down syndrome
care hub

Down Syndrome Survey
for Parents & Caregivers

Summary Report 2015

downsyndromecare.ca

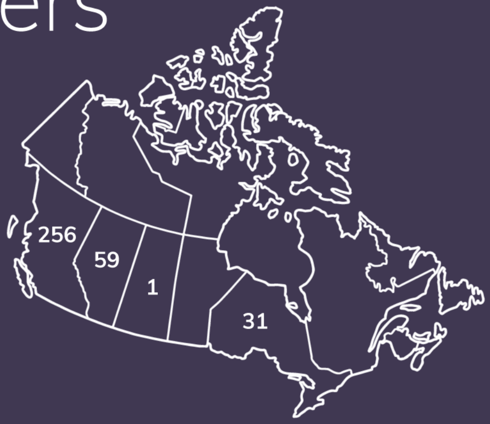
2015 Down Syndrome Survey for Parents & Caregivers

346 respondents

291 mothers | **42** fathers | **29** other

12 average age of their child

<1 ro 57 range



46% have eye conditions

39% have ENT conditions

35% have heart conditions

34% have skin conditions

97% have a primary physician

72% underwent surgery

Parents & caregivers of people living with Down syndrome

48% knew neighbourhood contacts with Down syndrome (4 contacts on average)

60% of caregivers use online resources

People living with Down syndrome

27% aged 13–18 years helped at home

71% aged 19 years+ worked in some capacity

Overview of Results

Down Syndrome Survey

for Parents/Caregivers of Children/Youth/Adults with Down syndrome

BC CHILDREN'S HOSPITAL
An agency of the Provincial Health Services Authority

CHILD & FAMILY RESEARCH INSTITUTE

UBC THE UNIVERSITY OF BRITISH COLUMBIA

Down Syndrome Research Foundation
Together. Hand in Hand.

TIDE BC

NeuroDevNet

Children's Sleep Network

Contributors

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Letter from the Down Syndrome Research Foundation

Many of us are facing a multitude of challenges in the orchestration of the chronic care needs of our children with Down syndrome. We developed this survey in collaboration with physicians from BC Children's Hospital and the University of British Columbia, in order to get a better understanding of the current health statuses of children and adults with Down syndrome (DS), and what kind of needs and gaps exist in real life.

We are supported by various research networks aiming at improving lives of children with developmental conditions such as NeuroDevNet, TIDE-BC and Children's Sleep Network.

This 80-question survey was designed to capture an understanding of the main needs of individuals with Down's syndrome. Only with the help of individuals from the community can we help construct a solid plan aiming to improve health and quality of life quality for children and adults with DS. Each individual who contributed to this survey has increased the significance of our findings, adding additional value to our publication; direct quotes from the survey responses may also be used in teaching materials for healthcare professionals, to bring awareness to common challenges children, youth, and adults with DS experience.

If you are interested in joining our community and would like to connect with the Down Syndrome Research Foundation (e.g. to join a parent group or seek specific information), please click on the following link to email your contact information [http://www.dsrf.org/contact-us/]

Sincerely,
Ms. Dawn McKenna & Ms. Pat Hanbury
on behalf of the Down Syndrome Research Foundation

Down Syndrome Research Foundation
Together. Hand in Hand.

Dr. Sylvia Stockler, BC Children's Hospital
Dr Osman Ipsiroglu, Sunny Hill Centre for Children
Dr. Linlea Armstrong, Department of Medical Genetics, UBC
on behalf of the Medical Research Team

Survey Structure

Format:

REDCap (Research Electronic Data Capture) based survey: *hosted on The Down Syndrome Research Foundation (DSRF) webpage, and advertised by the DSRF via social media:*

http://www.dsrf.org/research/participate-in-research-studies/

***80* Questions**

5 Sections:

1. *Basic Demographics*
2. *Diagnoses/Medications/Supplements*
3. *Development*
4. *Sleep/Wake-Behaviours*
5. *Feedback & Testimonials*

**Survey Approved by the University of British Columbia Research Ethics Board (H14-02305)*

Timeline:

OCT. 2014 – FEB. 2015	MAR. 2015 – APR. 2015	MAY 2015 – AUG. 2015
Development & peer review of the DOWN SYNDROME SURVEY + REVIEW by 5 FAMILIES of individuals with Down syndrome	Survey first released in BC + ALBERTA & ONTARIO for last 2 weeks	DATA ANALYSIS by the *Sleep/Wake-Behaviours Clinic & Research Lab team*

Section 1: Demographics & Healthcare Information

Basic Demographics

364 parents/caregivers of individuals with Down syndrome (DS) responded to the ***Down Syndrome Survey***, between ***March-April 2015***

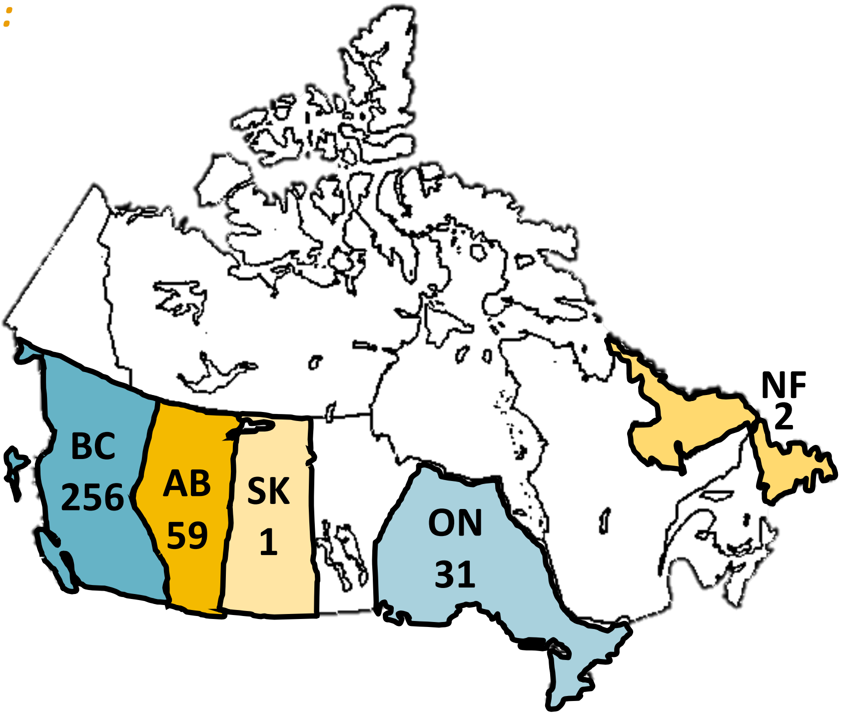
Where were the parents/caregivers from?

The breakdown:

349 Canadians

6 Americans

9 Did not specify



Further analysis in this report focuses on the three major sources of respondents: ***346*** respondents from **British Columbia**, **Alberta** and **Ontario**.

Which parents/caregivers filled out the survey? n %

Of the 346 of BC, AB and ON, the following caregivers responded:

Mothers *291* *84%*

Fathers *42* *12%*

Others (e.g. teachers, service providers) *13* *4%*

Other Relatives *11* *3%*

Siblings *5* *1%*

Where do these individuals with DS currently live? n %

1. **At home with family** 315 91%
2. **Home share** 14 4%
3. **Other (see below)** 11 3%
4. **In a protected group home** 7 2%
5. **With other relatives** 3 1%
6. **With foster parents** 1 0.003%
7. **With a partner** 0 %

The majority of individuals with DS live **at home with family**. However, a number of the older individuals live in other settings, such as the following

"Shares an apartment with a roommate who is not special needs."

Age 34

"Lives by herself in her own condo and spends weekends with parents."

Age 47

"Lives with: Mother 2 weeks/month; Caregiver 2 weeks/month; Father 2 weekends/month."

Age 23

"Lives at home but is beginning to transition to living in a small condo by herself."

