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IDcare: Cohort profiles

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IDcare – a longitudinal register study of pre-pandemic and pandemic diagnostic profiles among people with intellectual disabilities: A cohort profile

The presentation will be available at
<http://www.lupop.lu.se/IDcare>



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Sweden

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

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Skåne

- Population of ~1.2 million
- ~140 km from north to south
- Rural and urban areas
- 13 cities
- 120 inhabitants/km²

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 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



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

Quality registers

- For a particular diagnosis or treatment
- Run in collaboration with healthcare providers
- Inclusion is optional



Registers

National Board of Health and Welfare

- **National Register of Municipal Support and Service for Persons with Certain Functional Impairment (LSS)**
- National Cause of Death Register (CoD)

Region Skåne (Skåne County Council)

- **Skåne Healthcare Register (SHR)**

Statistics Sweden

- Various registers containing sociodemographic data

Public Health Agency of Sweden

- National Vaccination Register (NVR)

Quality registers

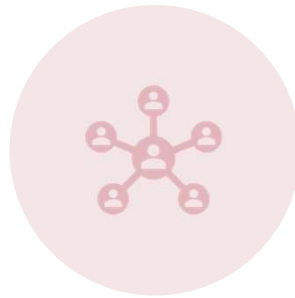
- The Swedish Intensive Care Register (SIR)
- The Swedish Register of Palliative Care (SPC)



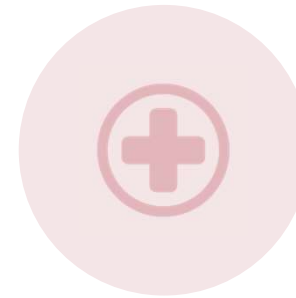
The LSS register



INFORMATION ABOUT ALL SERVICES PROVIDED ACCORDING TO THE LSS ACT



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



NO DIAGNOSES RECORDED



Skåne healthcare register (SHR)



PUBLIC AND PRIVATE
HEALTHCARE



PRIMARY AND SECONDARY
HEALTHCARE



DIAGNOSES ACCORDING TO
ICD-10 (NOT FOR PRIVATE
CARE PROVIDERS)



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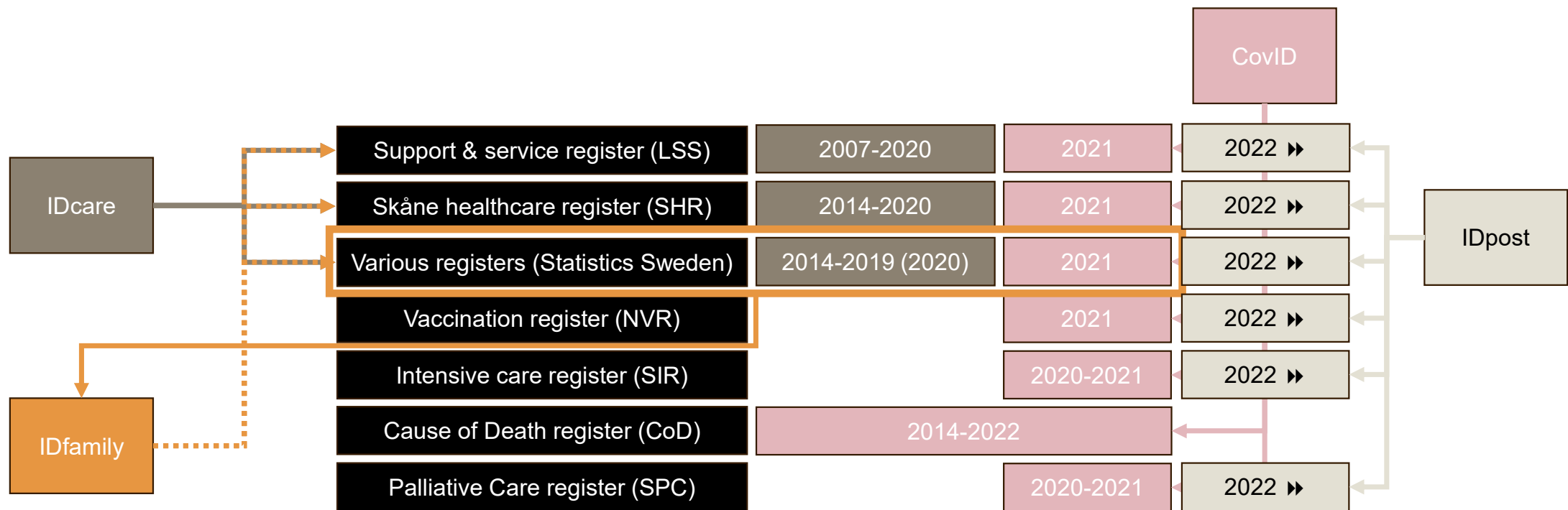
ICD-10

