



LUND
UNIVERSITY

Digital healthcare use during the COVID-19 pandemic among people with intellectual disabilities compared to the general population (IDcare)

MAGNUS SANDBERG. RN. ASSOCIATE PROFESSOR. DARREN CHADWICK. PROFESSOR.
ANNA AXMON. ASSOCIATE PROFESSOR



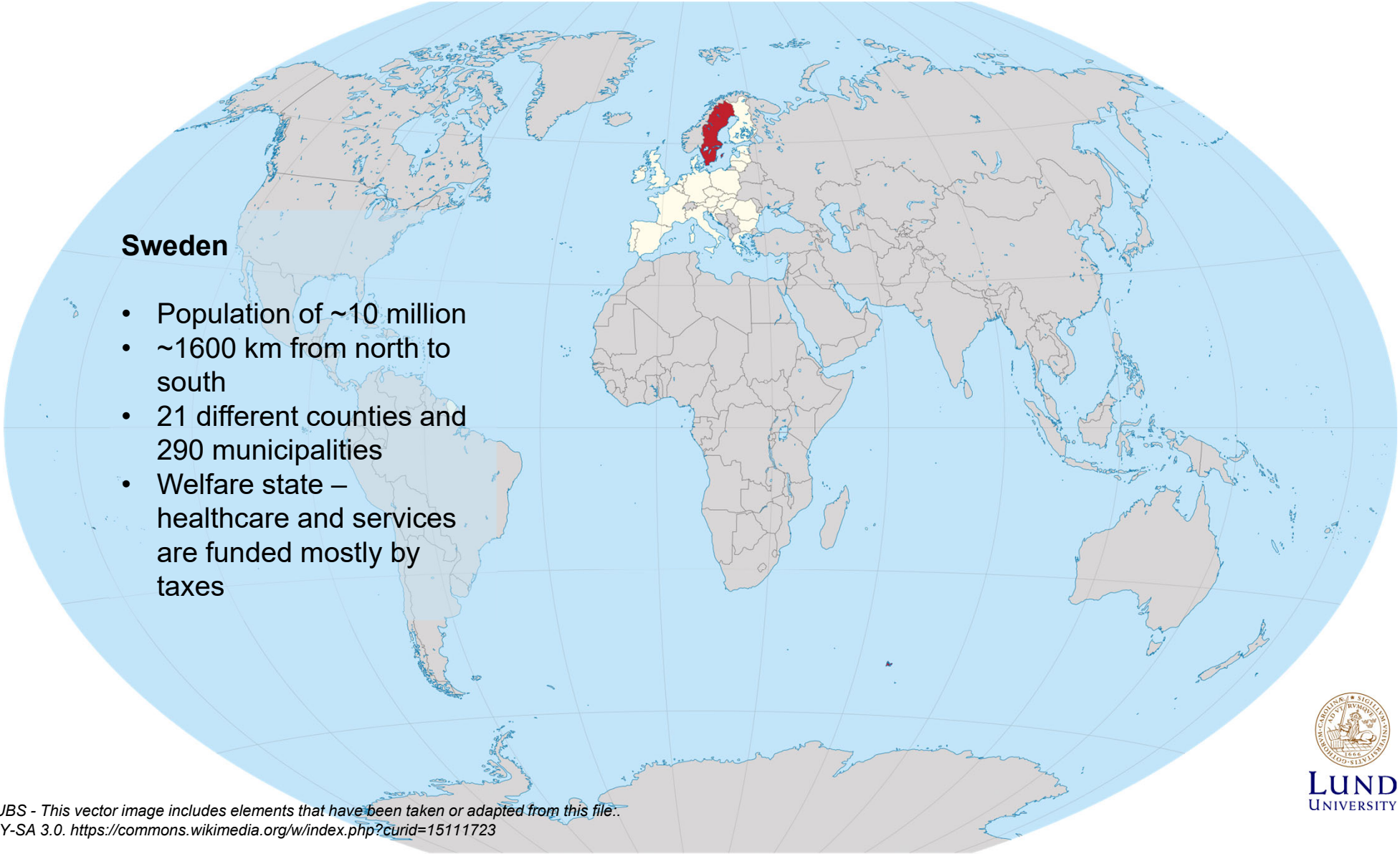
Funding and competing interests

- The project is funded by the Swedish Research Council for Health, Working Life and Welfare (Forte) (grants 2019-00105 and 2021-01862)
- We have no relevant financial or non-financial competing interests. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the funder.