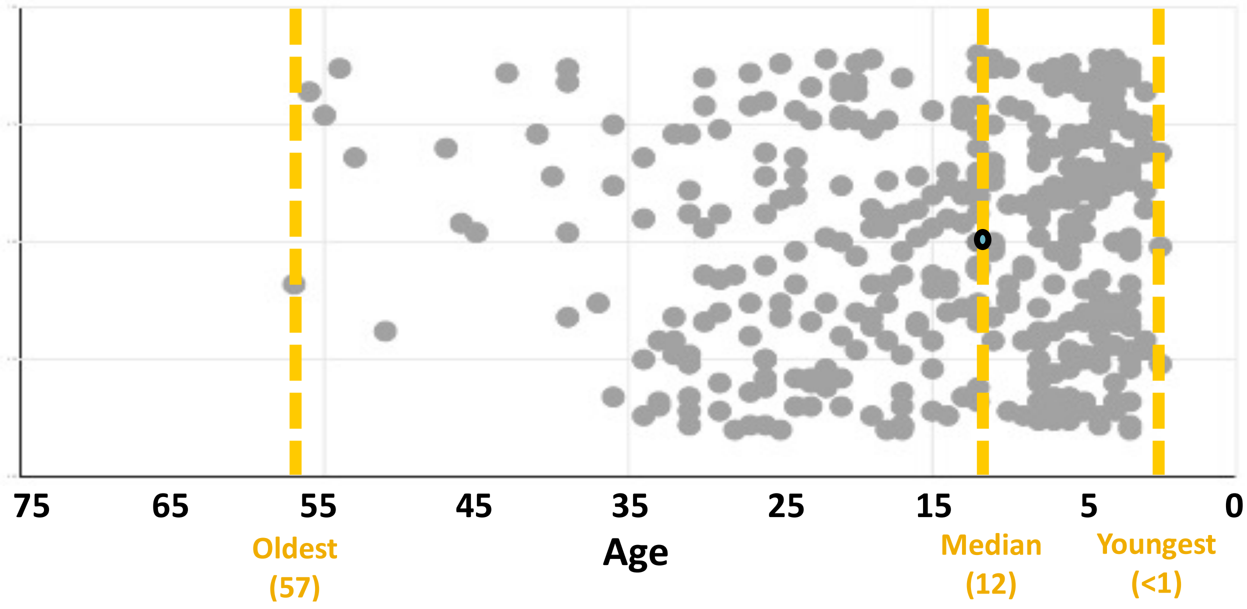
Age 21

Section 1: Demographics & Healthcare Information

How old are these individuals with DS?

The median age of individuals with Down syndrome in this survey is **12 years old.**

Age Range of Individuals with DS:



How many have siblings?

89% of individuals with DS have **siblings**, with an **average number** of **2** siblings.

How many individuals with DS have siblings? (n=346)	n (%)
Have siblings	**307 (89)**
Average number of siblings	2
Do not have siblings	**39 (11)**

How many have other family members with DS?

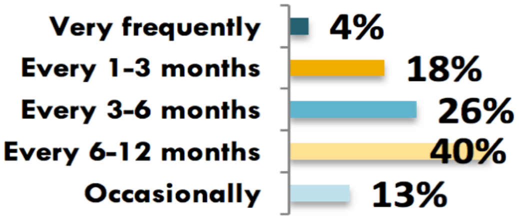
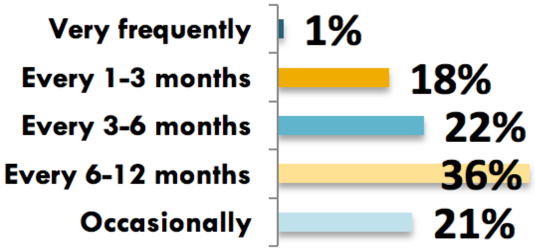
7% of individuals with DS had **other family members** who also have DS, with an **average number** of **1** other family member.

Do these individuals with Down syndrome have other family members with Down syndrome? (n=346)	n (%)
Yes	**23 (7)**
Average number of family members with DS	1
No	**321 (93)**
Unsure	**2 (1)**

Healthcare Services

Who is the primary physician of individuals with DS?

97% of the individuals with Down syndrome have a primary physician. **Pediatrician** were the main primary physician for **ages 0-18**, while adults most commonly were seen by **General Practitioners**.

	Ages 0-18 (n=234)	Ages 19+ (n=112)
Primary Physician	*Paediatrician* 63% *General* 31% *Other* 2%	*General Practitioner* 93% *Paediatrician* 4% *Other* 2%
Frequency of Visits		

Who is the secondary physician of individuals with DS?

88% of the individuals with Down syndrome also have a secondary physician. **Dentists**, **ophthalmologists** & **ENTs** are in the top three of physicians seen in the past year.

	Ages 0-18 (n=234)	Ages 19+ (n=112)
Seen in the Past Year	*Dentist* 27% *Ophthalmologist* 21% *ENT* 19% *Cardiologist* 11% *Developmental Paediatrician* 4%	*Dentist* 47% *Ophthalmologist* 12% *ENT* 12% *Cardiologist* 10% *Endocrinologist* 4%
Seen 12+ Months Ago	*Cardiologist* 29% *ENT* 14% *Geneticist* 13% *Ophthalmologist* 9% *Gastroenterologist* 6%	*ENT* 34% *Cardiologist* 28% *Ophthalmologist* 20% *Geneticist* 20% *Orthopaedic Surgeon* 15%

What are common surgeries individuals with DS have had?

The two most common surgeries are for **ear tubes** and **adenoids/tonsils**; **72%** of the individuals with Down syndrome underwent at least one surgical procedure.

Most common surgical procedures (n=263)		**n (%)**
1	**Ear tubes**	**143 (57)**
2	**Adenoids/tonsils**	**105 (42)**
3	**Heart**	**90 (36)**
4	**Eyes**	**40 (16)**
5	**Dental**	**29 (12)**
6	**Bowel**	**23 (9)**
7	**Orthopaedic**	**21 (8)**
8	**Reproductive**	**18 (7)**
9	**Abdominal**	**15 (6)**
10	**G-tube insertion**	**14 (6)**
11	**Other (see below)**	**63 (25)**

Other common surgeries: n

Integumentary 13
Cysts 5
Abscess Cleft palate Gum tissue 1
Upper lip ties snipped Lancing boil
Removal of warts Removal of sweat glands
Lump on head

Digestive 10
Biopsy of intestines Endoscopy 2
Duodenal Atresia/Stenosis Gastroscopy
Gastro J tube insertion Pyloric stenosis
Esophageal Atresia Biopsy of liver 1

Tongue 8
Tongue reduction 5
Tongue surgery 2
Tongue snipped 1

Nervous 7
C1/C2 fusion 3
Brain aneurysm Cranial surgery
Neurosurgery Scoliosis 1

Others 10
Appendix removal IVAD placement 2
Nasal cavity infection Vein stripping
Nasolacrimal probing Tracheotomy
Nose surgery Pulmonary sequestration 1

Cancer 4
Central line/PICC 3
Cancer treatment 1

Urinary 4
Bladder/Vesicostom 2
Ureter re-implant

Other Ear-Related 7
Mastoidectom Ear surgery
Hearing device 2 Cholesteatoma 1

What alternative health specialists do individuals with Down syndrome see?

The two most common are **chiropractors and naturopaths**; **17%** of the individuals with Down syndrome saw at least one alternative health specialist.

Chiropractor *12%*

Naturopath *8%*

Homeopath *3%*

Biofeedback *1%*

Integrative Health Physician *1%*

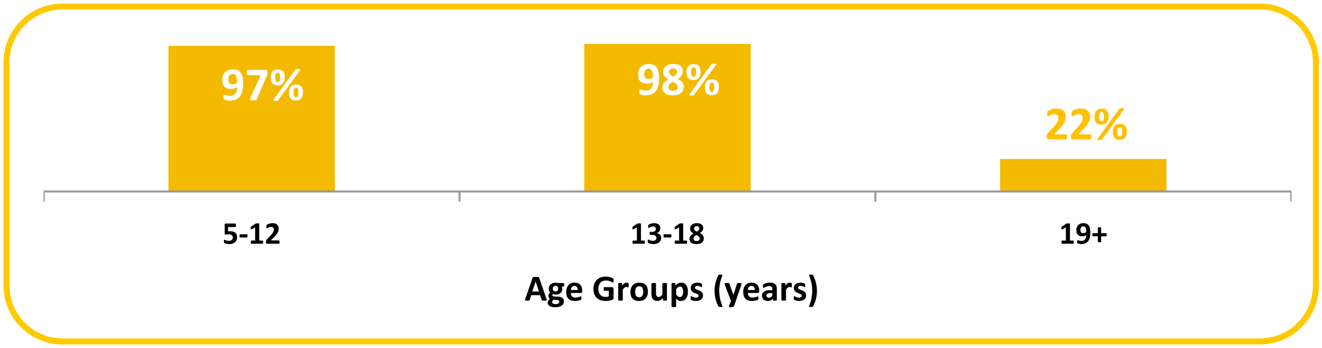
What health and community services do individuals with Down syndrome use?

Current: speech language pathology, occupational therapy and physiotherapy. **Over 12 months ago:** The Infant Development Program is a major community service used which corresponds to the median age of the individuals: 12. The top services never attended were sleep counseling, behavioural counseling and psychologists.

