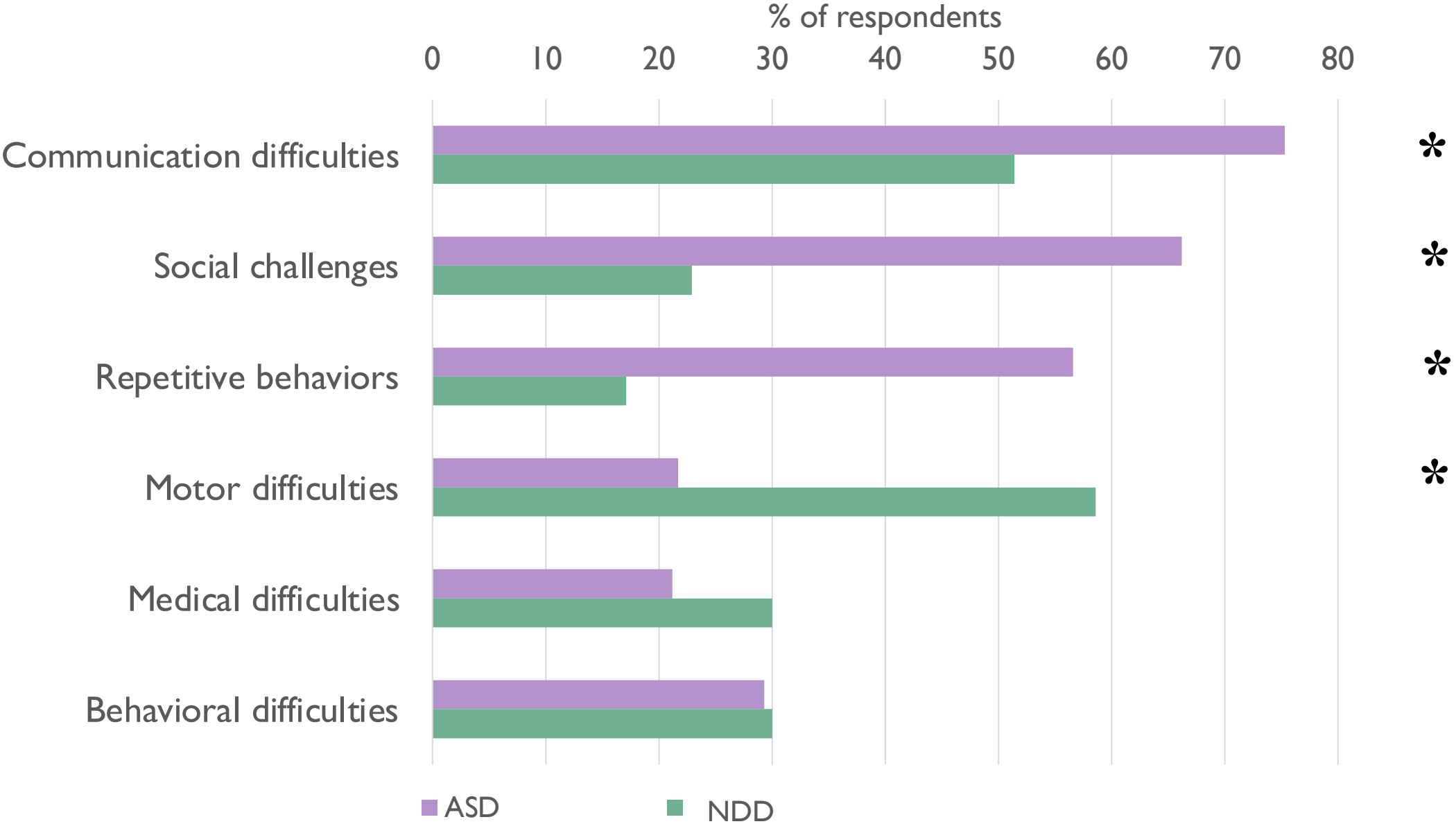


# Child Diagnosis based on ICD-10

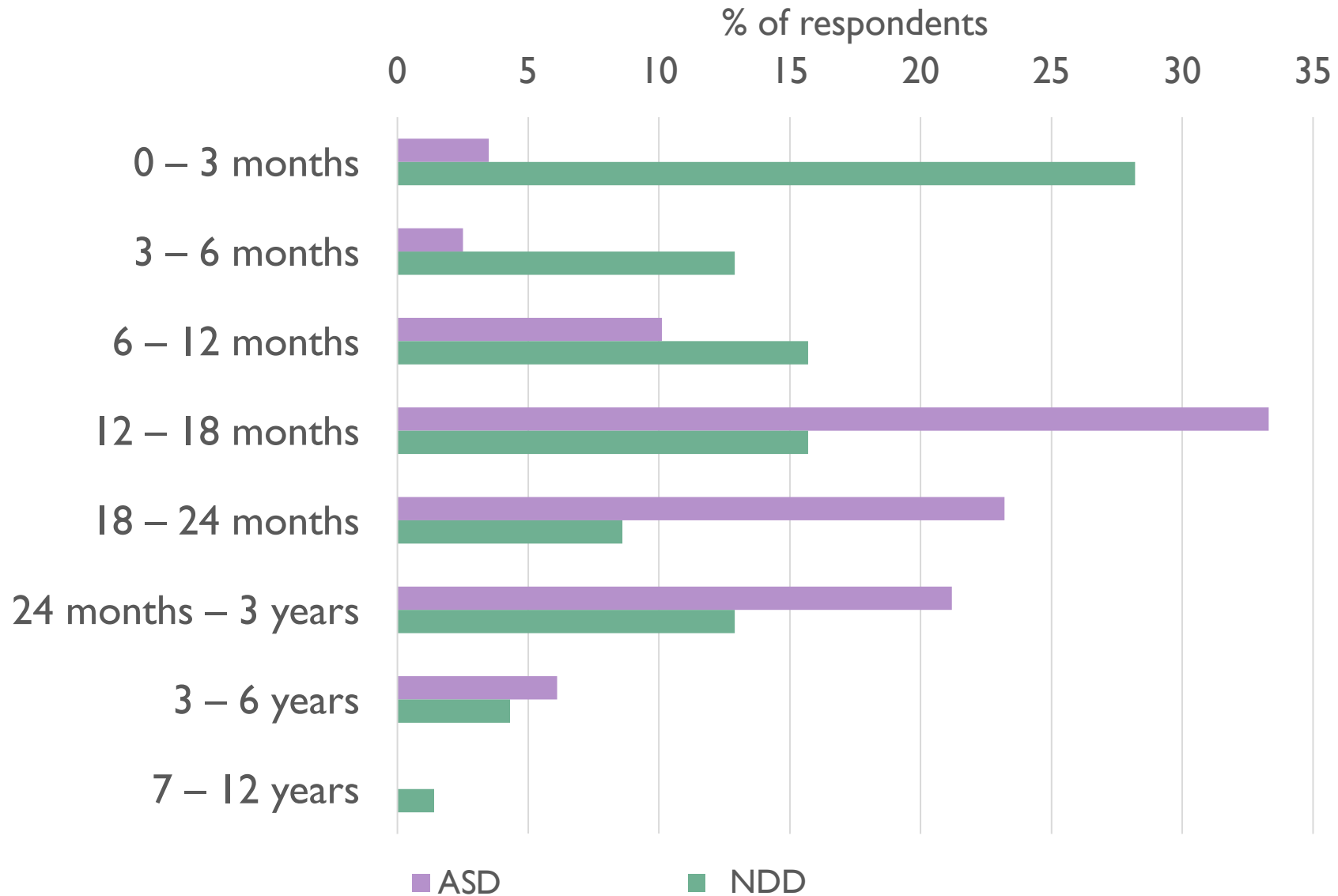




# Reasons for First Concern

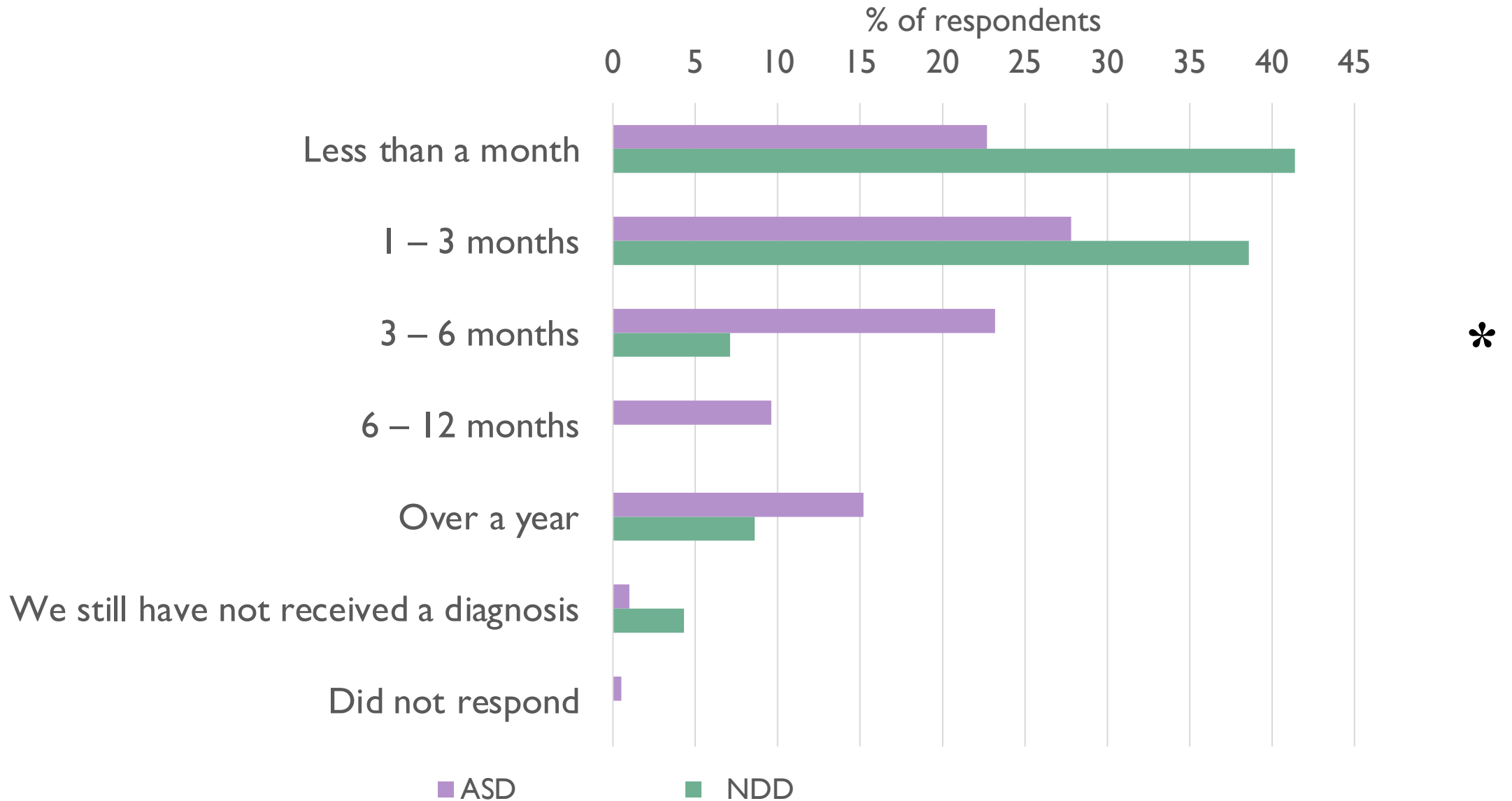


# Child's Age at First Concern

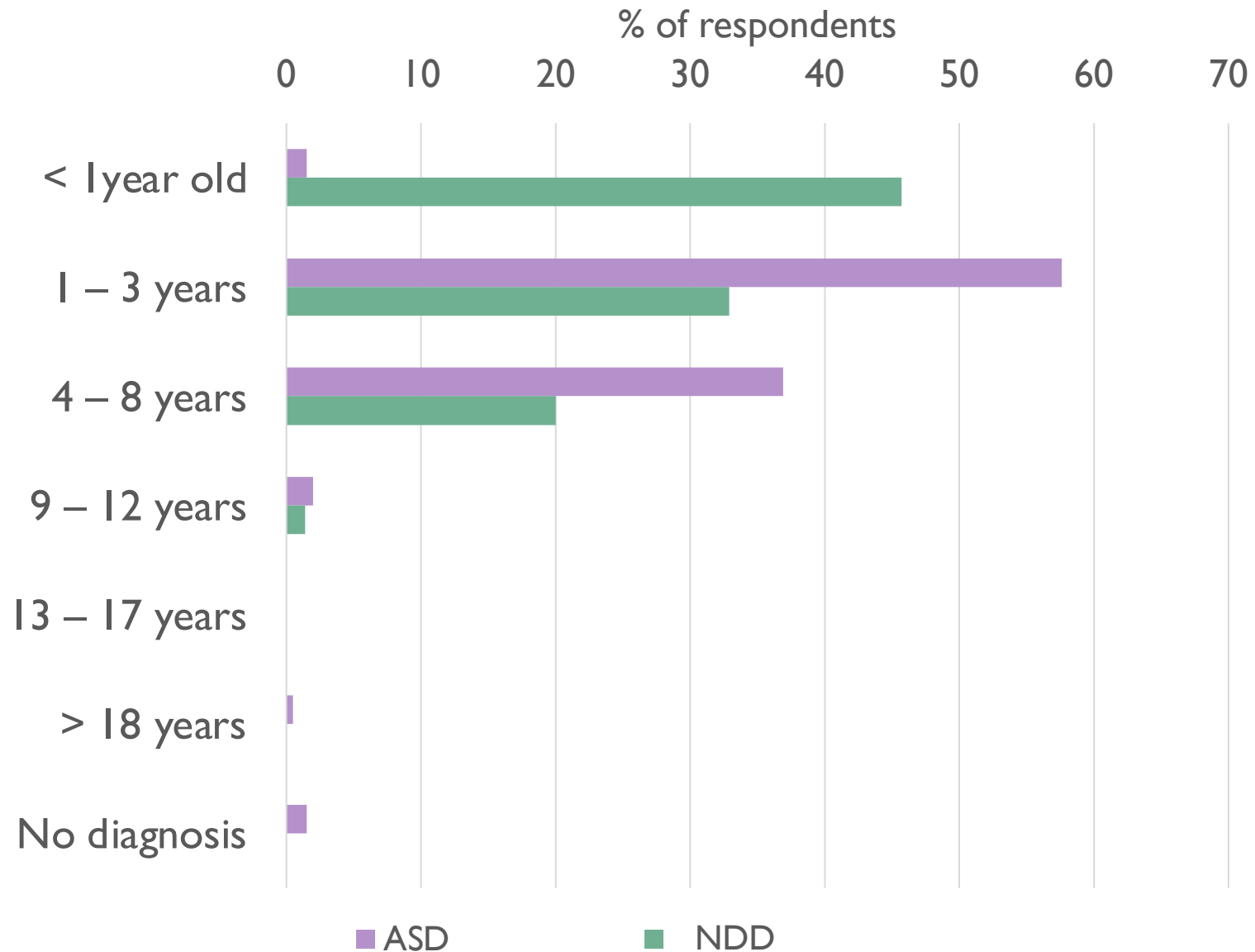


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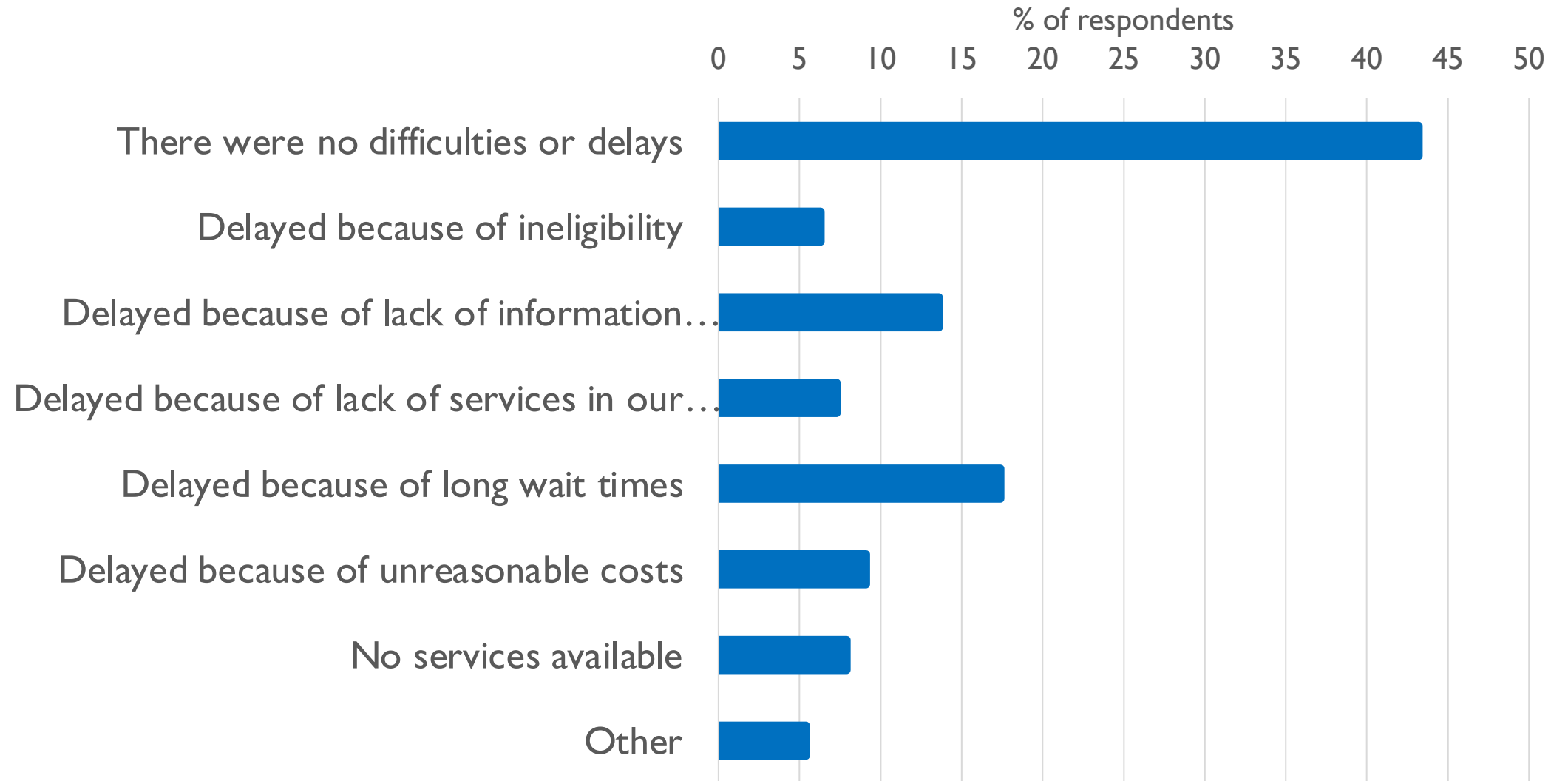
# Wait Time till Diagnosis