FORTE:

Swedish Research Council for
Health, Working Life and Welfare

The presentation will be available at
<https://portal.research.lu.se/en/projects/health-care-utilization-in-primary-and-specialist-care-among-peop/>



Sweden

- Population of ~10 million
- ~1600 km from north to south
- 21 different counties and 290 municipalities
- Welfare state – healthcare and services are funded mostly by taxes

By TUBS - This vector image includes elements that have been taken or adapted from this file:
CC BY-SA 3.0. <https://commons.wikimedia.org/w/index.php?curid=15111723>



LUND
UNIVERSITY

Skåne

- Population of ~1.2 million
- ~140 km from north to south
- Rural and urban areas
- 13 cities



LUND
UNIVERSITY

By Lokal_Profil - Based on SWE-Map Län2007.svg by Lokal_Profil and coloured similar to Svcmap blekinge.png.
CC BY-SA 2.5. <https://commons.wikimedia.org/w/index.php?curid=1930194>

Acts governing healthcare and services

The Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)

- All ages
- Municipalities' responsibility

The Health and Medical Services Act

- All ages
- County councils' responsibility

The Social Services Act

- For various groups (mostly children and persons 65+ years)
- Municipalities' responsibility



Provision of care. support and services

County Councils* (n=21)	Municipalities* (n=290)
Treatment, rehabilitation, and specialized medical inpatient care	Social support and services
Treatment, rehabilitation, and specialized medical outpatient care	Nursing homes/special accommodations
Primary care	Nursing home healthcare
Physician home healthcare	

* Could be provided by private care/service providers under contract with County Council/Municipality

Support and services according to LSS

Counselling and other personal support

Personal assistance

Companion service

Contact person

Relief service in the home

Short stay away from home

Daily activities

Residence with special services for adults or other specially adapted housing

Short period of supervision for school children over the age of 12

Living arrangements in a family home or in a residence with special services for children and adolescents



LUND
UNIVERSITY

Linking of register data

Personal identity numbers

- Everyone who is registered as a resident in Sweden receives a personal identity number as an identifier
- The number comprises date of birth (yymmdd) and four additional numbers (two to identify birth county, one to identify sex, and one checksum)
- Same number whole life
- Used for communication between government authorities, private companies, other organizations, and citizens

National and regional registers

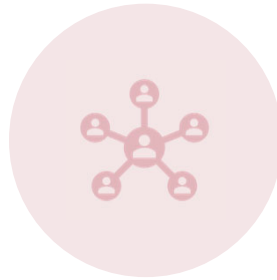
- Population based registers maintained by government and county authorities
- Inclusion is not optional



The LSS register



INFORMATION ABOUT ALL SERVICES
PROVIDED ACCORDING TO THE LSS
ACT



ENABLES DISTINCTION OF SERVICES
PROVIDED TO PEOPLE WITH "WITH
DEVELOPMENTAL DISABILITIES.
AUTISM OR AUTISM-LIKE
CONDITIONS"



NO DIAGNOSES RECORDED



LUND
UNIVERSITY

Skåne healthcare register (SHR)



PUBLIC AND PRIVATE
HEALTHCARE (SOMATIC AND
PSYCHIATRIC)