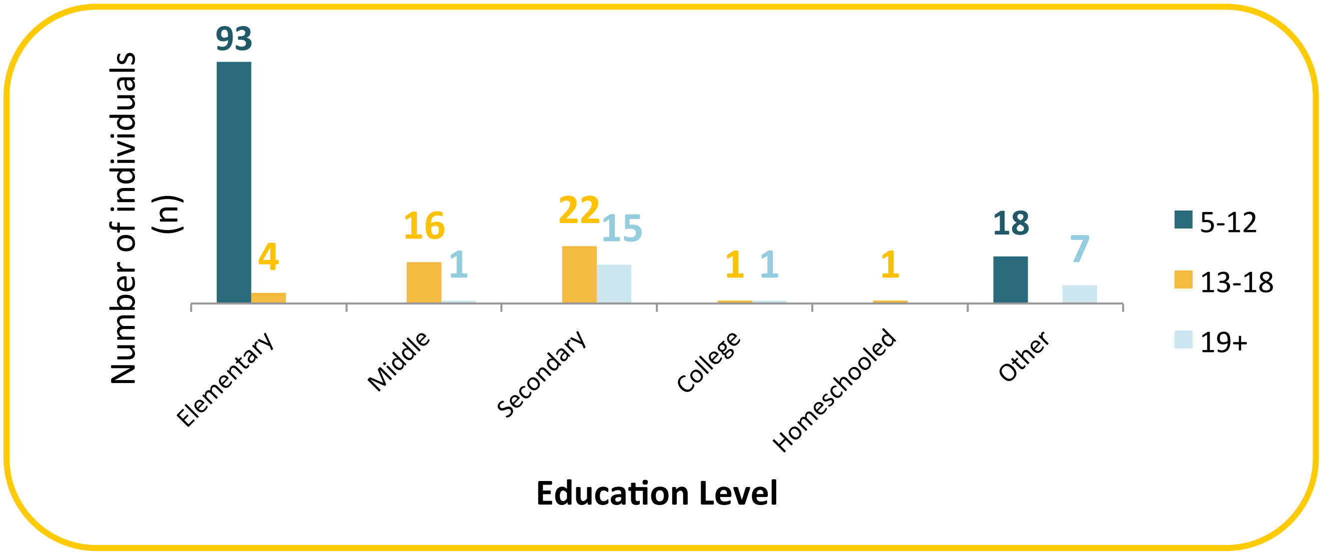
Service	Currently (%)	Over 12 months ago (%)	Has never attended (%)
Speech Language Pathology	54	28	3
Physiotherapy	27	39	13
Occupational Therapy	29	36	14
Infant Development Program	14	69	6
Community Health Services	8	38	22
Daycare	21	34	40
Psychologist	4	18	66
Behavioural Counselling	7	20	66
Sleep Counselling	4	11	73

Education

How many individuals with DS are currently attending school? Approximately **51%** of **all individuals** are currently in school; **almost all those aged 5-18** are in school, while that percentage **drops significantly for those of post-secondary age** (Ages 0 to 4 were excluded due to being too young)



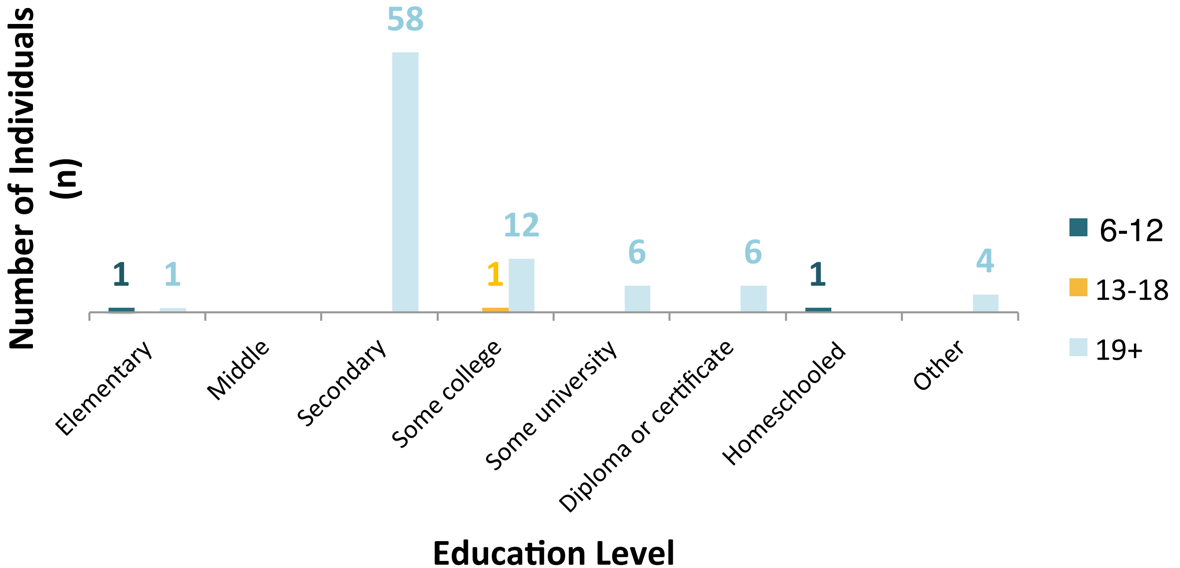
Based on their age, at what level of education are these individuals currently at? The most common current level of education for those **5-12** is **elementary school** and **secondary school** for those **13-18** and **19+**.



How many individuals currently attending school have a special education attendant?, **75% of those 19+** had special education attendants compared to **96% and 93%** for those **5-12 and 13-18, respectively**.

Of the individuals *not* currently attending school, what is the highest level of education they reached/completed?

These individuals were mostly **aged 19+**, and the majority **reached/completed at least secondary school**.



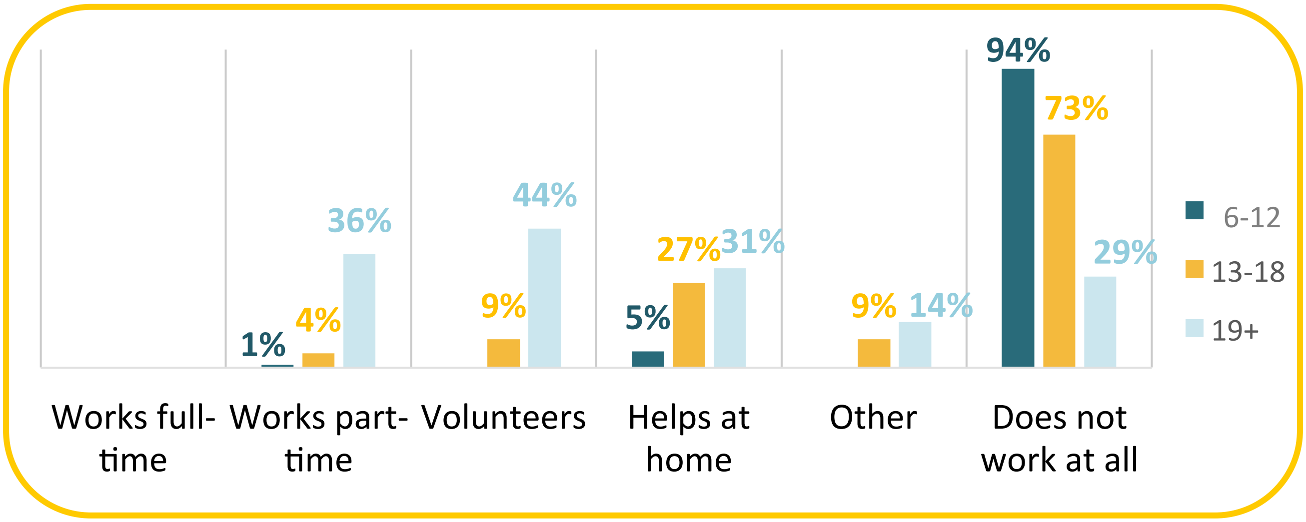
How many individuals *not* currently attending school had a special education attendant?

Of those **aged 19+**, 92% had a special education attendant when they were in school.

Work

Based on their age, how many individuals with DS work/volunteer/help at home?

Of those **aged 13-18**, individuals most commonly **help at home**; those **19+**, individuals most commonly **work part time, volunteer and/or help at home. Note: some individuals selected 2+ categories.**



What are some examples from the 'Other' category?