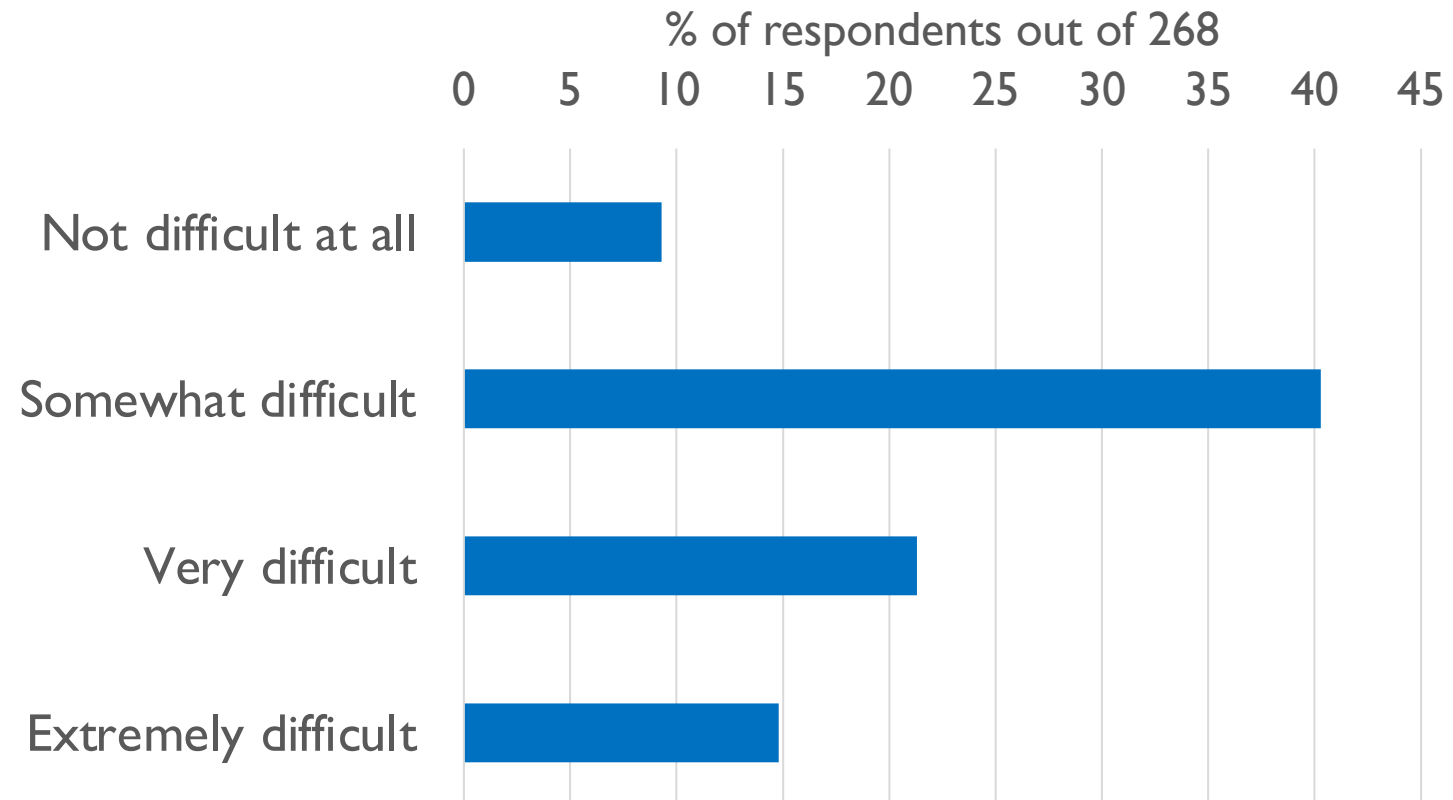
# Child's Age at Diagnosis



# Access to Medical Services

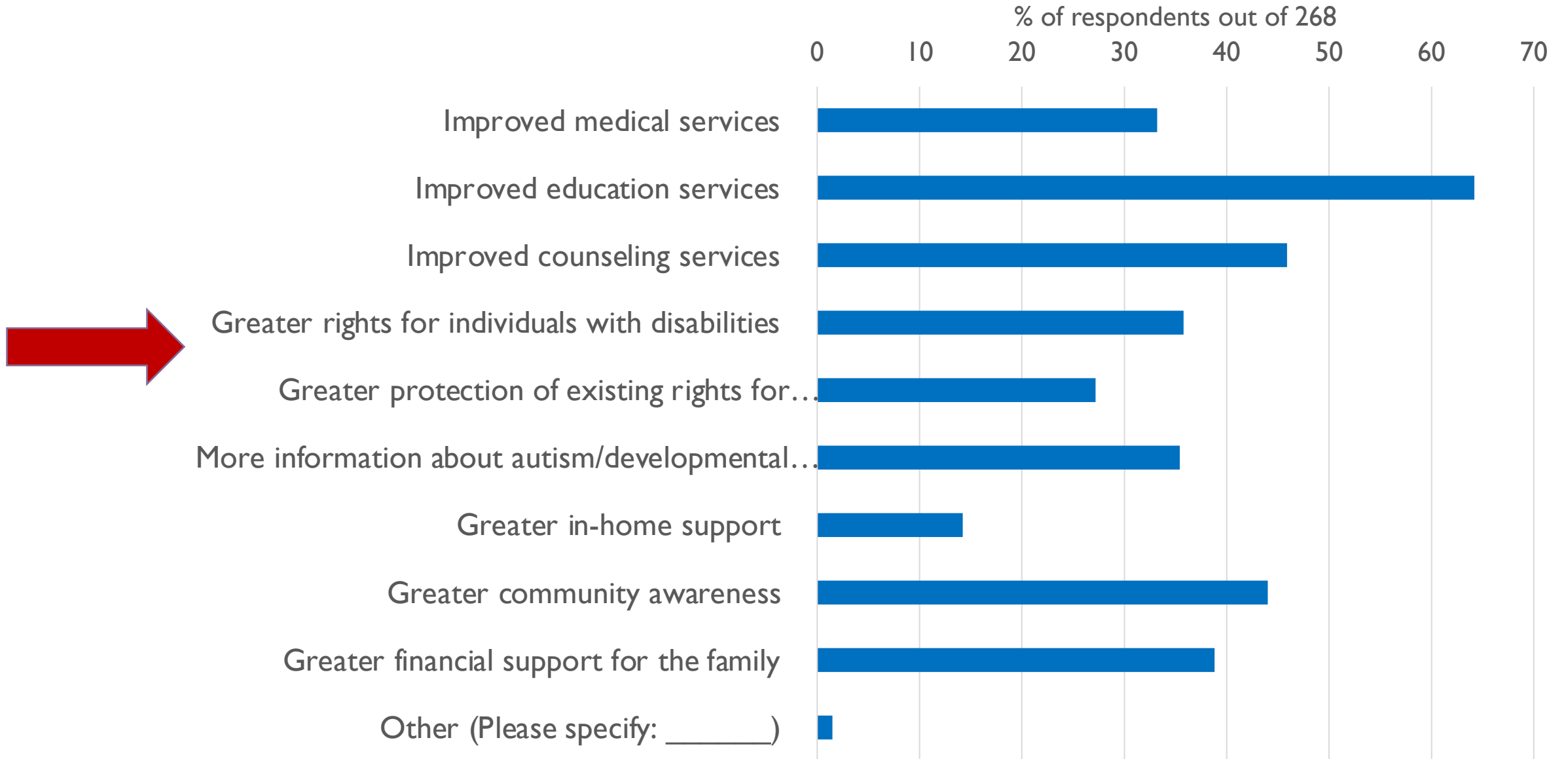


# Access to Information





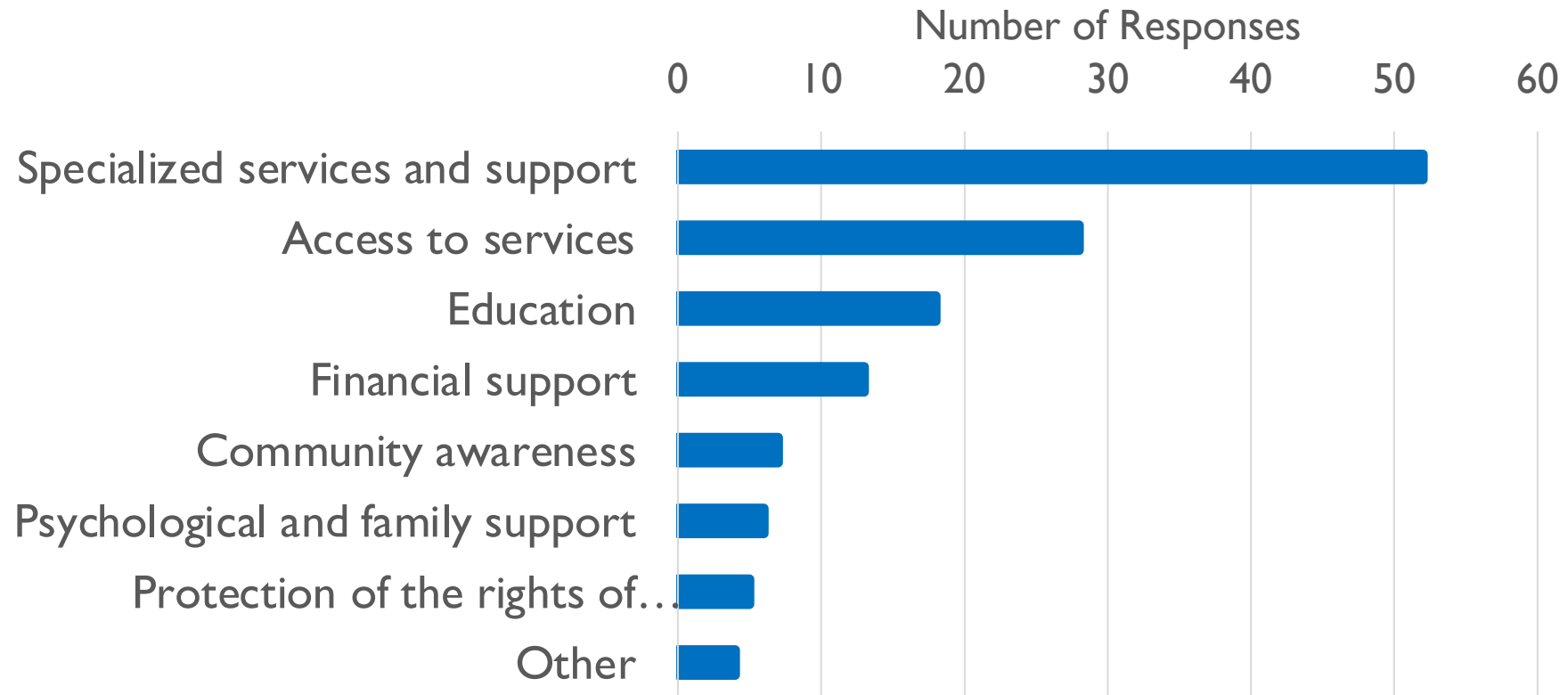
## Top 3 Priorities for Families



# THEME ANALYSIS OF THE COMMENTS

N = 118

## Caregivers' Comments by Category







Global Report on  
Developmental Delays,  
Disorders and  
Disabilities

COVID-19 caregiver  
survey

# Canada Highlights and lessons learned

April 28, 2021

# Research Team

2



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Associate Director, Azrieli Centre for Autism  
Research  
Director , Transforming Autism Care Consortium



**Keiko Shikako-Thomas**

Associate Professor, McGill University  
Canada Research Chair in Childhood Disabilities:  
Participation & Knowledge Translation



**Afiqah Yusuf**

Postdoctoral Fellow  
McGill University



**Miriam Gonzalez**



Postdoctoral Fellow  
McGill University  
Research Institute-McGill University Health  
Centre

- Joint initiative of WHO, UNICEF, Autism Speaks in partnership with researchers and country-level decision makers
- Aim: Increase awareness and provide guidance on strengthening health systems and multisectoral actions
- COVID-19 Pandemic Impact on families

## The Global Report on Developmental Delays, Disorders, and Disabilities



# Partners and Collaborators



## Methods

- Participatory Action Research
- Non-random convenience sample of caregivers from across provinces & territories
- Primary caregiver of a child (any age) with a neurodevelopmental condition

# Methods

Key references for  
COVID-19 impact  
questions



United Nations