- World Health Organization's International Statistical Classification of Diseases and Related Health Problems - 10th Revision
- Twenty-two chapters of codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases.
- Each chapter has underlying "blocks" followed by specific diagnosis. Sometimes additional information is added with additional numbers.

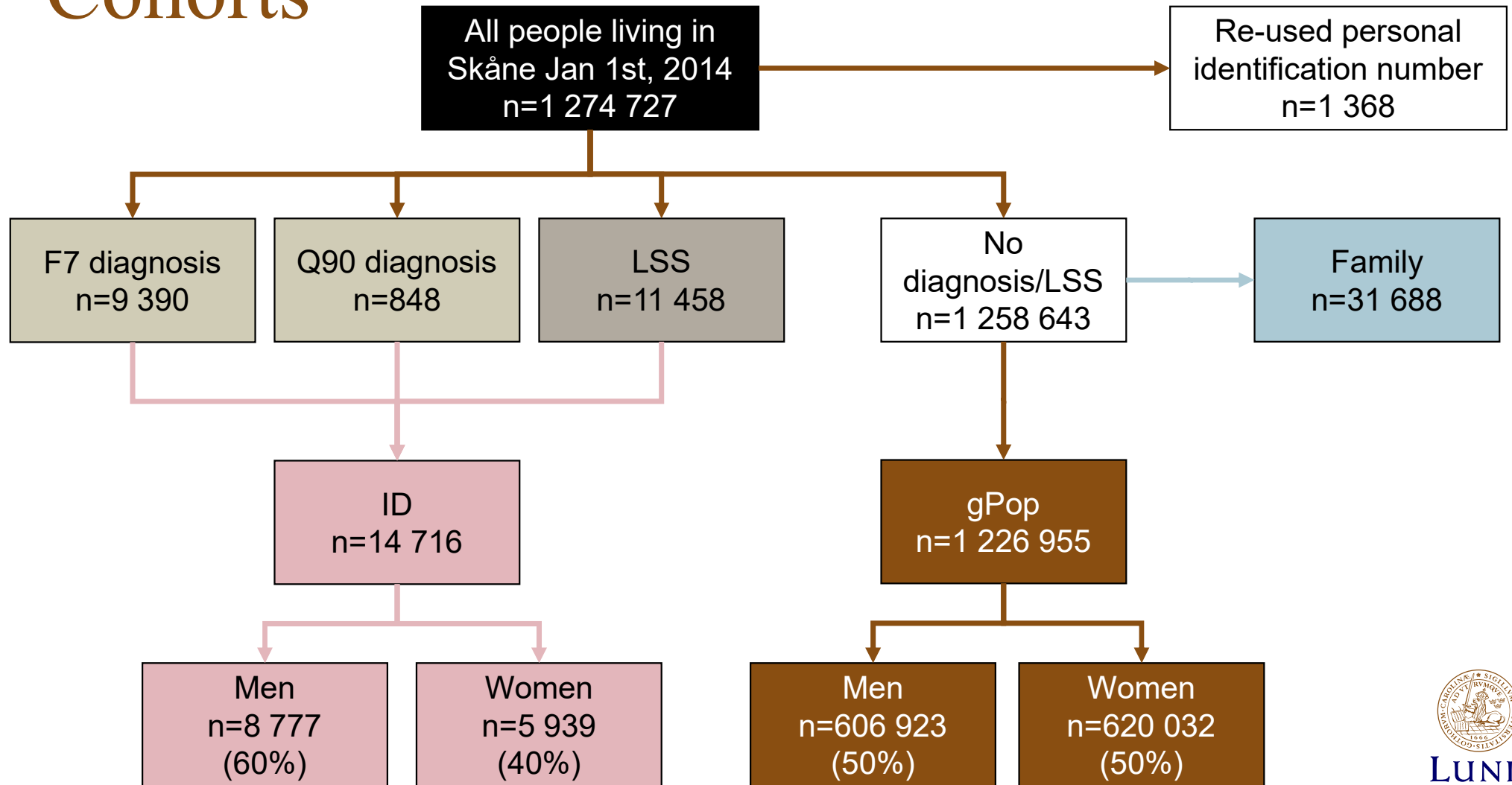
Chapter	Block	Diagnosis	Specified
Chapter VI Diseases of the nervous system (G00-G99)	Other degenerative diseases of the nervous system (G30-G32)	G30 Alzheimer disease	G30.0 Alzheimer disease with early onset



Past, current and future data collection



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 .

