

## Parents of children with Down syndrome – a survey about your encounter with the health service

### Introduction

#### Dear parents

**You have consented to participate in a survey that focuses on your child who is diagnosed with Down syndrome, and on how you have perceived your encounter with the health service in this context.**

**We greatly appreciate your participation and hope that your answers can help ensure that children and adolescents with Down syndrome can be better taken care of in the future.**

#### Thanking you in advance

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**Hedmark Habilitation Service**

**The Norwegian Network for Down Syndrome**

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### Background questions

**This section contains some background questions about your child.**

**\* 1. How old is your child?**

- |  |                                   |
|--|-----------------------------------|
| <input type="radio"/> 0-3 years              | <input type="radio"/> 10-12 years |
| <input type="radio"/> 4-6 years              | <input type="radio"/> 13-17 years |
| <input type="radio"/> 7-9 years              |                                   |
| <input type="radio"/> Other (please specify) |                                   |

**\* 2. Do you have a daughter or a son?**

- ☐ Daughter
- ☐ Son

**\* 3. Does your child have any secondary diagnoses? Put a cross for all that apply.**

- |   |   |
|---|---|
| <input type="checkbox"/> No secondary diagnoses             | <input type="checkbox"/> Ear, nose or throat problems |
| <input type="checkbox"/> Heart defect                       | <input type="checkbox"/> Sleep apnoea                 |
| <input type="checkbox"/> Epilepsy                           | <input type="checkbox"/> Gastrointestinal problems    |
| <input type="checkbox"/> Autism                             | <input type="checkbox"/> Slow metabolism              |
| <input type="checkbox"/> Any other, please describe briefly |   |

**\* 4. How old was your child when he/she was able to walk without support?**

- |  |   |
|--|---|
| <input type="radio"/> Before the age of 1                      | <input type="radio"/> Between 3 and 5 years |
| <input type="radio"/> At 12–18 months                          | <input type="radio"/> After the age of 5    |
| <input type="radio"/> At 19–24 months                          | <input type="radio"/> Cannot walk unaided   |
| <input type="radio"/> Over the age of 2, but less than 3 years |   |

**\* 5. How does your child communicate best?**

By 'alternative and supplementary communication (ASC)' we mean sign-to-speech, graphic signs, tactile/material signs and/or hand gestures.

- ☐ Speaks well enough (good verbal skills), does not use ASC
- ☐ Speaks, but also uses ASC
- ☐ Able to express needs, otherwise little verbal language
- ☐ Normally unable to express needs

**\* 6. Does your child independently initiate activities that he/she is fond of? By activities we mean play, being outside, visiting people etc.**

- ☐ Yes
- ☐ Sometimes
- ☐ No

\* 7. How would you describe your child's level of physical activity?

- ☐ Very active
- ☐ Active
- ☐ Largely inactive

Describe briefly if needed

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### Health services

**In this section, we will focus more on questions about your experiences with the health service.**

\* 8. Approximately how many times per year do you go to check-ups/examinations in the health service?

	0-2	3-5	6-10	> 10
GP/primary health service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paediatrician/habilitation service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other specialties (e.g. cardiologist ear, nose and throat specialist etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 9. Have you received genetic counselling?

By this we mean a consultation with a doctor/counsellor in a department of genetics.

- ☐ Yes, before our child was born
- ☐ Yes, but after the child was born
- ☐ No

\* 10. Is your child being followed up with regular check-ups of:

	Yes	No	Don't know
Endocrine disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hearing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 11. In general, how satisfied are you with the follow-up provided by the health service?

	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied
GP/primary health service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paediatrician/habilitation service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other specialties (e.g. ear,nose and throat, vision etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 12. What is your impression of the level of knowledge about Down syndrome in the health service?

	Very good	Good	Neutral	Poor	Very poor
GP/primary health service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paediatrician/habilitation service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other specialties (e.g. ear, nose and throat, vision etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 13. How do you assess the provision of follow-up in the following medical areas in the health service? (consider the primary and specialist health services overall).

	Very good	Good	Neutral	Poor	Very poor	No need for consultation regarding this
Sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Puberty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gastrointestinal and nutrition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ear, nose and throat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Epilepsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heart	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Endocrine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vision/eyes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other, please describe briefly

**\* 14. Have you had any negative experiences in your encounters with the health service, and if yes, what do you believe have been the main reason(s)?**

	Attitudes	Knowledge level	Both attitudes and Knowledge level	Have had no negative Experiences
GP/primary health service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paediatrician/habilitation service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other specialties (e.g. ear, nose and throat, vision etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**\* 15. Has the diagnosis of Down syndrome ever caused your child not to receive the treatment that you felt that he/she needs?**

	Yes	No	Uncertain
GP/primary health service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paediatrician/habilitation service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other specialties (e.g. ear, nose and throat, vision etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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## Some final questions

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**\* 16. In which health regions does your child receive his/her primary follow-up and treatment?**

- ☐ South-Eastern Norway Health Authority
- ☐ Western Norway Health Authority
- ☐ Central Norway Health Authority
- ☐ Northern Norway Health Authority

Please add a comment if necessary

**\* 17. Who completed this questionnaire?**

☐ Mother

☐ Father

☐ Both

**18. Free-text field – feel free to add comments or feedback to the survey here**

## Thank you for participating in our survey!

The results will be summarised and presented as a master's degree thesis in medical studies at the University of Tromsø, and will also be presented on the website of the Norwegian Network for Down Syndrome.