Creative Work

"My daughter is an artist now. Has worked in the past but not any longer." **age: 46**
"Occasionally sells crafts at neighbourhood craft sale." **age: 22**
"Makes crafts and sells them." **age: 30**

Hands-on Work

"Works in a sheltered workshop." **age: 35**
"Has a paper route and delivers papers two times a week." **age: 12**

Day Programs

"Held a part-time job years ago, but currently attends a day program for adults who developmental disabilities." **age: 54**
"Does shredding for a community center & helps set up tables & chairs for a community coffee house with his day program peers & staff" **age: 23**

Support Systems

How many parents/caregivers are in contact with other individuals with DS in their area?

48% of caregivers of individuals with DS know of other neighbourhood contacts with DS. Caregivers had an average number of **4 neighbourhood contacts**.

How many parents/caregivers belong to a DS parent group in their area?

52% of caregivers belong to a DS parent group, which was most commonly an **in-person group**

In-person/Community Group	*150*	*43%*
Facebook Group	*98*	*28%*
Others (e.g. Lower Mainland Down Syndrome Society, informal)	*19*	*6%*

What are the support systems of individuals with DS?

94% of caregivers of individuals with Down syndrome receive some form of aid

1. ***Family members*** *80%*
2. ***Friends*** *61%*
3. ***Community Professional*** *36%*
4. ***Community volunteer*** *6%*
5. ***Other*** *18%*
    - *Institutional support (e.g. Family Support Institute, DSRF) 6%*
    - *Church 2%*
    - *Parent groups 2%*
    - *Child care & Day programs 2%*

What online resources are used by parents/caregivers of individuals with DS?

60% of caregivers of individuals with Down syndrome use online resources as a source of information, of which **Facebook groups** are the most commonly used.

Facebook Groups 58

DSRF website 43
Canadian DS Society 35
Google Search 27
Lower Mainland DS Society 13
National DS Society 7
General Blogs 7
Edmonton Down Syndrome Society 7
Family Support Institute 6
Special Olympics Canada 4

Alberta Association for community living 1
Medical Publications 2
e-magazines 2
YouTube 2
Wikipedia 3
Noahsdad.com 3
Fraser Valley Down Syndrome Society 3
Simon Fraser Society for Community living 4

Section 2: Diagnoses, Medications, & Supplements

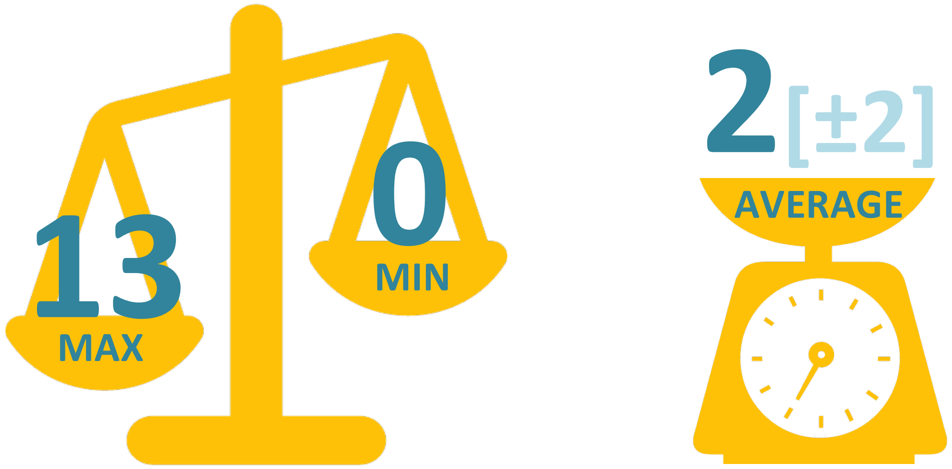
Top 10 diagnoses of individuals with DS:

1. Ophthalmic conditions 46%
2. ENT/Respiratory conditions 39%
3. Cardiovascular conditions 35%
4. Dermatological conditions 34%
5. Endocrine conditions 26%
6. Sleep diagnoses 22%
7. Gastrointestinal conditions 21%
8. Orthopaedics conditions 18%
9. Mental health conditions 14%
10. Neurodevelopmental conditions ~12%

Medications & Supplements

How many individuals with Down syndrome have ever taken medications and/or supplements? 80% of individuals.

Taking Currently 81%
Not currently taking 16%
Did not specify 2%



 # OF MEDICATIONS AND/OR SUPPLMENTS PER INDIVIDUAL

Top medications taken by individuals with DS:

		n=305
THYROID	(e.g. Levothyroxine, Tapazole)	23%
GASTROINTESTINAL	(e.g. Ranitidine, Lansoprazole, Omeprazole)	9%
FALLING ASLEEP	(e.g. Melatonin regular & long acting)	7%
ASTHMA	(e.g. Salbutamol/Albuterol, Advair)	6%
ANTIDEPRESSANT	(e.g. Prozac, Cipralex)	5%
ANTIPSYCHOTICS	(e.g. Risperdal, Quetiapine)	5%
LAXATIVE	(e.g. PEG3350)	4%
NASAL SPRAY	(e.g. Mometasone Fuorate, Fluticasone Fuorate)	4%
HORMONE REGULATION	(e.g. Birth control)	4%
SEIZURES	(e.g. Valproic Acid, Carbamazepine)	3%
HEART	(e.g. Coumadin)	3%
BENZODIAZEPINE	(e.g. Ativan, Atomoxetine)	2%
DIABETES	(e.g. Insulin, Metformin)	2%

As reported by respondents, the following were…

Prescribed for behaviour:

		n=305
STIMULANTS	(e.g. Concerta, Dexedrine)	7%
ANTIPSYCHOTICS	(e.g. Risperdal, Seroquel, Zyprexa)	4%
BLOOD PRESSURE MEDS	(e.g. Clonidine)	1%
OTHER	(e.g. Effexor XR, Ativan, Levothyroxine, Valium)	2%

Prescribed for sleep:

MELATONIN	(e.g. Regular, Long acting)	7%
ANTIPSYCHOTICS	(Seroquel)	1%
ANTIDEPRESSANT	(Trazodone)	1%

Top supplements taken by individuals with DS:

	n=305
VITAMINS (e.g. Vitamin D/C/Biotin/K2)	52%
CALCIUM	12%
IRON	10%
NATURAL THYROID MEDICATION	5%
PROBIOTICS	5%
OMEGAS	3%
FISH OILS	3%
MAGNESIUM	2%
CURCUMIN	1%
ACIDOPHILUS	1%
CoQ10	1%
TAURINE	1%
INULIN	<1%
LACTAID	<1%
ZINC	<1%

Development

Speech-language development:

Individuals with Down syndrome are at “a **great** risk for language difficulties” [1, p. 117]. There are **many** factors contributing to this, including but not limited to: cognitive deficits [2], hearing loss and low muscle tone [3-4], as well as poor oral motor skills [1].

Research has consistently shown that individuals with Down syndrome have **delayed** language [5] and typically experience more difficulties with expressing themselves than understanding speech [2-3, 6-8]. This section adds further evidence to the scientific literature, and also highlights the need for continued research into the speech and language development of individuals with Down syndrome.

Example of difficulties with expressive language:

*“[He] has difficulty with money concepts, number sense, and time sense. This causes **challenges** for him when he is trying to articulate his ideas **cohesively**.”*