Department of Economic and Social Affairs  
Disability

Home About Us COVID-19 CRPD COSP SDGs International Day Issues Resources Multimedia News

Home » Convention on the Rights of Persons with Disabilities (CRPD) » Article 11 – Situations of risk and humanitarian emergencies

## Article 11 – Situations of risk and humanitarian emergencies

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

## Disability considerations during the COVID-19 outbreak

**COVID-19**  
[www.who.int/emergencies/diseases/novel-coronavirus-2019](http://www.who.int/emergencies/diseases/novel-coronavirus-2019)

**NCDs and mental health**  
[www.who.int/ncds](http://www.who.int/ncds)  
[www.who.int/mental\\_health](http://www.who.int/mental_health)

**Disability**  
[www.who.int/health-topics/disability](http://www.who.int/health-topics/disability)

**In March 2020 the World Health Organization (WHO) declared the outbreak of a novel coronavirus disease, COVID-19, to be a pandemic, due to the speed and scale of transmission.**

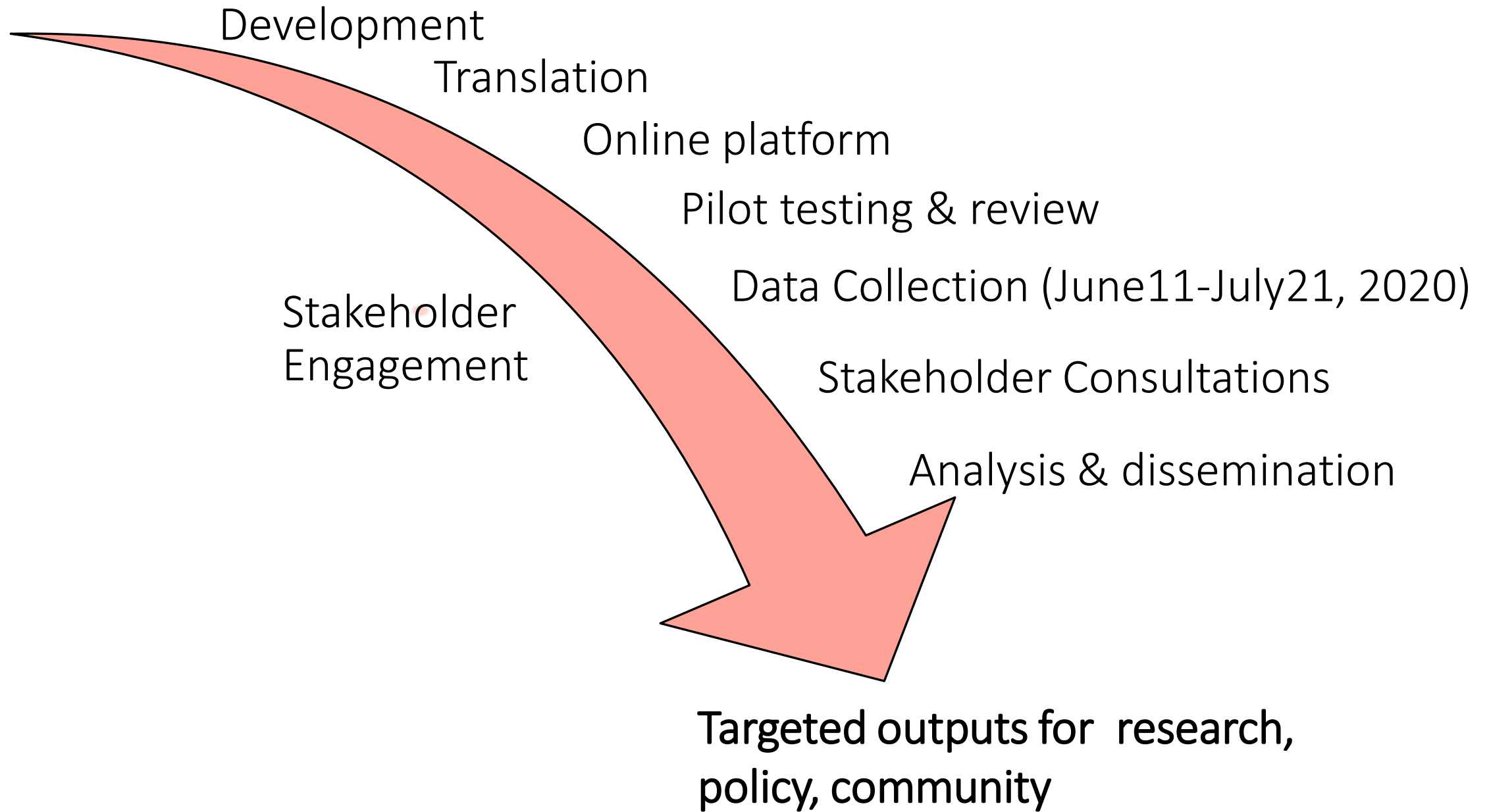
**WHO and public health authorities around the world are taking action to contain the COVID-19 outbreak. Certain populations, such as those with disability, may be impacted more significantly by COVID-19. This impact can be mitigated if appropriate actions and protective measures are taken by key stakeholders.**

COVID-19 response:  
Considerations for Children  
and Adults with Disabilities

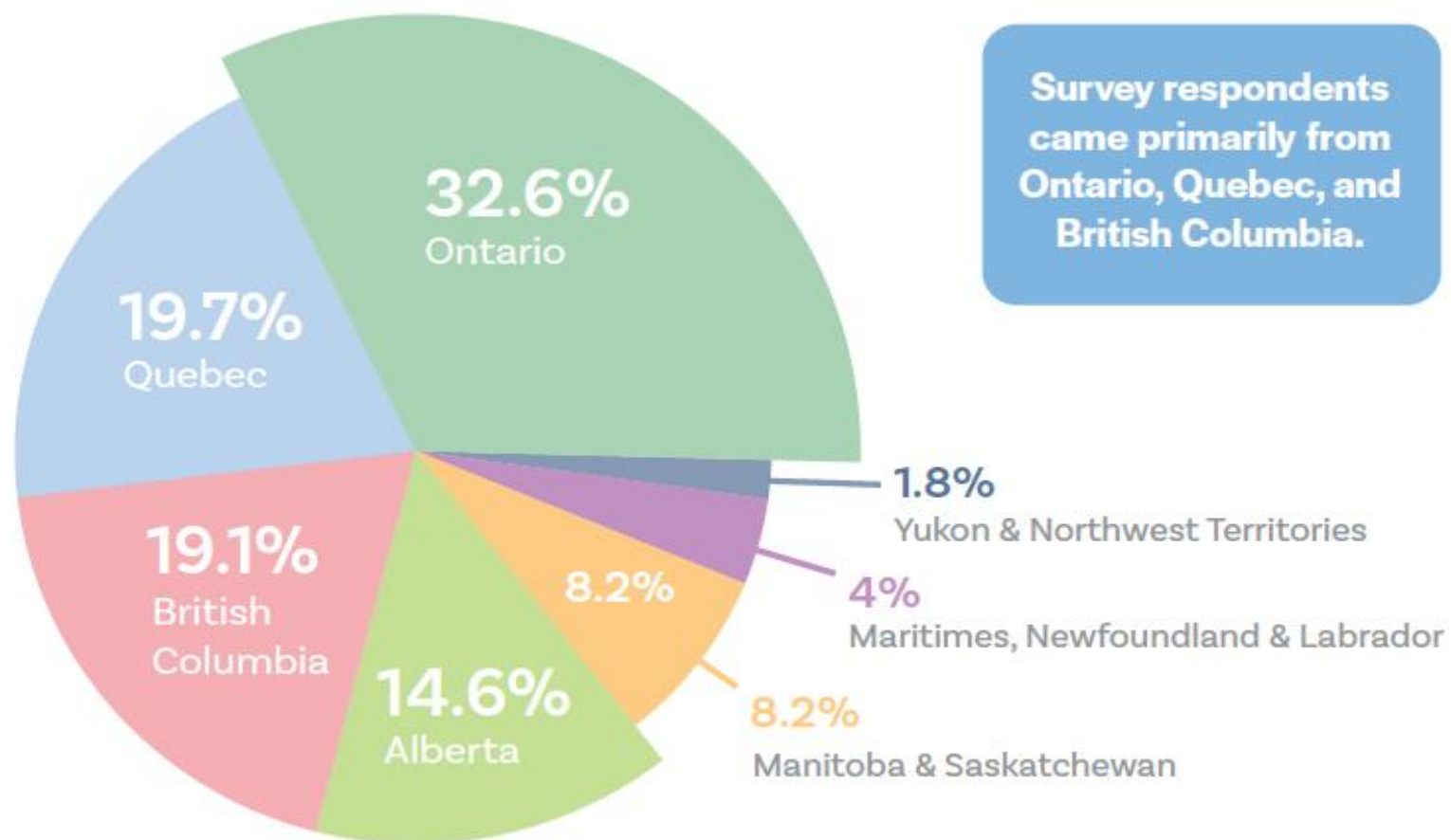
unicef   
for every child

# Survey Development

7



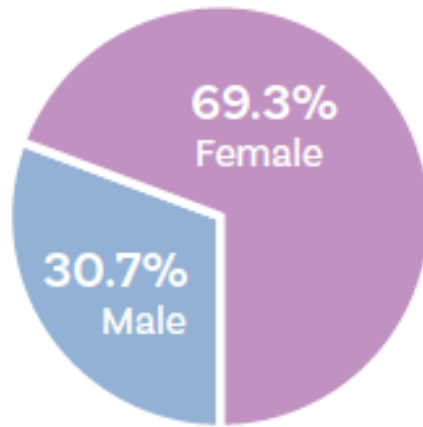
# Participants by Province



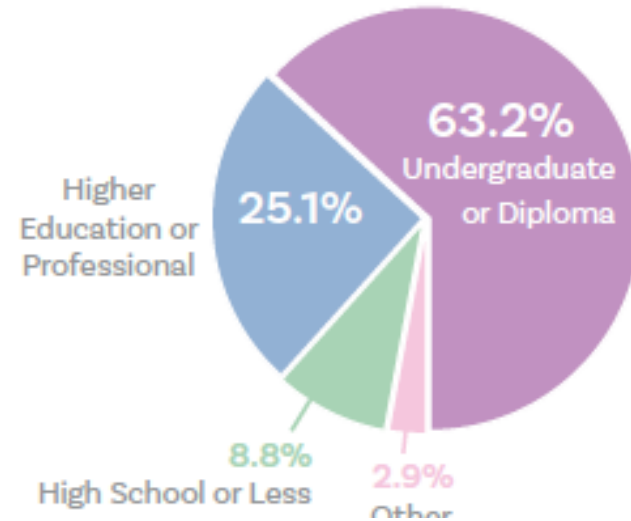
Total of 883 caregivers  
(737 ENG, 146 FR)