PRIMARY AND SECONDARY
HEALTHCARE



DIAGNOSES ACCORDING TO ICD-
10 (NOT FOR PRIVATE CARE
PROVIDERS) AND ADMISSION AND
DISCHARGE DATES



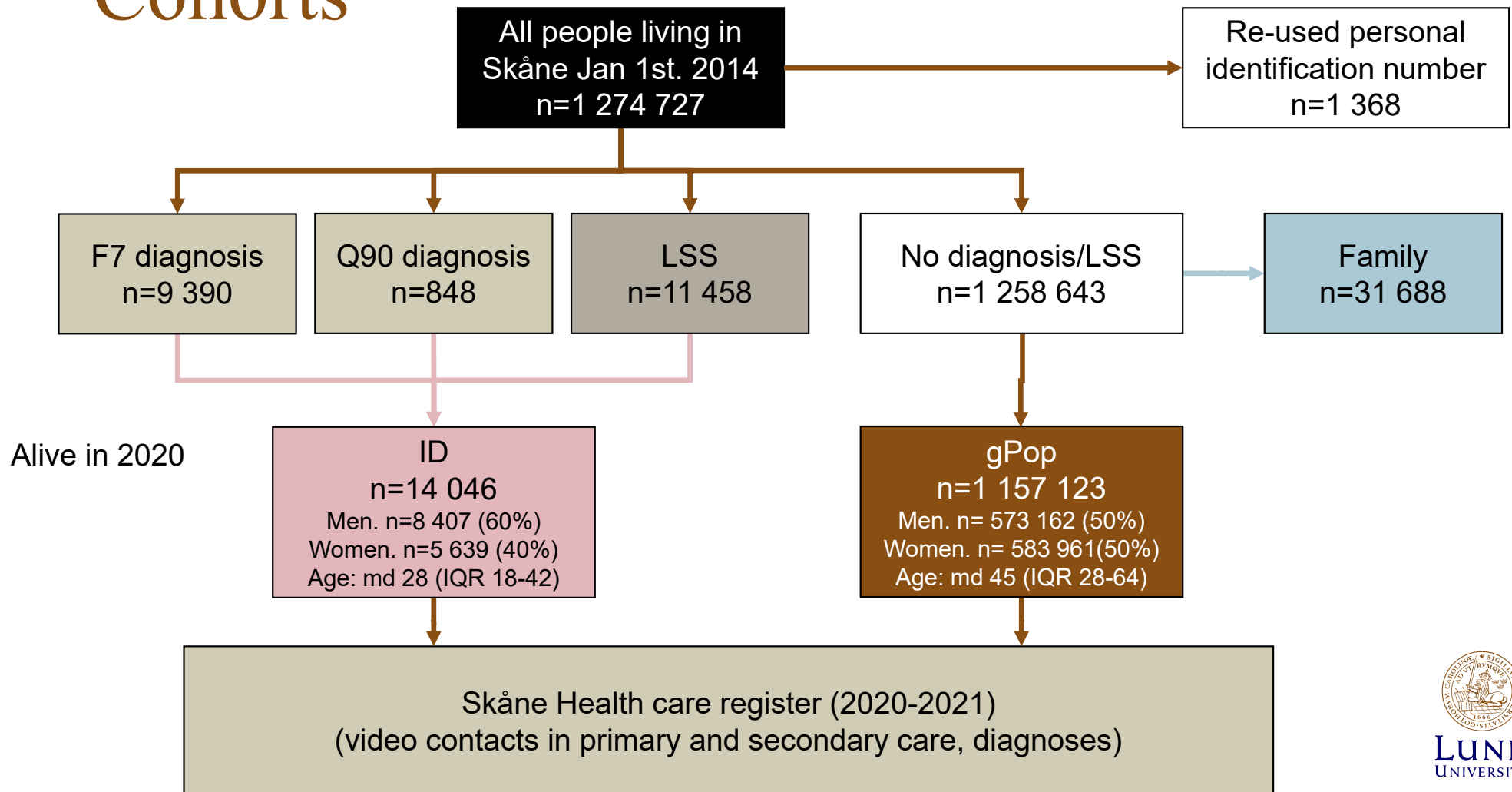
LUND
UNIVERSITY

Aim

- To explore to what extent people with intellectual disabilities in Sweden utilize video-conferencing as part of their healthcare compared to the general population.



Cohorts



Ethical considerations

- Ethical approval from Swedish Ethical Review Authority
- Additional secrecy review by Statistics Sweden and Swedish National Board of Health and Welfare before providing the data.
- Pseudonymized data.
- No presentations of groups <5.



Outcomes

- Registered video contact with physician, nurse, mental health professional (counsellor, psychologist, or psychotherapist), speech therapist, dietician, or physio- or occupational therapist.
- Those with at least one such contact
- Among those, the number of contacts



The ID cohort

- Registered severity of ID according to ICD-10 (most severe 2014-2021):
 - Mild ID: 28% (n=3 873)
 - Moderate: 8% (n=1 062)
 - Severe: 3% (n=387)
 - Profound: 1% (n=187)
 - “Unknown” or “other” ID: 24% (n=3 409)
- No registered severity: 37% (n=5 128)
- In addition 780 people had at least one diagnosis of Down syndrome.

Top five reasons for contact (ICD-10)

ID		gPop	
Prevalence (%)	Diagnosis	Prevalence (%)	Diagnosis
4.2	Pervasive developmental disorders (F84)	4.5	Anxiety disorders (F41)
4.0	Other anxiety disorders (F41)	3.9	Essential (primary) hypertension (I10)
3.0	Hyperkinetic disorders (F90)	2.6	Persons encountering health services in other circumstances (Z76)
2.6	Persons encountering health services in other circumstances (Z76)	2.2	Pain, not elsewhere classified (R52)
1.8	persons encountering health services for other counselling and medical advice, not elsewhere classified (Z71)	1.8	persons encountering health services for other counselling and medical advice, not elsewhere classified (Z71)

Results – overall 2020/2021

People with ID

21%

n = 2,961

Had at least one
video contact

vs

General Population

25%

n = 291,315

Had at least one
video contact

Relative Risk (RR)

0.84

95% CI 0.81–0.87

16% lower likelihood
in people with ID



LUND
UNIVERSITY

Video Contacts in Specialist Outpatient Care among People with Intellectual Disabilities (ID) Compared to the General Population (gPop)

Number of contacts and relative risk (RR) with 95% confidence interval (CI), 2020 vs 2021



More video contacts in 2021

Across all professions, video contacts increased from 2020 to 2021.



Highest likelihood (ID vs gPop)

Doctors showed the highest likelihood of video contact among people with ID compared to the general population (RR 5.85 in 2020; RR 5.41 in 2021).