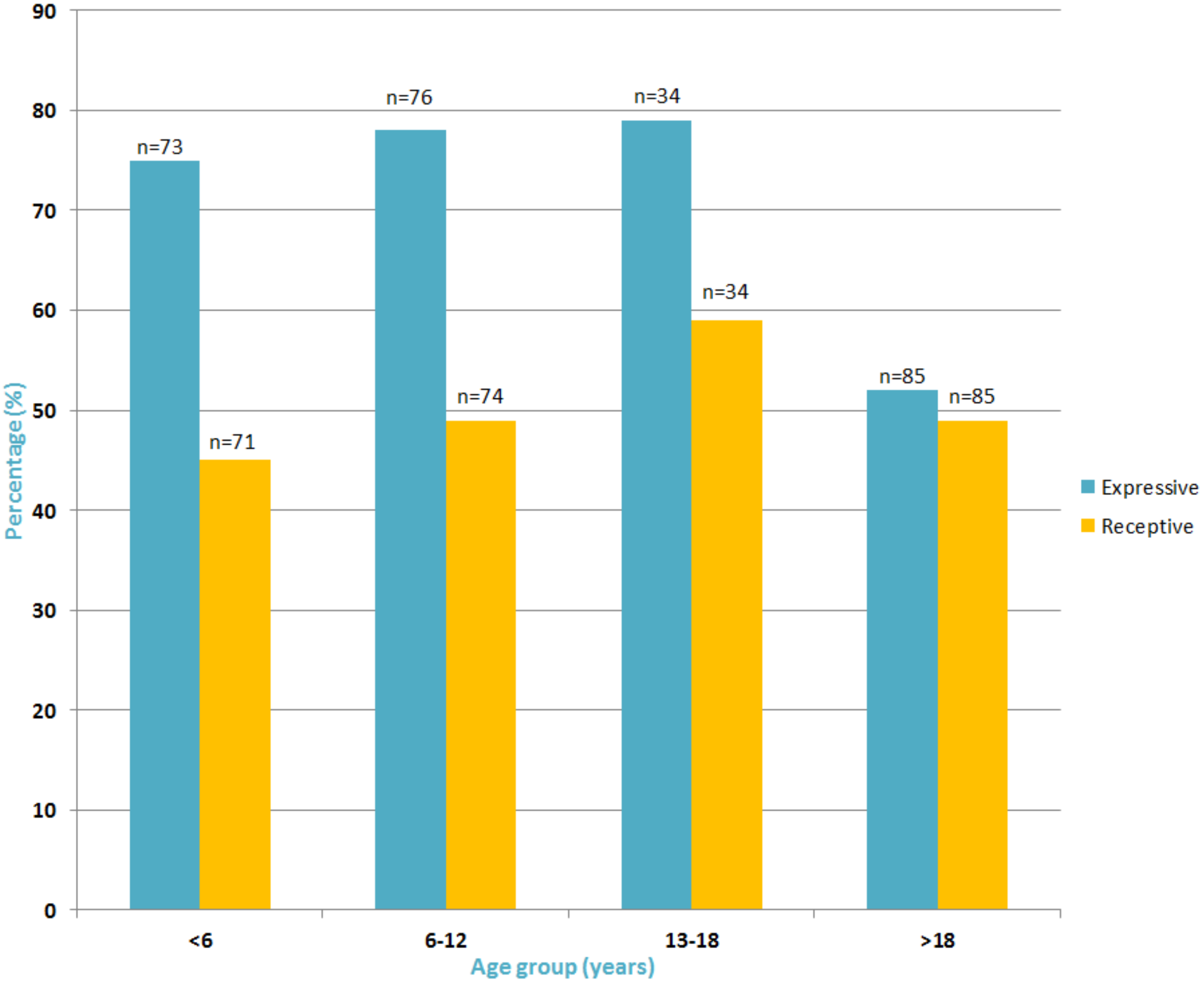
Example of difficulties with expressive language:

*“[His weakness] is with verbal communication due to [a] stroke in the womb. [He] can **understand much better** than [communicating] verbally.”*

76% of individuals with Down syndrome in the survey **experience difficulties** with language. Most individuals with Down syndrome in the survey typically have **more difficulties with expressive language** (ability to put thoughts into words or sentences in a way that makes sense) **than receptive language** (ability to understand or comprehend language which is heard or read).

> *"[He] is 8 and still isn't verbal. [He] **understands a lot** but has **difficulty communicating back**."*

Percentage of individuals who experience difficulties with language



How do individuals with Down syndrome communicate with their parents/caregivers?

	Does gesture (spontaneously or prompted)				
	Age separation: (%)				Average (n=196)*
	<6 yrs (n=65)	6-12 yrs (n=60)	13-18 yrs (n=27)	>18 yrs (n=44)	
Greet	90%	97%	96%	99%	93%
Refuse	92%	92%	89%	80%	88%
Request object or activity	82%	95%	93%	91%	89%
Request information	11%	56%	85%	76%	50%
Request assistance	64%	93%	96%	98%	85%
Request re-occurrence	81%	97%	96%	93%	90%
Acknowledge	42%	80%	82%	78%	67%
Comment	48%	83%	89%	80%	72%

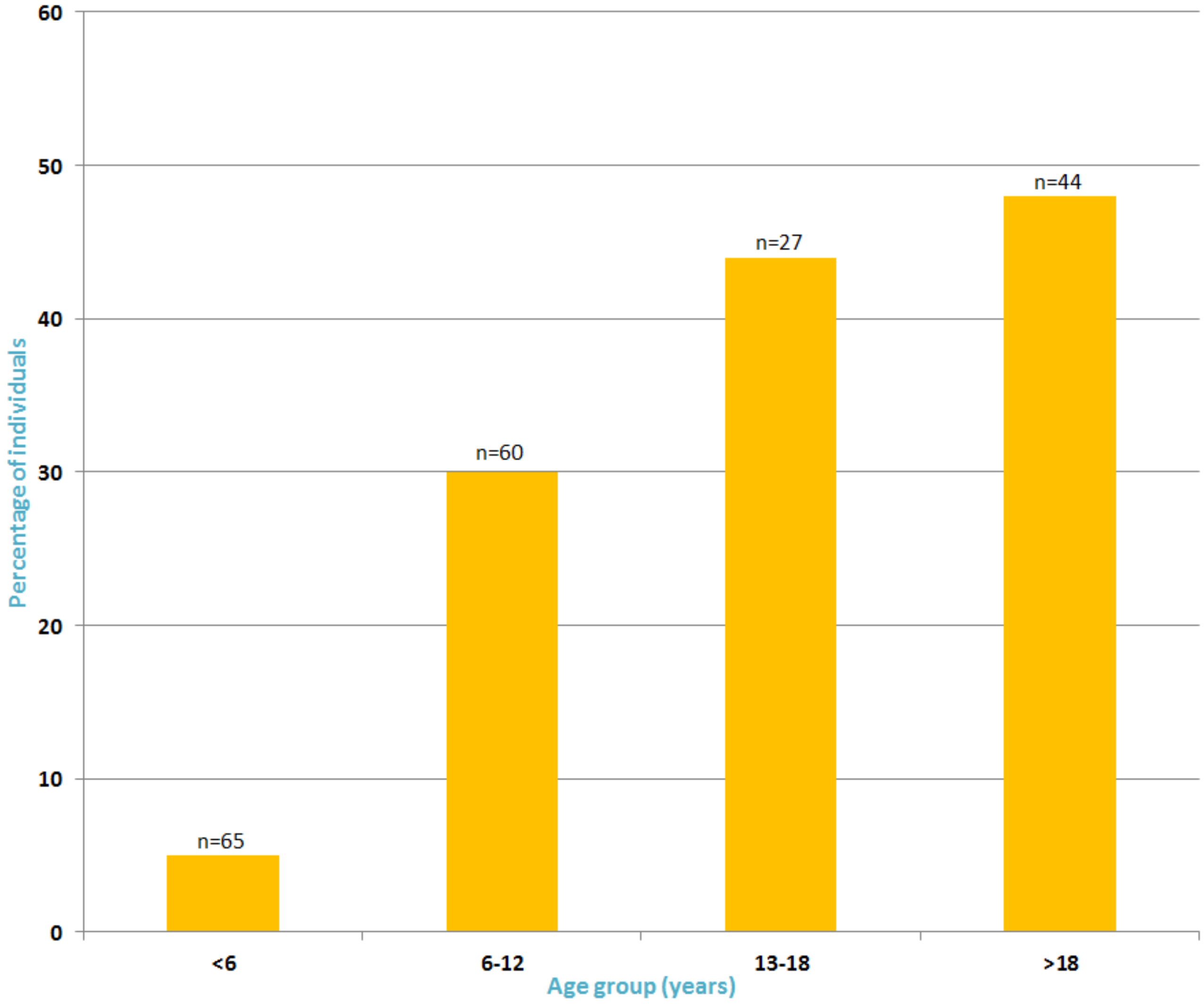
*Please note that not all of the sample sizes are n=196. “Greet” and “Acknowledge” are both n=197, and “Comment” is n=195.