# Caregiver Characteristics

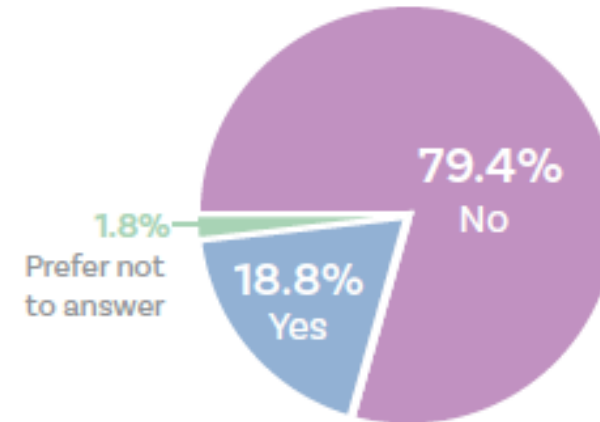
Gender



Education



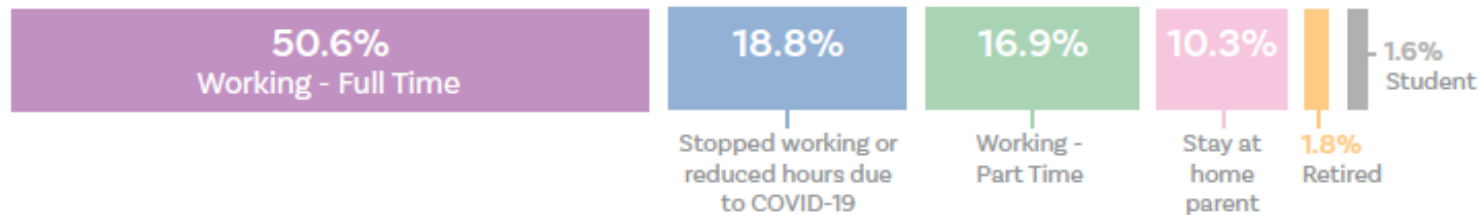
Disability



Relation to person with disability



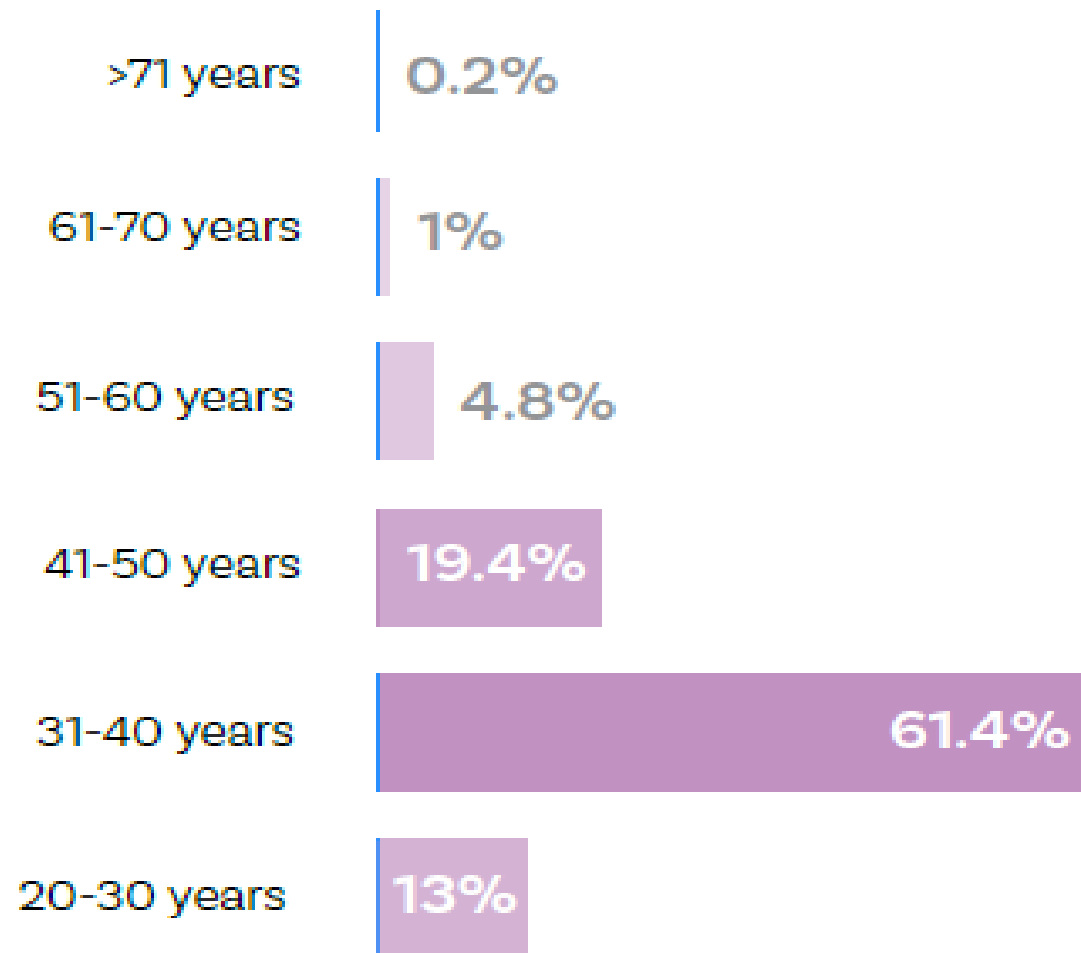
Work status



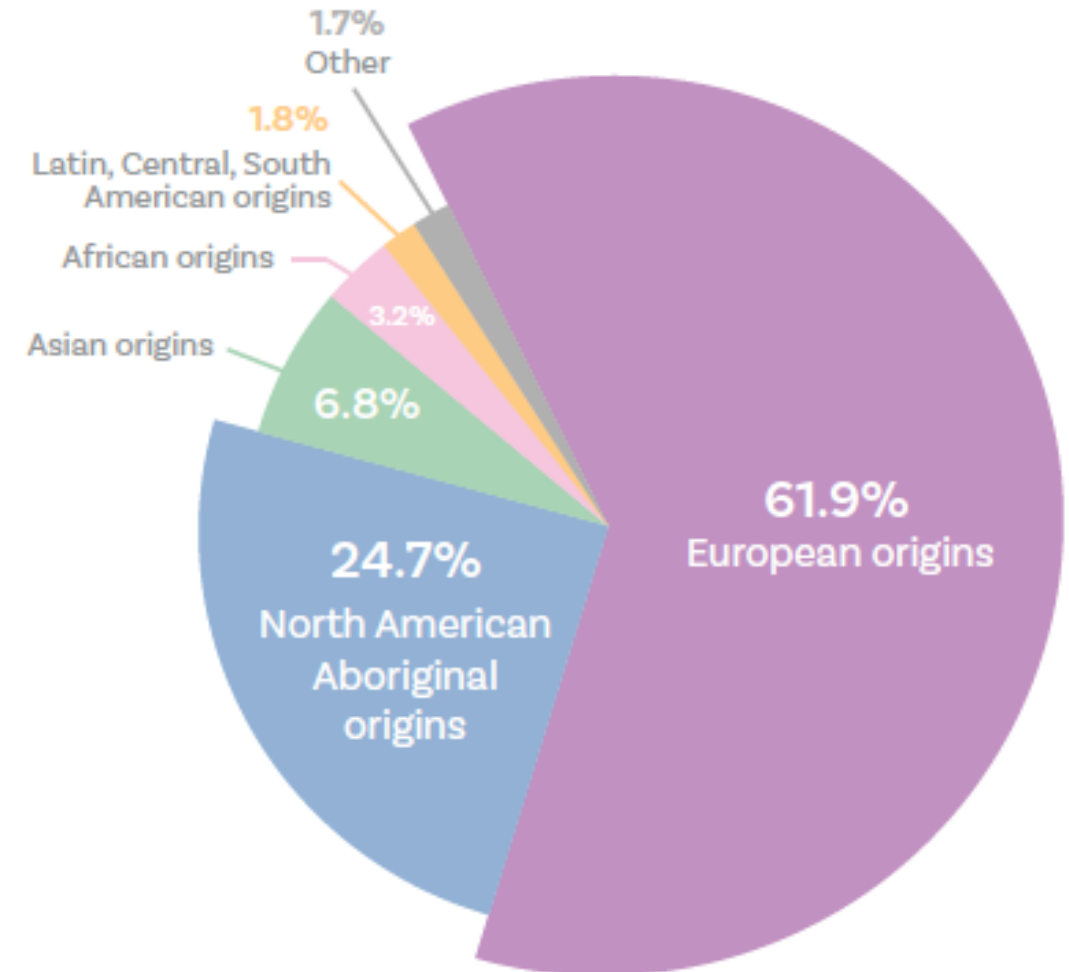
# Caregiver Characteristics

10

Age



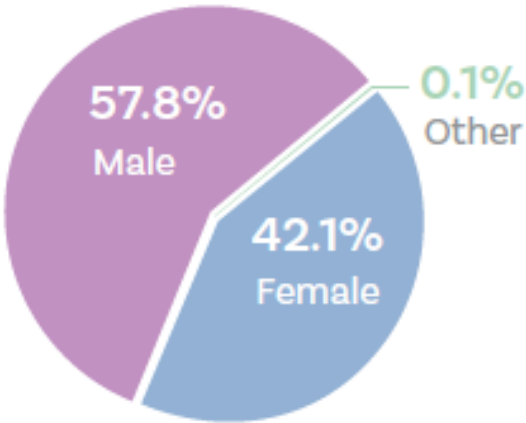
Ethnicity



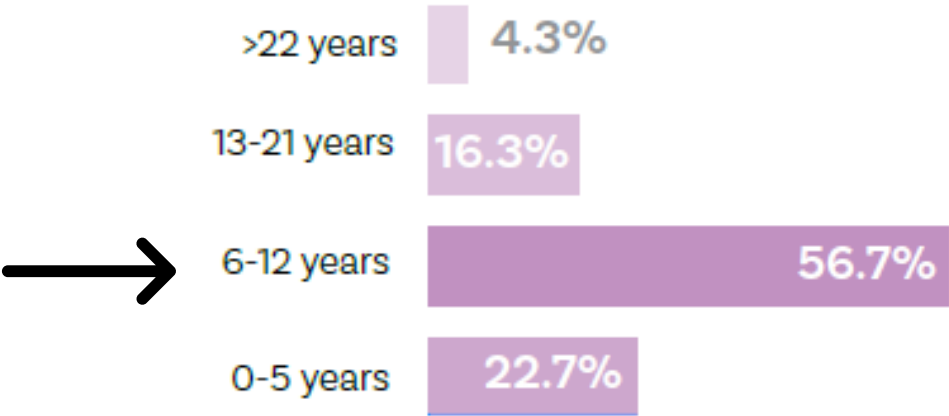


# Child Characteristics

Gender

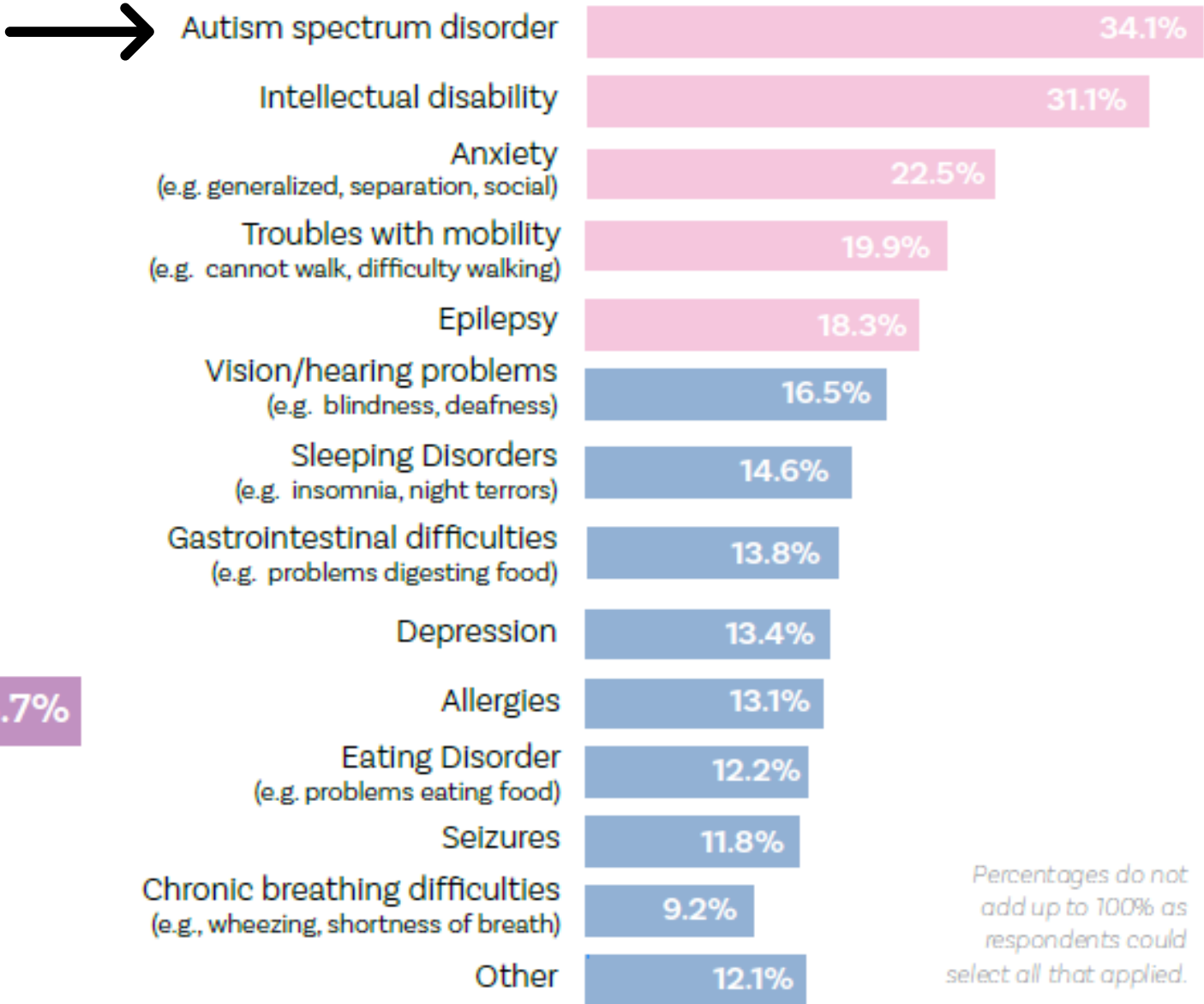


Age



The mean age for the child or adult with the disability was 9 years (age range of 0 to 41 years).