Most video contacts

Doctors had the largest number of video contacts in both 2020 and 2021.



Largest increase in volume

Mental health professionals had the largest increase in the number of video contacts from 2020 to 2021.

Profession	Year	gPop n (%)	ID n (%)	ID vs gPop (RR 95% CI)	
				At least one contact	Number of contacts
Dietician	2020	–	–	–	–
	2021	243 (0.0)	9 (0.1)	3.05 (1.57–1.93)	2.77 (1.48–5.21)
Doctor	2020	1070 (0.1)	76 (0.5)	5.85 (4.64–7.38)	5.91 (4.78–7.31)
	2021	2940 (0.3)	193 (1.4)	5.41 (4.67–6.26)	6.04 (5.34–6.84)
Mental health professional	2020	1229 (0.1)	41 (0.3)	2.75 (2.01–2.36)	2.56 (2.02–3.23)
	2021	6161 (0.5)	150 (1.1)	2.01 (1.71–2.36)	1.69 (1.53–1.86)
Nurse	2020	816 (0.1)	52 (0.4)	5.25 (3.97–6.95)	4.27 (3.30–5.52)
	2021	2903 (0.3)	123 (0.9)	3.49 (2.91–4.18)	2.77 (2.44–3.14)
Physio/occupational therapist	2020	–	–	–	–
	2021	489 (0.0)	8 (0.1)	1.35 (0.67–2.71)	0.78 (0.42–1.45)
Speech therapist	2020	–	–	–	–
	2021	–	–	–	–

Notes: Values are number (percentage) unless otherwise stated.
Bold values indicate statistically significant relative risks.
 RR = relative risk, CI = confidence interval.

Source: Specialist outpatient care data, 2020–2021.



LUND
UNIVERSITY

Video Contacts in Primary Care among People with Intellectual Disabilities (ID) Compared to the General Population (gPop)

Number of contacts and relative risk (RR) with 95% confidence interval (CI), 2020 vs 2021



More video contacts in 2021

Across all professions, video contacts increased from 2020 to 2021.



Lower likelihood (ID vs gPop)

People with ID had a lower likelihood of video contact than the general population for all professions except Dietitians.



Most video contacts

Doctors had the largest number of video contacts in both 2020 and 2021.



Largest increase in volume

Doctors showed the largest increase in the number of video contacts from 2020 to 2021.

Profession	Year	gPop n (%)	ID n (%)	ID vs gPop (RR 95% CI)	
				At least one contact	Number of contacts
Dietician	2020	234 (0.0)	14 (0.1)	4.93 (2.87–8.45)	6.91 (4.60–10.40)
	2021	261 (0.0)	13 (0.1)	4.10 (2.35–7.16)	2.97 (1.80–4.89)
Doctor	2020	104 616 (9.0)	938 (6.7)	0.74 (0.69–0.79)	0.84 (0.80–0.88)
	2021	145 277 (12.6)	1320 (9.4)	0.75 (0.71–0.79)	0.81 (0.78–0.84)
Mental health professional	2020	5 041 (0.4)	53 (0.4)	0.87 (0.66–1.14)	0.68 (0.56–0.82)
	2021	9 521 (0.8)	82 (0.6)	0.71 (0.57–0.88)	0.45 (0.39–0.53)
Nurse	2020	65 384 (5.7)	546 (3.9)	0.69 (0.63–0.75)	0.81 (0.76–0.86)
	2021	101 981 (8.8)	846 (6.0)	0.68 (0.64–0.73)	0.79 (0.76–0.83)
Physio/occupational therapist	2020	1 286 (0.1)	9 (0.1)	0.58 (0.30–1.11)	0.46 (0.24–0.89)
	2021	2 218 (0.2)	21 (0.1)	0.78 (0.51–1.20)	0.77 (0.53–1.11)
Speech therapist	2020	–	–	–	–
	2021	–	–	–	–

Notes: Values are number (percentage) unless otherwise stated.
Bold values indicate statistically significant relative risks.
 RR = relative risk, CI = confidence interval.

Source: Primary care data, 2020–2021.



LUND
UNIVERSITY

Conclusions, clinical implications and further research

- Except for dieticians, digital healthcare for people with ID seems to be less implemented in primary care compared to outpatient specialist care
- The reason might be that specialist outpatient care within hospitals experienced demands for social distancing differently from primary care facilities located in community settings
- They might have been exposed to an unnecessary COVID-19 risk as they overall did more physical visits than the general population
- Further research is needed to investigate if video contacts were evenly implanted across specialist settings and, to see if it differed between people with different degrees of ID, and/or of different age and sex.
- Also planning to stratify with respect to those that also had physical visits vs. those with video contacts only
- We will also have the possibility the investigate the pattern for post-COVID years (2022-2025).



LUND
UNIVERSITY

magnus.Sandberg@med.lu.se