Individuals with Down syndrome communicate with their parents/caregivers in a variety of ways. The top 4 most frequent ways of communicating were:

- **greeting:** 93%
- **requesting re-occurrence:** 90%
- **requesting an object or activity:** 89%
- **refusing:** 88%

> *“[Our] daughter can communicate spontaneously in **all** the ways provided, but **frequently chooses not to**, even if prompted.”*

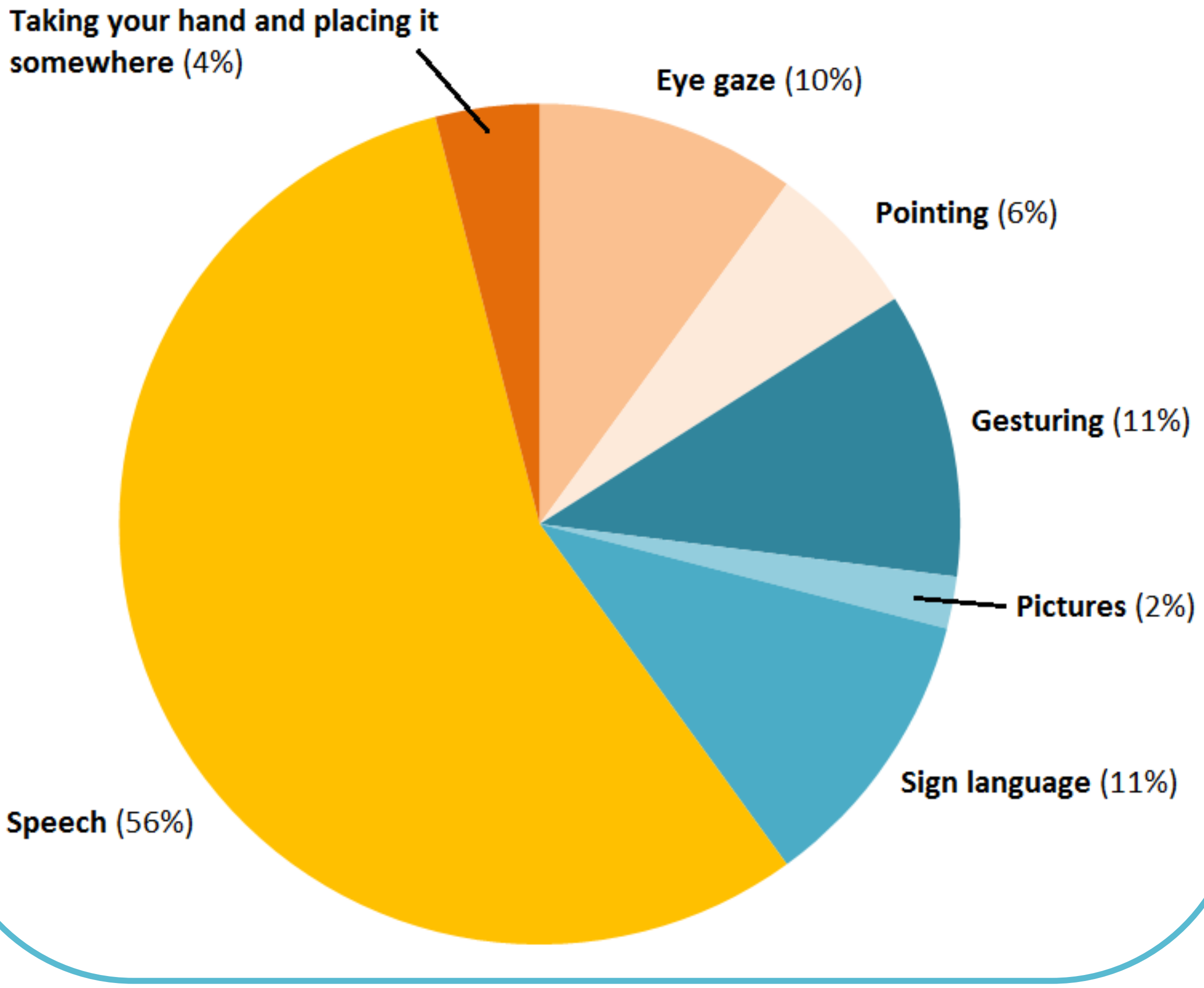
How many individuals with Down syndrome can use 5 or more words in phrases when speaking/signing?



There is an overall **increase** in the number of individuals who can use 5 or more words in phrases when speaking/signing.

"At a little over 2 years old, my son [can] ***recognize*** *the alphabet, [and]* ***say*** *the name of* ***all*** *of the letters and their sounds. He also recognizes* ***over 100*** *sign language signs and can somewhat accurately* ***produce*** *about half of them."*

What are the most common modes of communication used by individuals with Down syndrome? (n=193)



Individuals with Down syndrome **most commonly use speech** to communicate with their parents/caregivers.

> *"She will use* ***phrases*** *taken from* ***books, TV shows, or movies*** *to express herself."*

Compared to other individuals with Down syndrome, parents/caregivers believe their child/youth/adult's overall communicative ability is:

	Age separation: (%)				Average (n=265)
	<6 yrs (n=72)	**6-12 yrs** (n=74)	**13-18 yrs** (n=34)	**>18 yrs** (n=85)	
Worse on average	14%	28%	41%	33%	26%
The same on average	35%	20%	15%	24%	25%
Better on average	33%	35%	32%	42%	37%
Unsure*	18%	16%	12%	1%	11%

*"Unsure" denotes that the parent/caregiver did not know any other individuals with Down syndrome who were of the same (or similar) age as their individuals with Down syndrome at the time of answering this question.

*"Development is overall similar to a typical 4-year-old, but with **significant speech delays**. She however appears to do **better** overall with communication when compared to [others]."*

*"[He] has **good communication skills** for a child with Down syndrome. Difficulty in receptive language is with **questions** [and] expressive language lacks in **providing adequate context** for the listener for the comments that are made."*

The majority of parents/caregivers felt that their child/youth/adult's overall communicative ability is **better** than others of the same (or similar) age.

General development:

Feeding problems in individuals with Down syndrome are recognized as a **concern** in the medical community [9]. Approximately "**31% to 80%** of children with Down syndrome have [difficulties] eating, drinking, and swallowing, which **often persist** into adulthood" [10, p. 52]. Previous research has described feeding problems as very **complex** and noted the underlying causes are not well understood [11].

Also, very little is known about pain perception in individuals with Down syndrome [12], although some researchers found that individuals with Down syndrome typically **rely on others** for pain assessment. The same study also found that parents believe that their "children with Down syndrome are **less sensitive** to pain than their siblings" [13].

Example of feeding difficulties:

*"[My] child is **orally** sensitive to textures."*

Example of pain perception:

*"It is difficult to judge pain tolerance, since he is **nonverbal**, but he seems to **withstand** what others might deem uncomfortable or painful."*

Eating habits of individuals with Down syndrome

	Age separation: (%)				Average (n=265)
	<6 yrs (n=72)	6-12 yrs (n=74)	13-18 yrs (n=34)	>18 yrs (n=85)	
Tube feeding	3%	0%	3%	0%	1%
Needs to be fed	14%	3%	0%	0%	5%
Needs help	31%	8%	9%	1%	12%
Mostly independent	43%	66%	41%	18%	41%
Independent	8%	24%	47%	81%	41%
Unsure	1%	0%	0%	0%	0%

82% of individuals with Down syndrome have **fairly independent** eating habits and only **18%** need some form of help.

Dressing habits of individuals with Down syndrome

	Age separation: (%)				Average (n=265)
	<6 yrs (n=72)	6-12 yrs (n=74)	13-18 yrs (n=34)	>18 yrs (n=85)	
Needs to be dressed	76%	23%	6%	4%	29%
Needs help	18%	61%	29%	18%	31%
Independent	0%	16%	65%	79%	38%
Unsure	6%	0%	0%	0%	2%

60% of individuals with Down syndrome **need some form of help** with dressing themselves compared to **38%** who are fully independent.

When do individuals with Down syndrome have incontinence?

	Age separation: (%)				Average (n=265)
	<6 yrs (n=72)	6-12 yrs (n=74)	13-18 yrs (n=34)	>18 yrs (n=85)	
☼ **Urine (day)**					
Never	18%	38%	74%	78%	50%
Occasionally	18%	39%	15%	18%	23%
Always	46%	32%	13%	5%	22%
Unsure	18%	1%	0%	0%	5%
☾ **Urine (night)**					
Never	18%	43%	71%	85%	53%
Occasionally	10%	23%	12%	8%	13%
Always	6%	32%	15%	6%	28%
Unsure	17%	1%	3%	1%	6%
☼ **Stool (day)**					
Never	22%	53%	76%	76%	55%
Occasionally	14%	30%	15%	19%	20%
Always	46%	16%	9%	5%	20%
Unsure	18%	1%	0%	0%	5%
☾ **Stool (night)**					
Never	31%	65%	79%	91%	66%
Occasionally	15%	22%	12%	5%	13%
Always	38%	12%	6%	4%	15%
Unsure	17%	1%	3%	1%	6%

Most individuals with Down syndrome do **not** have urine incontinence. Of those who do, it most frequently occurs at night. Most individuals with Down syndrome do **not** have stool incontinence. Of those who do, it most frequently occurs during the day.