Conditions child has been diagnosed with

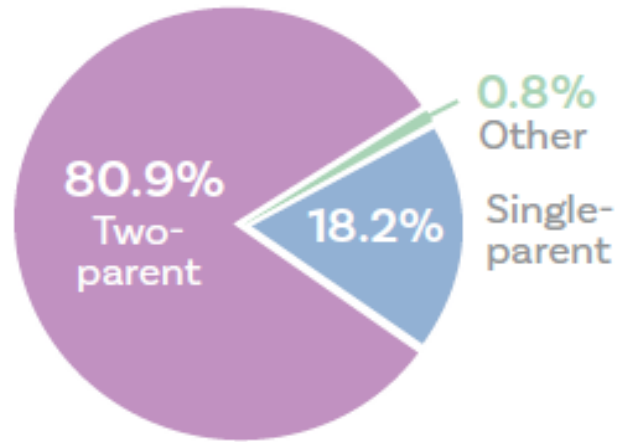


Percentages do not add up to 100% as respondents could select all that applied.

# Household Characteristics

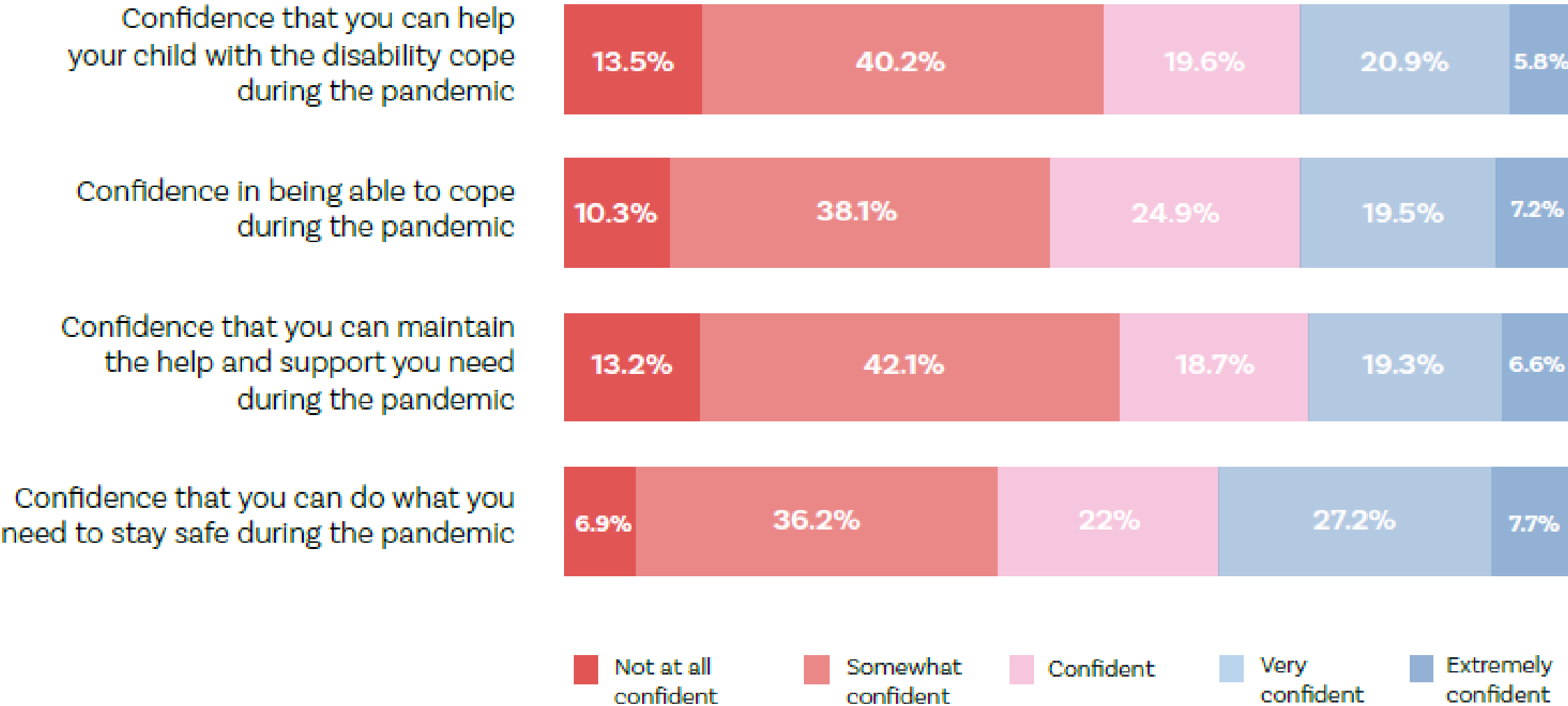
12

Household Status



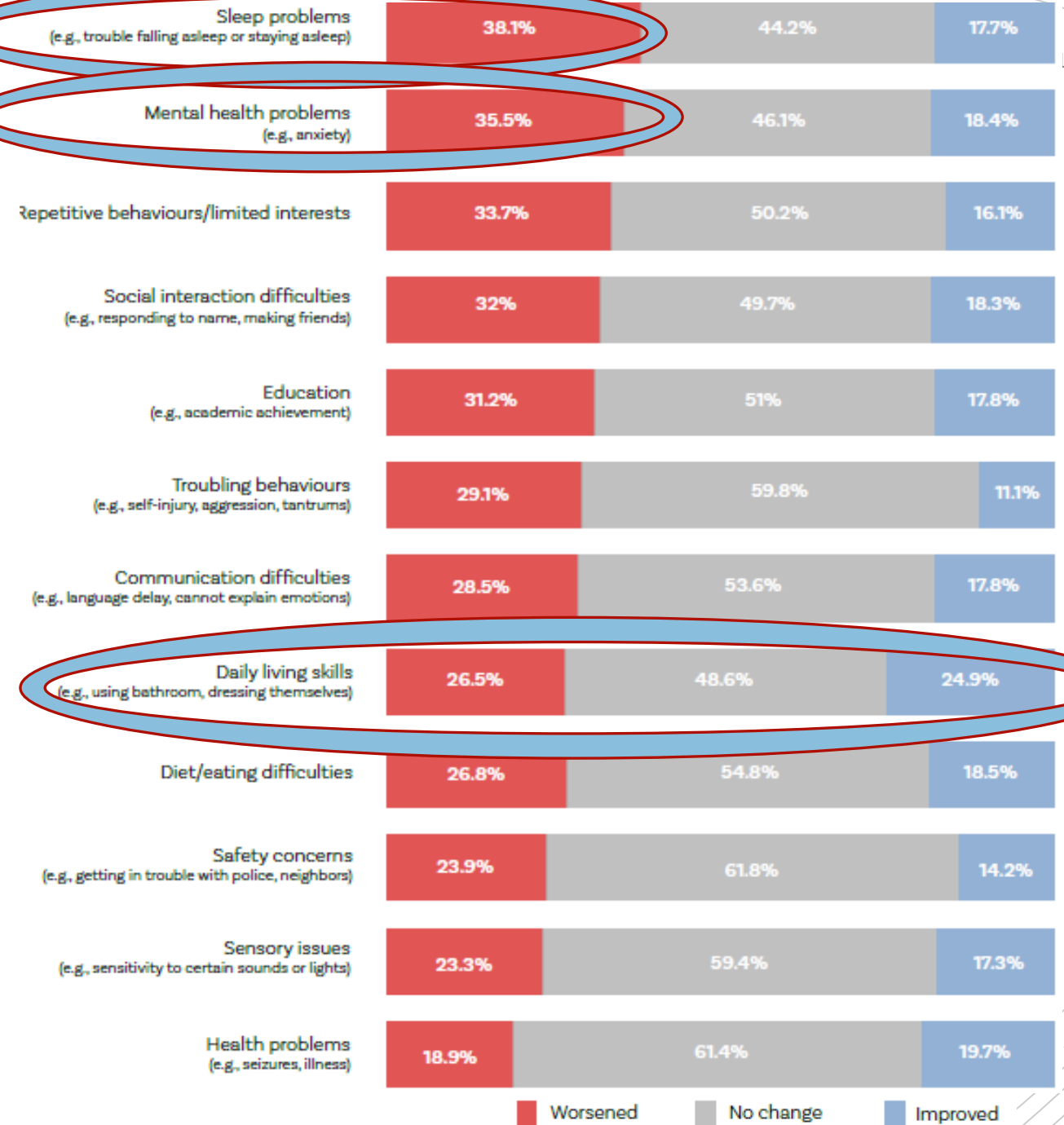
# Impact of the Pandemic

## Confidence to Cope



# Impact of the Pandemic

## Changes in Child Behavior



# Impact of the Pandemic

## Accessing Information, Services, and Supports (for child)

Have you gotten enough information, services, or support in the following areas for your child:

Not enough

Somewhat enough

Enough

Financial help for technology to help with schooling at home

41.4%

38.7%

19.9%

Educational plans for schooling at home

28.1%

42.2%

29.7%

Education for your child in a school/other educational setting

32.6%

43.7%

23.7%

Services for your child's mental health with a professional over phone/video

33.4%

40.5%

26.1%

Services for your child's mental health in a clinic

46.1%

35.2%

18.7%

Services for your child's physical health with a professional over phone/video

29.5%

39%

31.5%

Services for your child's physical health in a clinic

44.4%

30.2%

25.5%

Information about COVID-19 that is suitable for their level or ability

30.2%

48.6%

21.2%

# Prior to the Pandemic

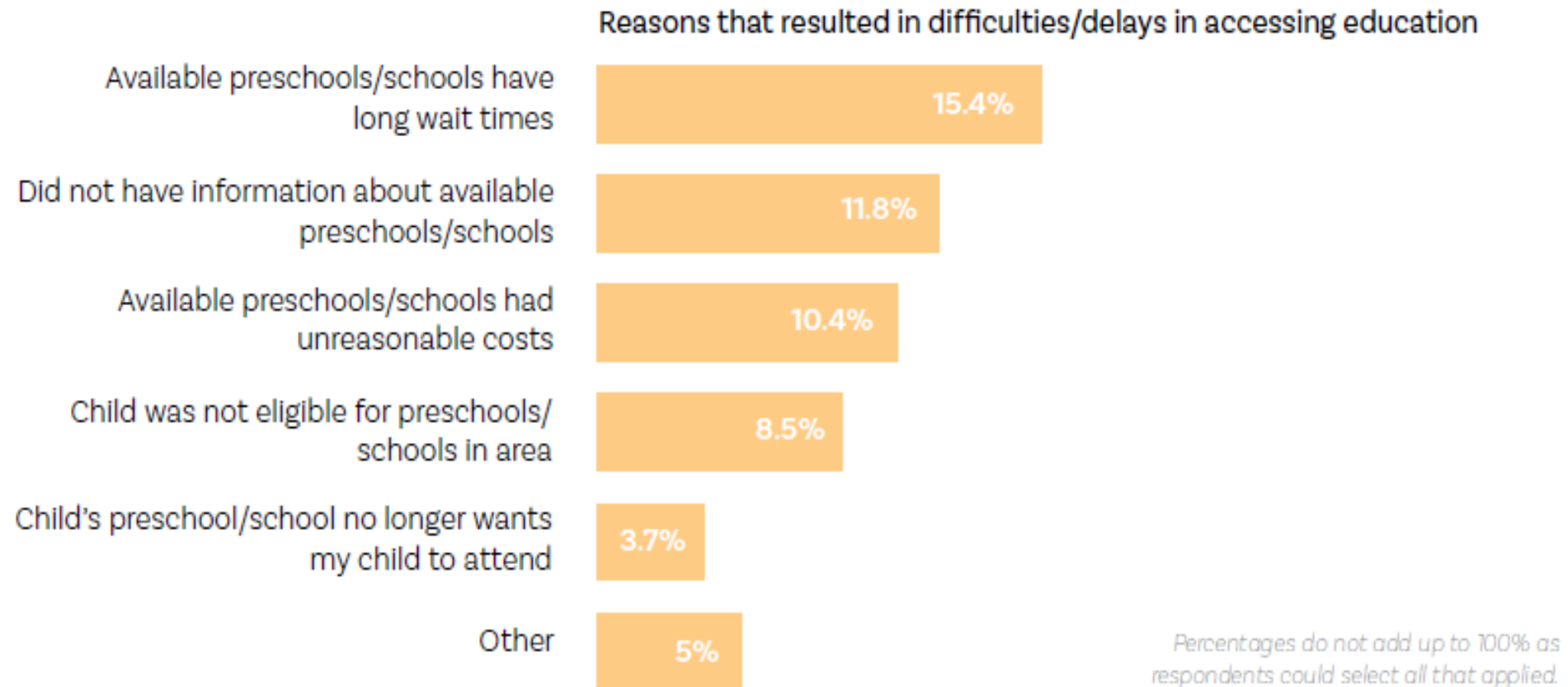
- Access to services:
  - 20% services have long waiting times
  - 29.9% no difficulties or delays

Services	n	%*
Early intervention programs for preschool age children (e.g., speech-language or occupational therapy)	200	22.7
Recreational / leisure programs	160	18.1
Social skills / friendship programs	152	17.2
Activity-based programs (e.g., physical activity, art, or music)	148	16.8
Respite care (in- and or out-of-home)	144	16.3
Daycare/preschool programs	143	16.2
Diagnostic and/or developmental/skill assessment services (including ASD diagnosis)	117	13.3
Life skills training (e.g., money management, self-care, hygiene, using transportation, etc.)	112	12.7
Specialized summer camps or other specialized summer activities	110	12.5
Mental health treatment (e.g., for anxiety or depression)	107	12.1
Early Intensive Behaviour Intervention program for preschool age children.	105	11.9
After-school programs	97	11.0
Specialized transportation	79	8.9
Early detection	76	8.6
Programs for behaviour management, e.g., reducing challenging behavior	73	8.3
Community safety training	43	4.9
Housing / residential options	41	4.6
Crisis intervention / management	34	3.9
Other services not listed here	32	3.6
Employment or adult day programs	30	3.4
Post-secondary education programs (e.g., community college, university)	7	0.8

\*Percentages do not add up to 100% as respondents could select all that applied.

# Prior to the Pandemic

## ■ Delays to access educational services

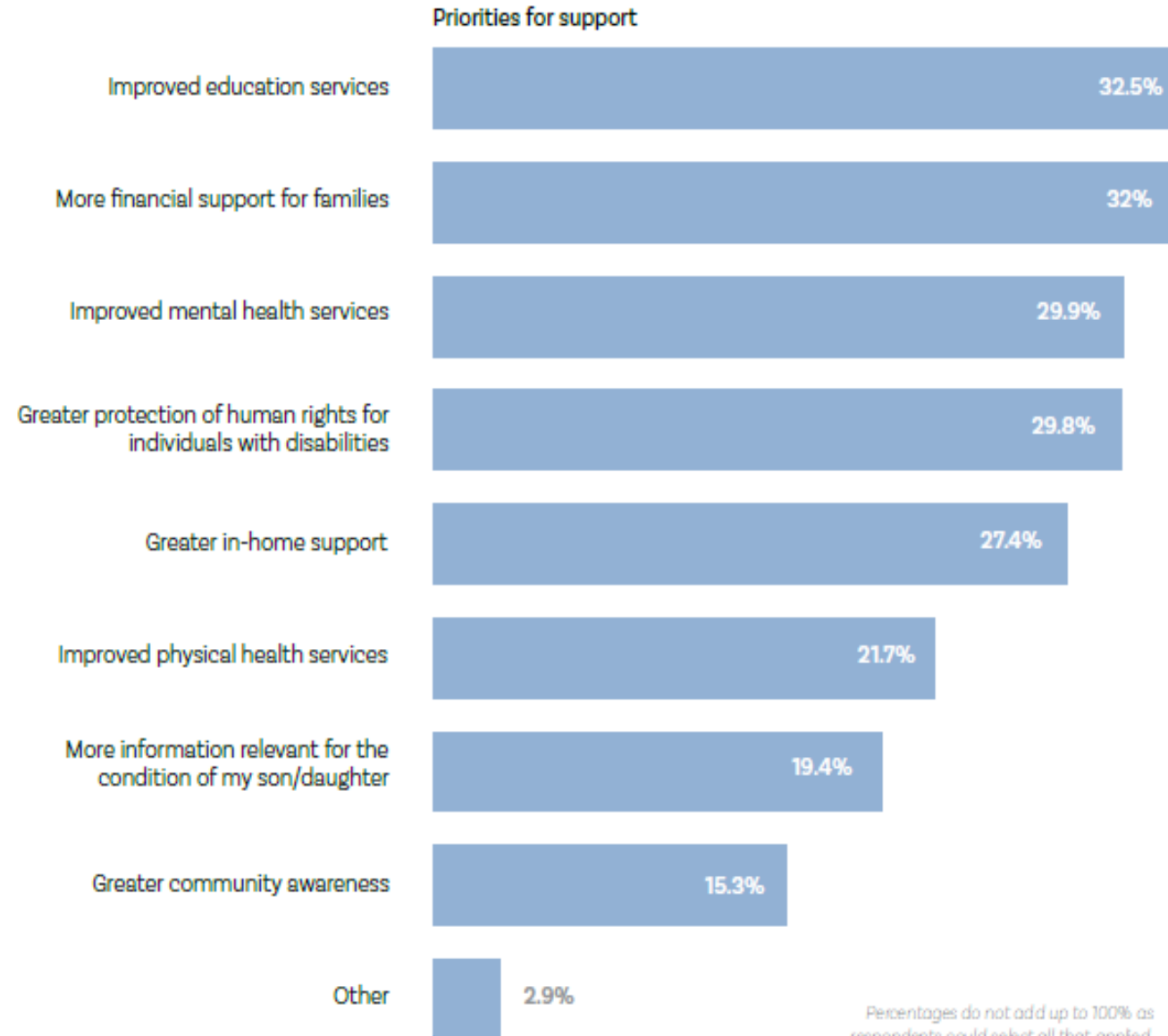




# Priorities for Support Identified by Caregivers

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- Education
- Financial support
- Mental health



## Next steps

- Inform systems of care that are:
  - Integrated: education, health (including mental health), community
  - Family-centered
- Human rights-based approaches
  - Emergency preparedness
  - Right to health, education, play, community living



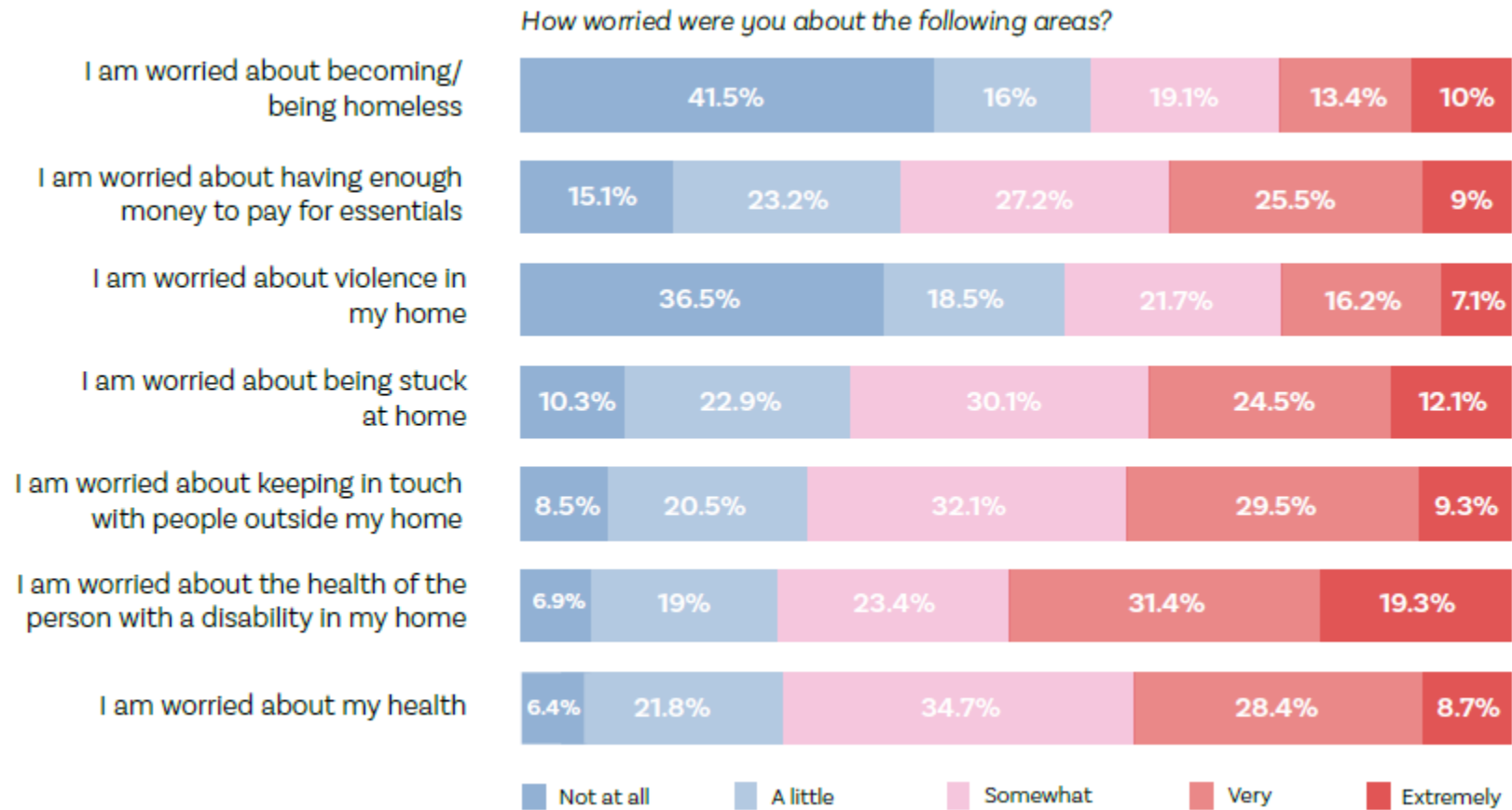
Merci!

## The Global Report- Canadian Activities to date

- Other related initiatives
  - ACAR-led COVID-19 Coordination Group
  - Caregiver Skills Training, Elsabbagh et al (PHAC & ACAR)
  - Policy Monitoring, Hunt et al (RSPQ, REPAR)
  - Nothing without us: Towards inclusive COVID-19 responses for children with disabilities, Zwicker, Shikako-Thomas et al. (CIHR)
  - Mental Health of children during the COVID-19 pandemic, Camden, Shikako-Thomas et al. (CIHR)

# Impact of the Pandemic

## (b) Caregiver Worries

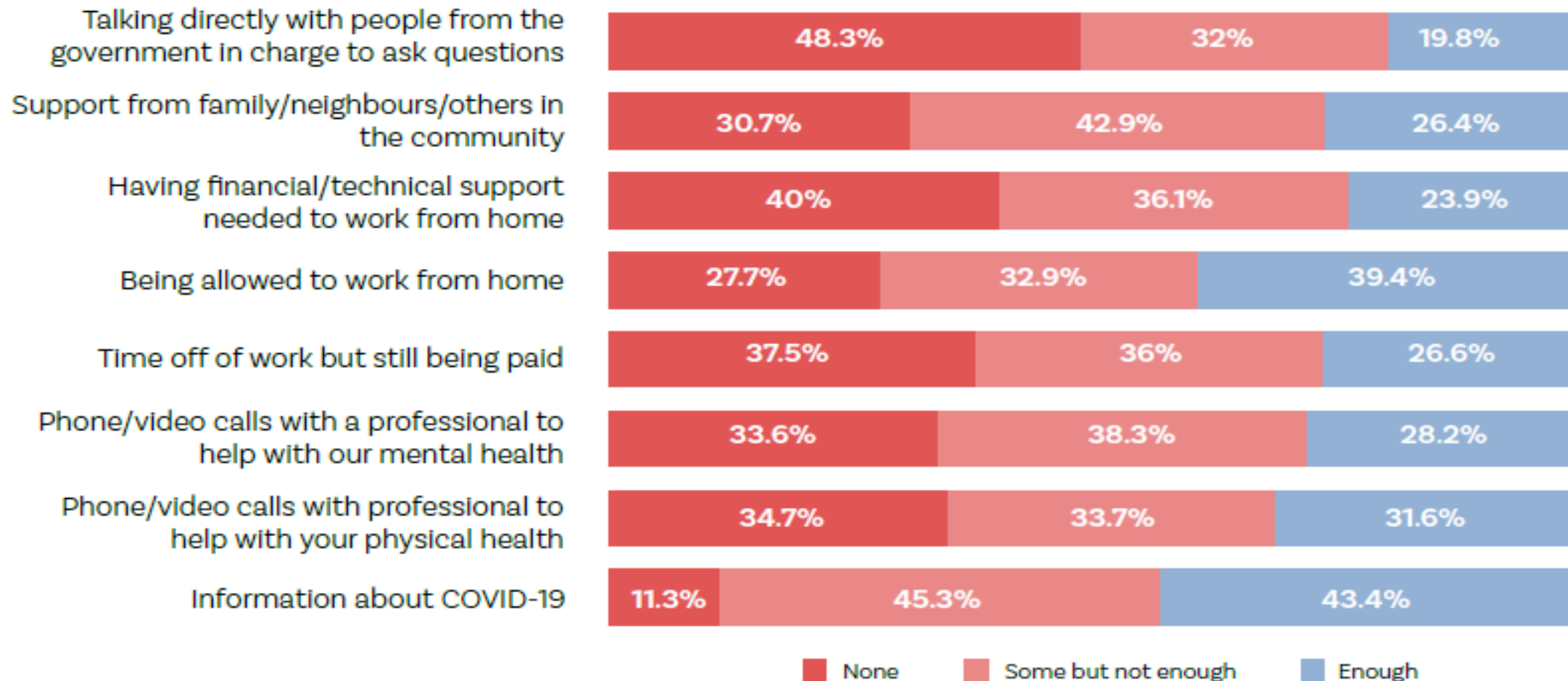


# Impact of the Pandemic

23

## Accessing Information, Services, & Supports (Caregiver)

*Have you gotten enough information, services, or support in the following areas:*