> *"Nighttime urination is **excessive** (wears pull-up, gets woken up and taken to toilet but still soaks [pajamas], sheets, and mattress pad every night)."*

This quote exemplifies that many of the children were very young, so the incontinence did not apply.

> *"[My] son is **too young** to [play] video games, [use a] computer, or [read, but] he does watch movies. My son is **still in diapers**, so the incontinence is N/A."*

Social interaction skills of individuals with Down syndrome*

	Age separation: (%)				Average (n=265)
	<6 yrs (n=72)	6-12 yrs (n=74)	13-18 yrs (n=34)	>18 yrs (n=85)	
Play with toys	99%	99%	71%	45%	78%
Share with others	71%	89%	71%	51%	69%
Play/interact with others	90%	96%	88%	80%	88%
None of the above	0%	0%	3%	8%	3%
Unsure	0%	0%	0%	6%	2%

*Parents/caregivers were able to select more than one answer for this question.

95% of individuals with Down syndrome exhibited at least one social interaction skill listed above. The most common skill is **interacting with others**.

> *"She keeps herself **very busy** without needing encouragement."*

> *"[Supported] social activities include going to **movie theatre**."*

> *"My child also attends **outings**, **youth group** and **adult group** with the Lower Mainland Down Syndrome Society."*

What sports activities do individuals with Down syndrome participate in?*

	Age separation: (%)				Average (n=265)
	<6 yrs (n=72)	6-12 yrs (n=74)	13-18 yrs (n=34)	>18 yrs (n=85)	
Swimming	63%	88%	88%	88%	81%
Hiking	17%	32%	62%	56%	40%
Biking	17%	41%	44%	40%	34%
Dancing	51%	66%	85%	85%	71%
Yoga	7%	19%	21%	44%	24%
Working out	0%	4%	41%	60%	26%
Other	31%	64%	76%	82%	62%

*Parents/caregivers were able to select more than one answer for this question.

92% of individuals with Down syndrome participate in one of the sports activities listed above, with most participating in **swimming**. Activities that were **not listed** include:

- Special Olympics,
- bowling,
- canoeing,
- horseback riding/equine-assisted therapy,
- gymnastics/rhythmic gymnastics, and
- soccer.

> *"[He] can sometimes go [and] go [and] go **all day long** just running, jumping, yelling/screaming."*

> *"[Physiotherapy] has **helped** a lot with **confidence** in walking, running and climbing [and] daycare has **helped** with social interaction."*

What leisure activities do individuals with Down syndrome participate in?

	0-1 hour				
	Age separation: (%)				Average (n=265)
	<6 yrs (n=72)	6-12 yrs (n=74)	13-18 yrs (n=34)	>18 yrs (n=85)	
TV	57%	31%	35%	22%	36%
Video games	96%	82%	76%	72%	82%
Computer games	92%	84%	76%	72%	81%
Reading	56%	66%*	68%	77%*	67%*

	1 hour or more				
	Age separation: (%)				Average (n=265)
	<6 yrs (n=72)	6-12 yrs (n=74)	13-18 yrs (n=34)	>18 yrs (n=85)	
TV	43%	69%	65%	78%	64%
Video games	4%	18%	24%	28%	18%
Computer games	8%	16%	24%	28%	19%
Reading	44%	34%*	32%	23%*	33%*

*There were 73 responses for the 6-12 yrs group and 84 responses for the >18 yrs group. Consequently, the total sample size for reading is n=262.

37% of individuals with Down syndrome also participate in a leisure activity not listed above, including:

- board and card games,
- drawing,
- music/listening to music,
- singing/karaoke, and
- watching videos/movies.

> *"My daughter belongs to my **garden club** and **participates** in activities with my fellow gardeners. She has also **travelled extensively** with me in England, New Zealand, US, Hawaii, BC, France, Europe, Italy."*

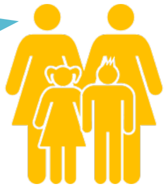
What sensitivities do individuals with Down syndrome have?*

	Age separation: (%)				Average (n=265)
	<6 yrs (n=72)	6-12 yrs (n=74)	13-18 yrs (n=34)	>18 yrs (n=85)	
Sensitive to clothing/textures	17%	30%	56%	35%	30%
Has a high pain tolerance	36%	55%	38%	52%	50%
Likes leg rubs/leg massages	29%	31%	82%	16%	24%
None of the above	35%	28%	15%	29%	29%
Unsure	13%	3%	3%	5%	6%

*Participants were able to choose more than one answer for this question.

65% of individuals with Down syndrome experience at least one of the sensitivities listed above. The most commonly experienced sensitivity is having a **high pain tolerance.**

> *"Our daughter has very **hypersensitive** hearing. She wears **head phones** to muffle sound in many public settings."*



> *"I'm only comparing his **high pain tolerance** to that of his brother. If he is crying for an extended period, I know that it must be really sore. If he cries over a bump, it's usually out of being scared."*

> *"[My] child was diagnosed with **Sensory Processing Disorder**. My child has hypersensitive hearing and taste, and hyposensitive vestibular and proprioceptive senses."*

Sleep/Wake-Behaviours

Definitions

Categorical diagnosis: an official diagnosis that has been confirmed or is suspected/under investigation **by a health care professional.**

Descriptive symptom: a symptom of a diagnosis that has been recognized **by a parent/caregiver.**

Making Comparisons

Categorical Diagnoses	vs.	Descriptive Symptoms
Asked in Section 2: Diagnoses		Asked in Section 4: Sleep/Wake-Behaviours

The following results show that **there is a discrepancy** between the frequency of categorical diagnoses and reported symptoms of sleep problems in **BC, Alberta & Ontario.**

How many individuals with DS have insomnia?

Categorical diagnoses:

***22%** (71 individuals) with DS have a **sleep disorder**:*

Confirmed insomnia 3% n=2

Suspected insomnia 13% n=9

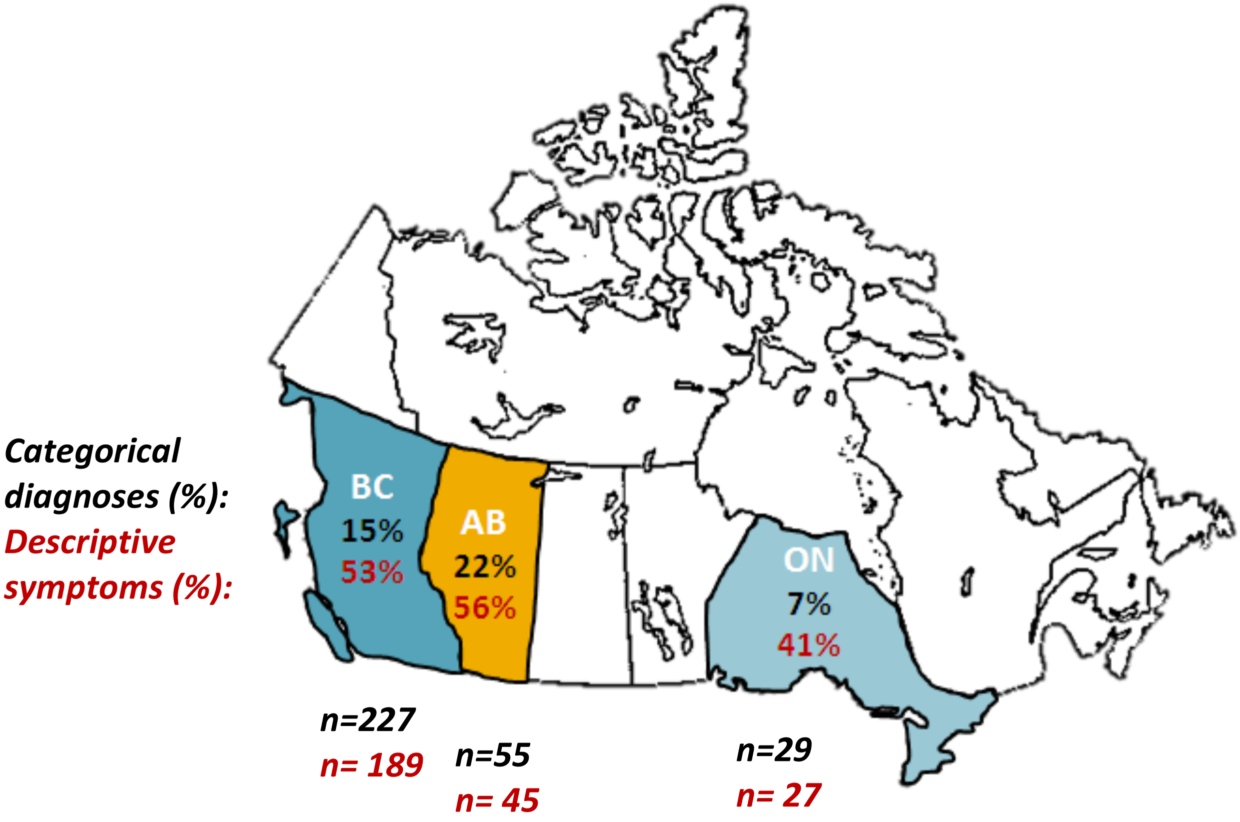
Vs.