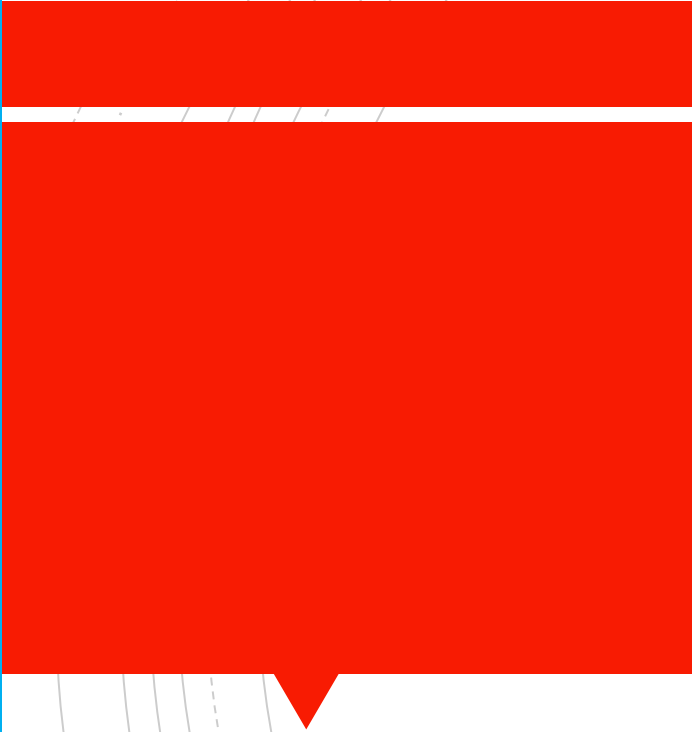


**Socio-economic disparities in access to services (Miriam & Jinan)**

**Resilience in children with NDDs (Afiqah & Nicky)**

**Qualitative data- barriers & facilitators to keeping safe (Ananya)**

**International collaborations (Argentina, Palestine, Serbia, South Africa, Iran)**



# Your Feedback/Requests for Next Steps



**Leave  
no one  
behind**

■ **Xxxx**

■ **Xxxxxxxxxxxxxxxxxx**

■ **Xxxxxxxxxxxxxxxxx**

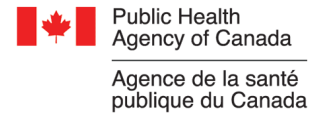
**<insert Qs you would like to  
add>**

# Your Feedback/Requests<sup>28</sup> for Next Steps

- Xxxx
- XXXXXXXXXXXXXXXXX
- XXXXXXXXXXXXXXXXX

<insert Qs you would like to  
add>





# DEVELOPMENT OF NASQ

A vertical line is positioned to the right of the text. In the bottom right corner, there is a yellow triangle pointing upwards and to the left, partially overlapping a light gray border.

# Background

- We set out to select items that are relatively common across different ASD measures
- The screening tool was designed to capture key autistic traits
- We aimed for a screening tool that has items across all the domains of DSM V while remaining brief



# Development Process



# Review of ASD tools

Looked at measures that are **parent report** and selected items that are fairly common across the different tools. Some of the reviewed measures include

- Neurodevelopmental Disorders Screening Tool (NDST)
- International Epidemiology Network Diagnostic Tool for ASD (INDT-ASD)
- Developmental and Well-Being Assessment (DAWBA)
- Social Communication Questionnaire (SCQ) (
- Developmental, Dimensional and Diagnostic Interview (3DI)
- Autism Diagnostic Interview-Revised (ADI-R)

# Expert Review: One

ASD experts with a focus on those from Nigeria were request to rate the items. A three Likert scale

- ✓ Very important
  - ✓ Somewhat important
  - ✓ Not important
- Experts were also asked to also suggest modifications to wording, format and general layout of the items
  - Items were revised and deleted/ modified based on the feedback from the team in Nigeria.
  - Based on this rating a longlist was reduced to a short list of 21 items

# Expert Review: Two

- We sort the opinion of experience data collectors.
- These are people who have administered parental report measures of ASD for parents and they could draw on their field experience to advise on which items can be used, required modifications
- We discussed item by items, making relevant modifications and adding locally relevant examples.

# Final tool

The final NASQ questionnaire included 26 questions eliciting dichotomous (yes/no) responses.

The first two questions assess the presence of expected levels of speech.

The remaining 24 questions assess core autism symptoms, including eight questions that assess early social communication/interaction skills and 16 items evaluating restricted/repetitive behaviors

# **Training of Field Workers on Nigeria Autism Screening Questionnaire (NASQ)**

**Dr. Muideen O. Bakare, *M.B.B.S, M.D, FMCPsych, MNIM***

**Chief Consultant Psychiatrist &  
Head Child & Adolescent Unit, Federal Neuropsychiatric Hospital, Enugu,  
Enugu State, Nigeria**

**E-mail – [mobakare2000@yahoo.com](mailto:mobakare2000@yahoo.com)**

**Website - <http://cndinitiatives.org/>**

# Introduction

- In 2016, Ike Foundation for Autism (IFA) and Autism Speaks facilitated incorporation of Nigerian Autism Screening Questionnaire (NASQ) into the National World Bank supported General Household Survey (GHS) with the initial goal of accruing information about the presence of autism symptoms in a representative sample of Nigerian population.
- After Experts in the field contributed to the development of the Questionnaire, Field Workers that were to engage un the General Household Survey were trained on use of the NASQ before they went on fiel study.

# Training of Trainers

- Location – Training Location was one of the Conference Halls of the Nigerian Bureau of Statistics (NBS), located in Federal Capital Territory, Abuja in Nigeria.
- The Trainees represented all the six (6) regions of the Country where the field study were expected to take place. These include North East, North West, North Central, South West, South East and South-South regions of the Country.
- The Trainees were Supervisor who are expected to train the other Field Workers and Supervise the process of the data collection.



# Training Procedure

- I coordinated and facilitated the training at the NBS, Abuja, Nigeria.
- The Field Workers (Supervisors) were given initial general information about symptoms constellation for Autism Spectrum Disorder (ASD) based on DSM-V Criteria.
- The symptom criteria were communicated in lay-man terms as much as was possible – This explanation was supported by video presentations depicting symptoms of ASD.
- Item by Item of the NASQ was treated and explained to the trainees and this were further elaborated with the aid of Audio-Visual Media.

# Training Procedure (Contd)

- The trainees were observed to conduct at least one independent interview with the Questionnaire before being deployed to the field for data collection.
- They were mandated to train the lower cadre field workers they would be supervising with the same procedure and ensure the conduct sample interview before being sent to the field.
- The Nigerian Autism Screening Questionnaire (NASQ) is an Informant Report Measure – Information about a particular child was obtained from the Parents or Guardians. NASQ contained 26- item Questions.

**THANK YOU**



# Nigerian Autism Screening Questionnaire

# Background

## **Data is a major challenge**

- Lack of data remains a major challenge to autism advocacy in many developing countries, especially in Africa
  - High cost of collecting autism data is prohibitive, and unaffordable for many autism advocates
  - Many African countries rely on donors to finance data collection and analysis
  - Autism data is not considered a priority in many developing countries
  - To address the data challenges, we have to think outside the box
-

# Case of Nigeria

- Nigeria has little or no data or support services for autism
- Nigeria will not use its own resources, borrow, or request grants to fund autism data collection
- No private funds are available for autism data collection

# Use of Household Surveys for Autism Data Collection

- Every five years international development agencies such as the World Bank, African Development Bank, etc. finance Household Surveys in their member countries to collect data for poverty and economic analysis
- Agencies are unlikely to include an autism questionnaire in their surveys, but may find Childhood Developmental Disabilities acceptable

# Consultation with World Bank and Nigerian Institutions

- We had consultations and approval by the World Bank
- Consultation and buy-in from the Nigerian counterpart, the National Bureau of Statistics
- Andy assembled a team that produced questionnaires that are acceptable to the World Bank
- NBS staff were trained on the administration of the questionnaire; and the rest is history



# Potential Lessons

## Household Surveys

Household Surveys could serve as a viable vehicle for collecting Autism data in developing countries at reasonable costs.

## Replicated Elsewhere

Nigerian experience could be replicated in other countries with some modifications to account for country circumstances.

**Thank you for listening!**





**autism speaks®**

# **Psychometric Properties of the Nigeria Autism Screening Questionnaire (NASQ)**

**Thomas W. Frazier, PhD**

**Chief Science Officer**

**April 28, 2021**

# **Comprehensive evaluation of psychometric properties**

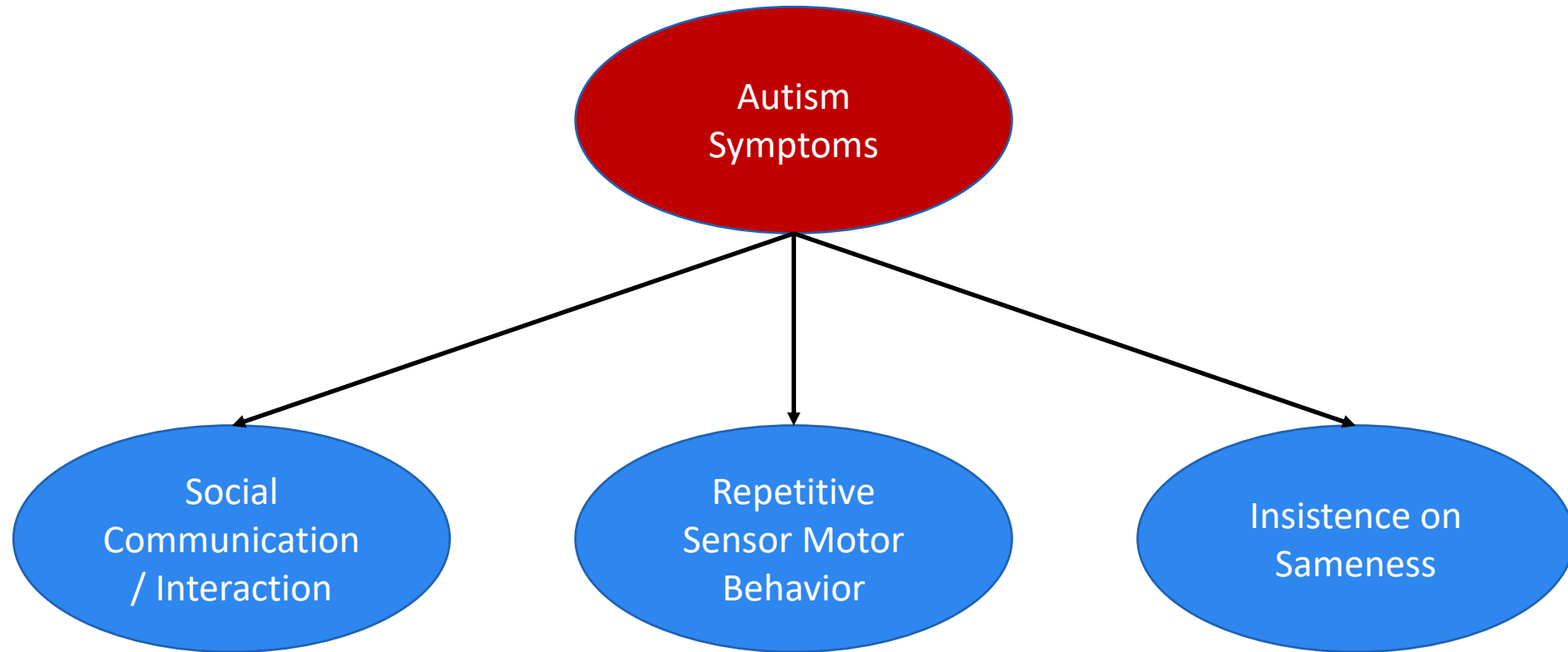
**Factor Structure – what is being measured?**

**Reliability – how reliable are scores?**

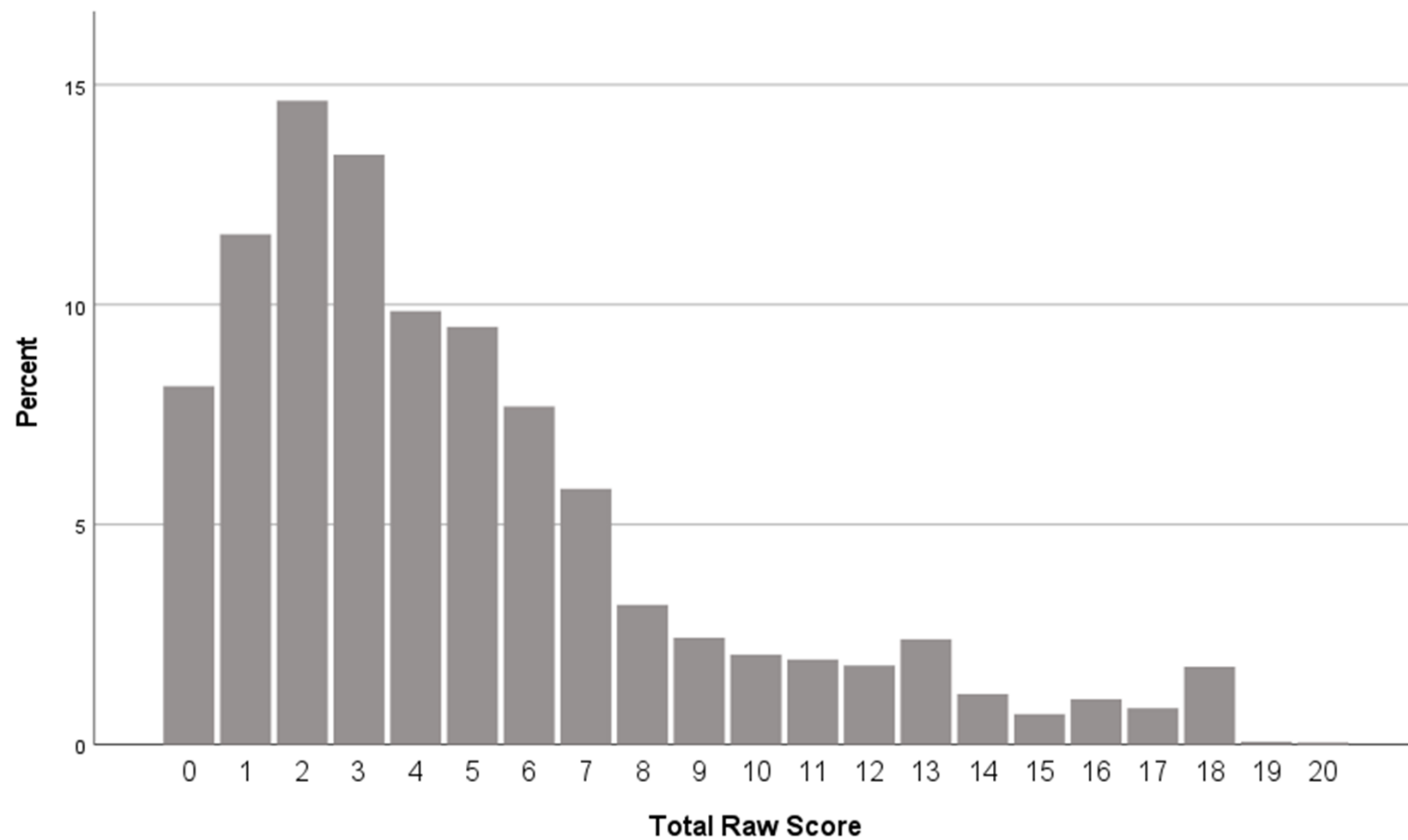
**Are there different score patterns?**

**Can the NASQ predict high risk cases?**

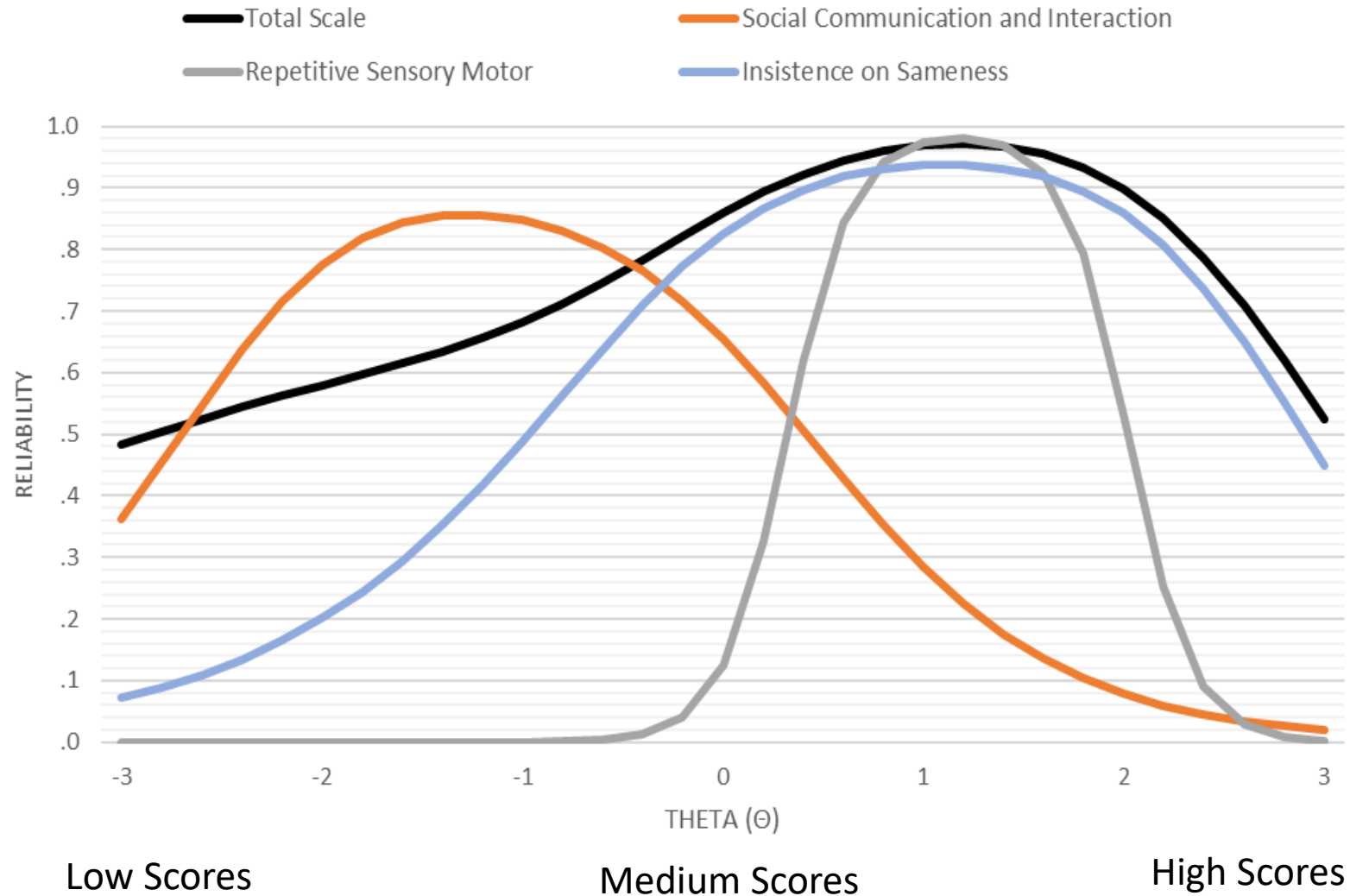
# Factor Structure



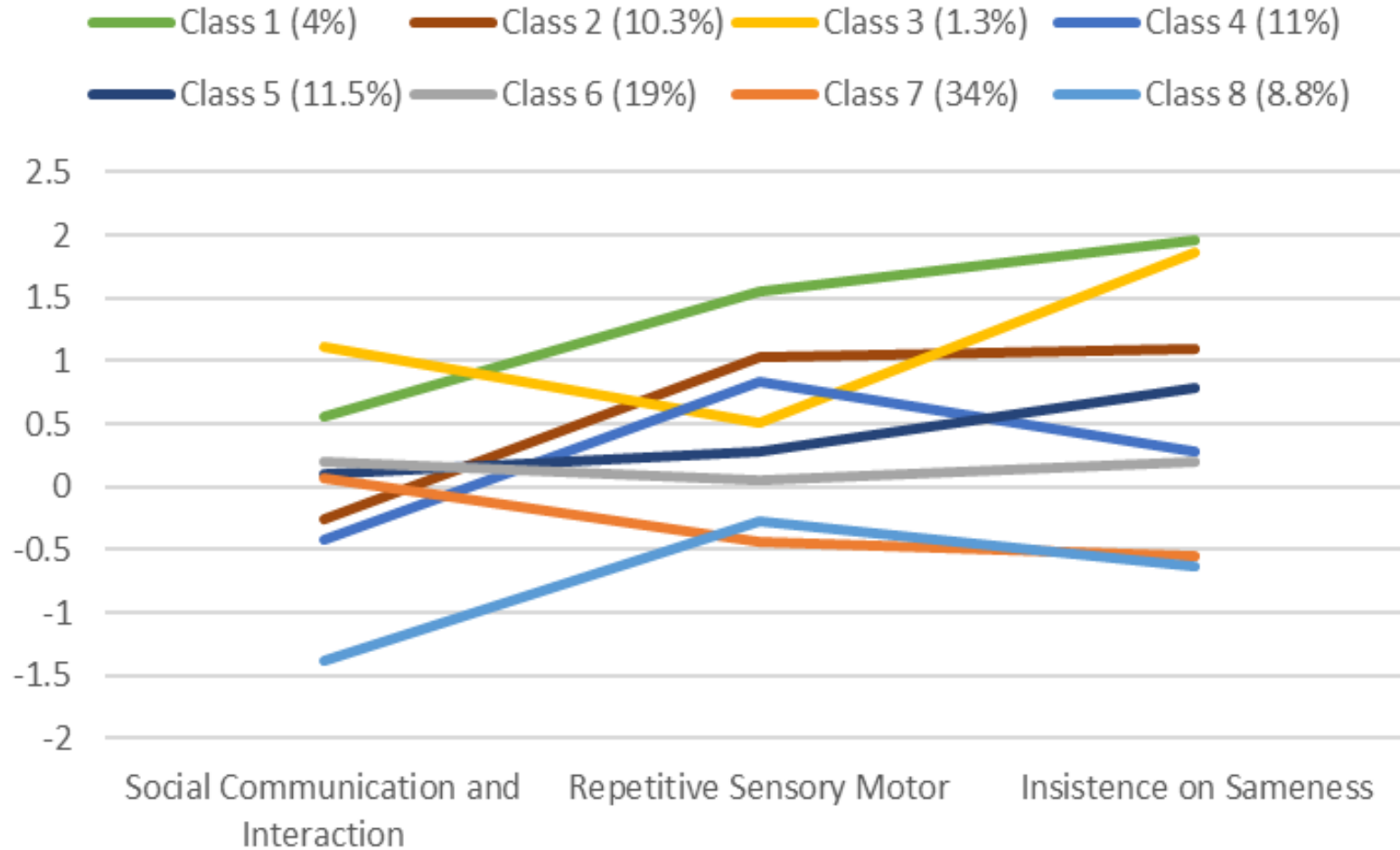
# NASQ Score Distribution



# Reliability Across the Score Range

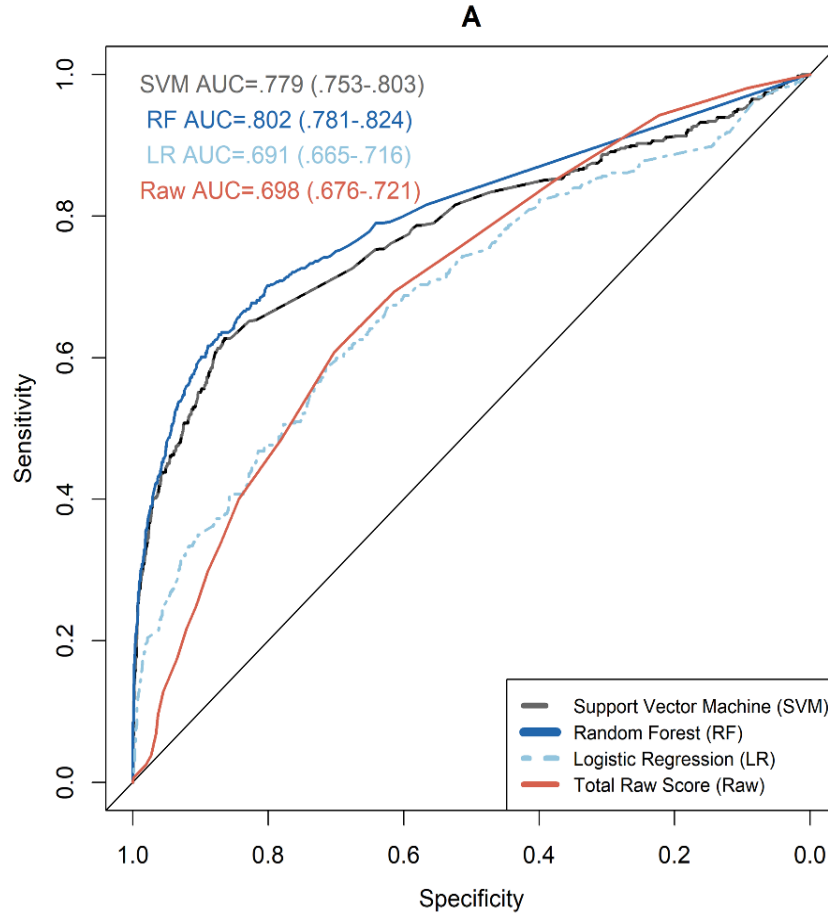


# 8 Different Score Patterns

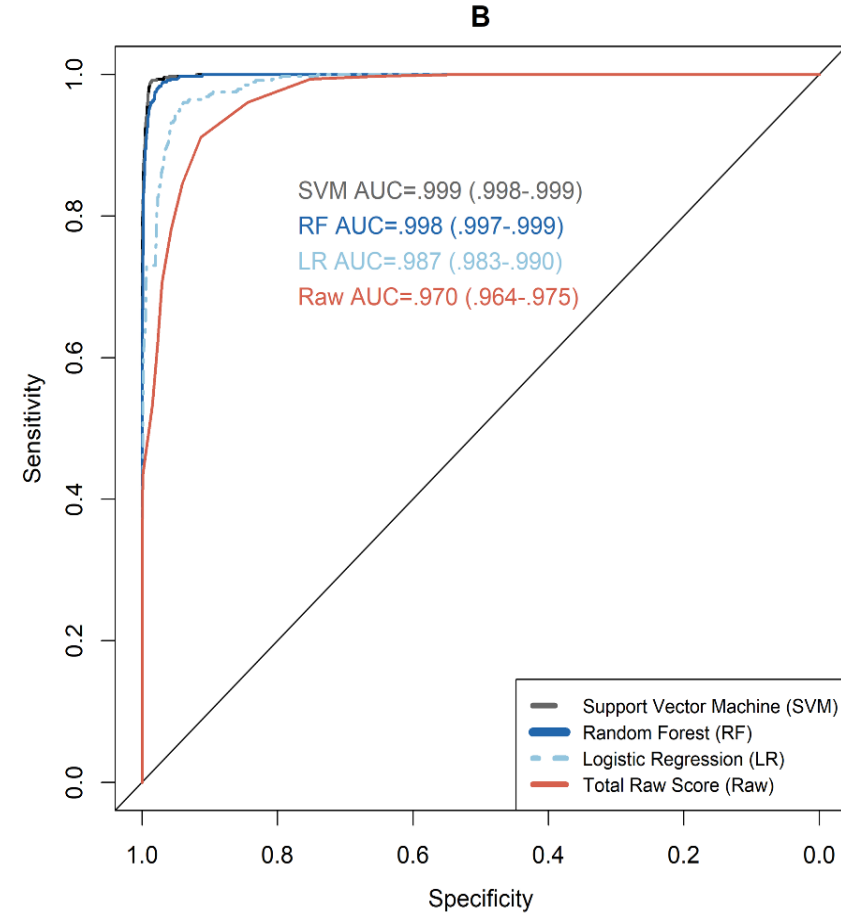


Classes 1 and 2 have autism-like patterns and were considered high-likelihood cases

# Good prediction of high-likelihood cases



ASD Concern



High Likelihood Classes





**THANK YOU**