Descriptive Symptoms:

***52%** (137 individuals) with DS experience **symptoms of insomnia**:*

1. ***Wakes up during the night*** 46% n=63
2. ***Problems falling asleep*** 23% n= 32

What is the breakdown by province?



How many individuals with DS have parasomnias?

Categorical diagnoses:

22% *(71 individuals) with DS have a* ***sleep disorder****:*

Confirmed parasomnias *2%* n=1

Suspected parasomnias *2%* n=1

Vs.

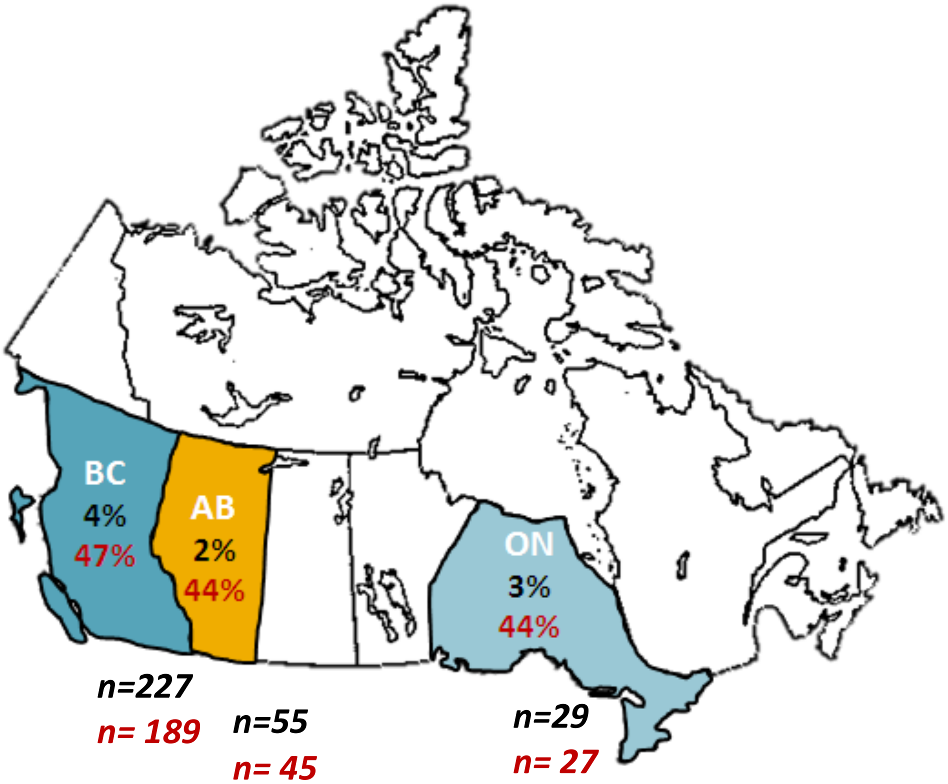
Descriptive Symptoms:

46% *(120 individuals) with DS experience* ***symptoms of parasomnias:***

1. ***Teeth Grinding*** *32%* n=38
2. ***Sleep Talking/Shouting*** *18%* n=2
3. ***Nightmares*** *8%* n=10
4. ***Getting up Confused/Disoriented*** *5%* n=6
5. ***Night Terrors*** *3%* n=4
6. ***Sleep Walking*** *2%* n=2

What is the breakdown by province?

Categorical diagnoses (%):
Descriptive symptoms (%):



How many individuals with DS have sleep disordered breathing?

Categorical diagnoses:

22% *(71 individuals) with DS have a* ***sleep disorder****:*

Confirmed sleep disordered breathing *14%* n=10

Suspected sleep disordered breathing *5%* n=2

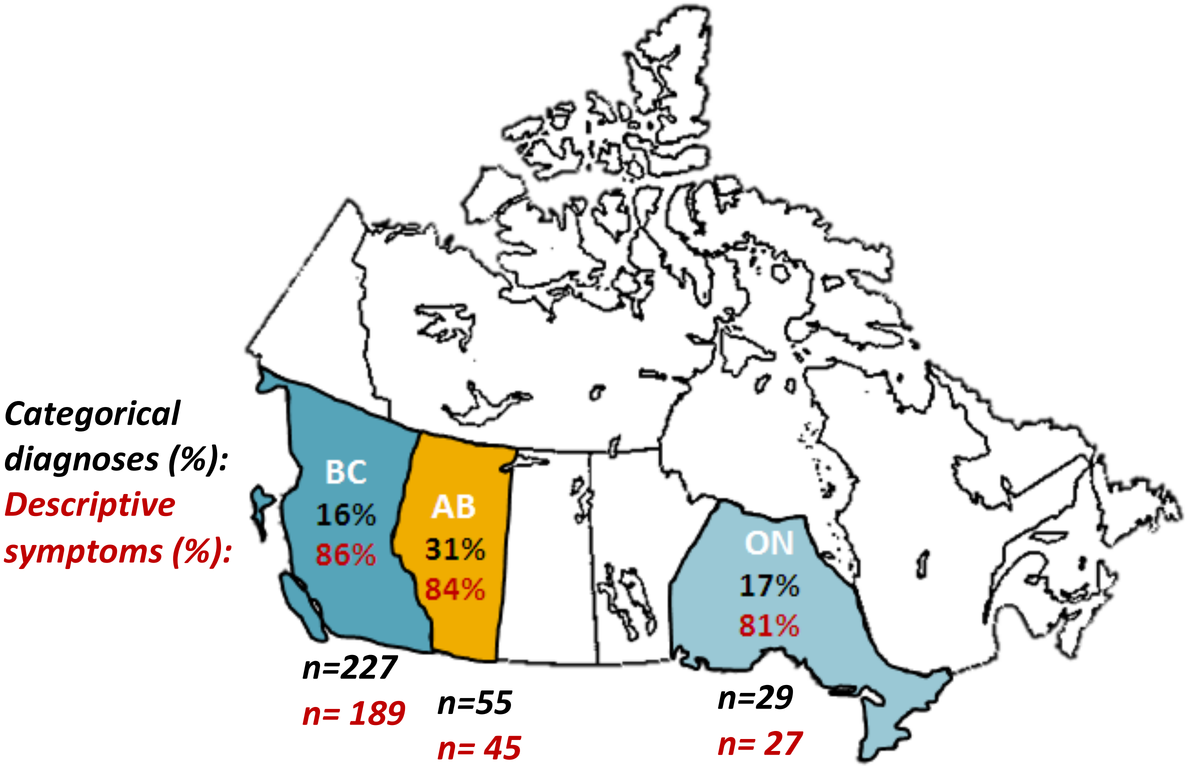
Vs.

Descriptive Symptoms:

85% *(222 individuals) with DS experience* ***symptoms of sleep disordered breathing:***

1. **Mouth breathing** 59% n=131
2. **Snoring during sleep** 54% n=120
3. ***Restless sleep/a lot of movement during sleep*** *43%* n=95
4. ***Breathing pauses during sleep*** *30%* n=67
5. *Bedwetting during sleep* *16%* n=36
6. *Gasping during sleep* *15%* n=33

What is the breakdown by province?



Section 4: Sleep/Wake-Behaviours

How many individuals with DS have a regular sleep/wake schedule? 90%

How many individuals have had a sleep study? 30%

How difficult is it for these individuals with DS to wake up in the morning?

36% Very easy:
50% Easy
11% Difficult
3% Very Difficult

How many individuals are overtired or sleepy over the day? 29%

How many individuals are hyperactive during the day? 8%

How did parents/caregivers rate the quality of life of individuals with DS?

32% said would increase
With improved sleep

Currently

With improved sleep

How did parents/caregivers rate the quality of life of individuals with DS?

29% said would increase
With improved sleep

Currently

With improved sleep

> *“**I wish we would have been able to do a sleep study years ago**. Our daughter could sometimes groan for hours in the night. When she started **groaning AND teeth grinding we got her a mouth guard** which she loves to wear and it has **helped a lot!** So the **quality of life values were a lot lower back then!!!**”*

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