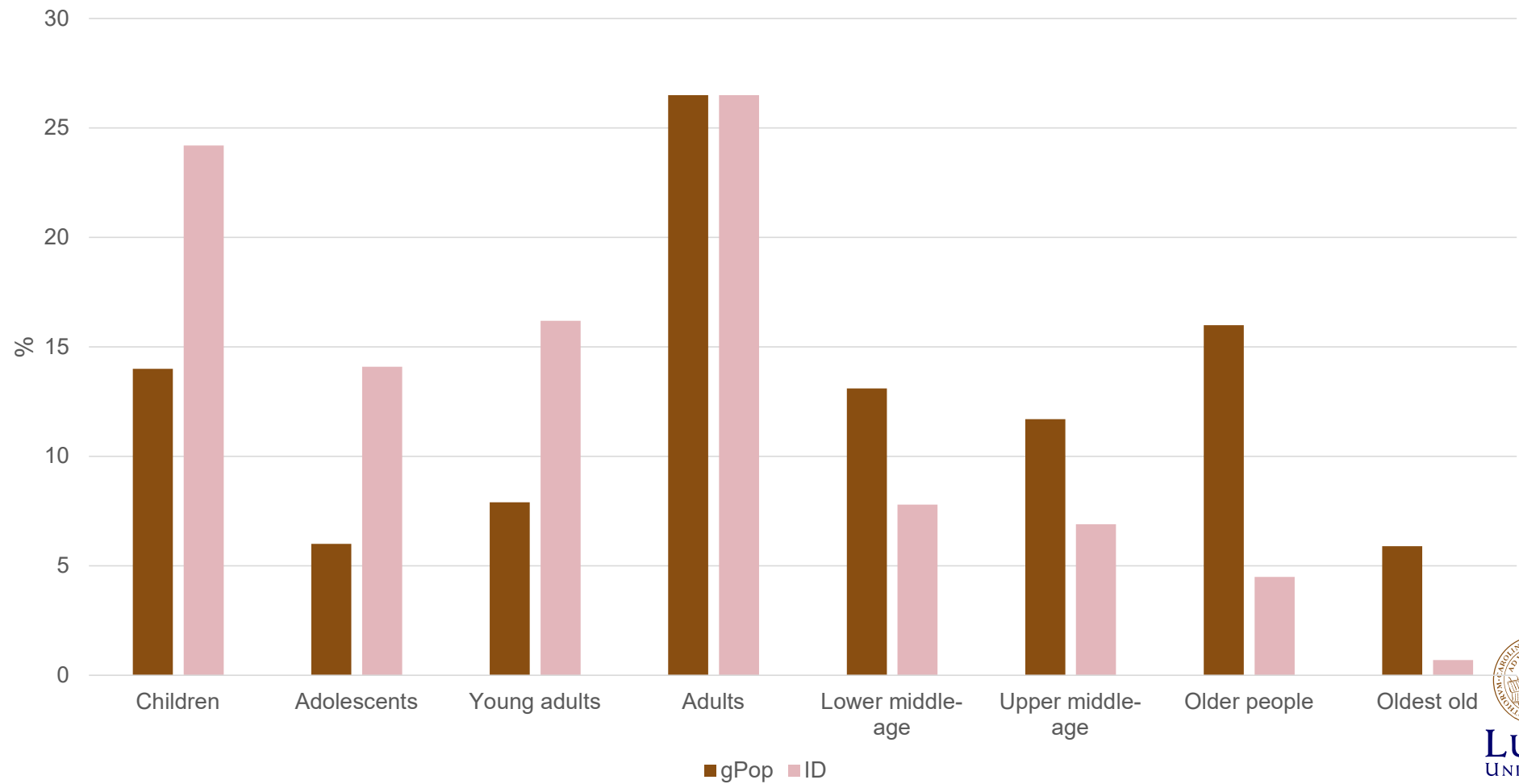


Age categorization

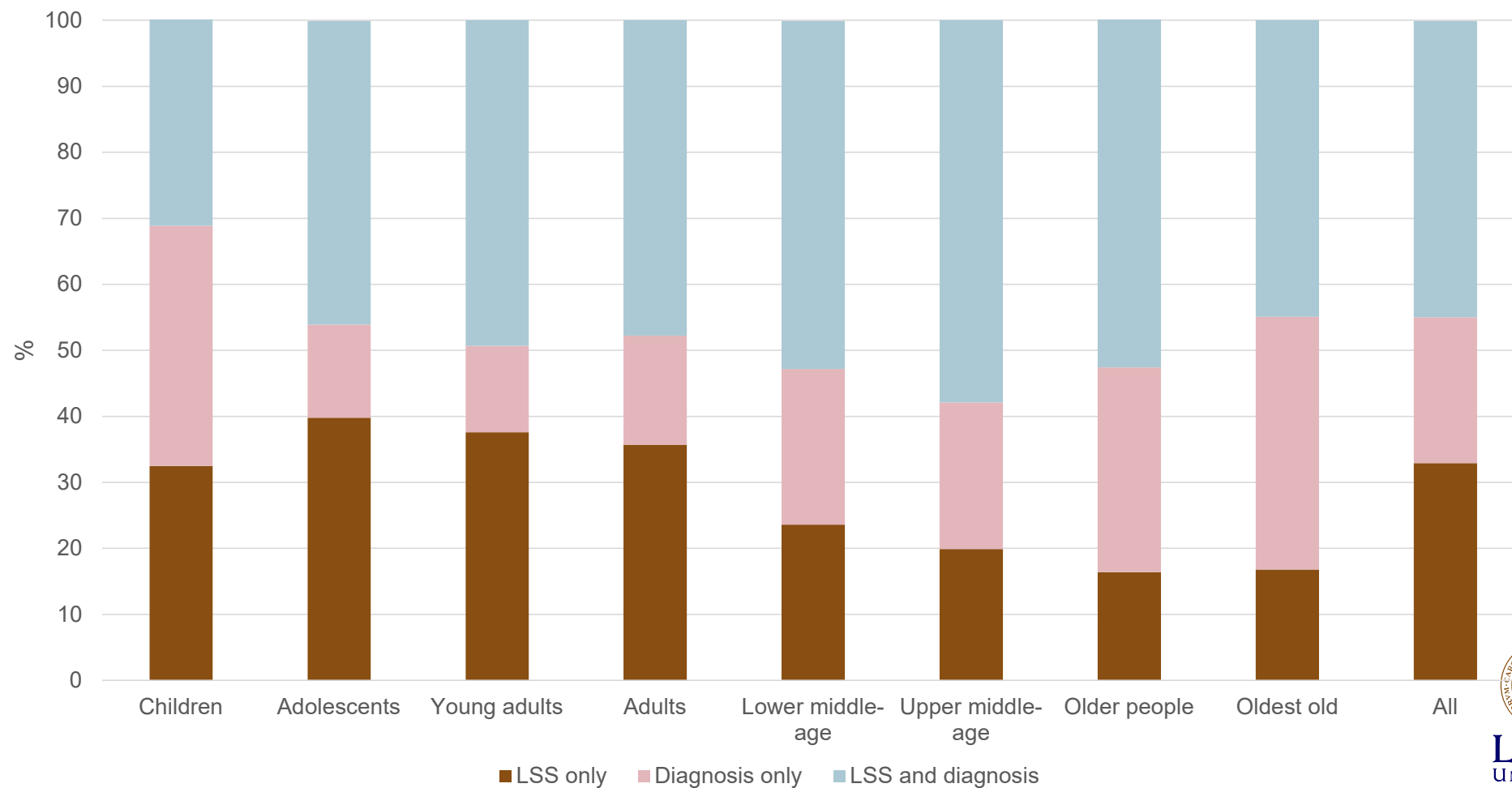
Age category	Age in 2014	Born	gPop (n)	ID (n)
Children	0-12 years	2002-2014	171 688	3 565
Adolescents	13-18 years	1996-2001	72 081	2 072
Young adults	19-24 years	1900-1995	96 811	2 380
Adults	25-44 years	1970-1989	324 553	3 902
Lower middle-age	45-54 years	1960-1969	160 913	1 147
Upper middle-age	55-64 years	1950-1959	143 057	884
Older people	65-79 years	1935-1949	183 875	659
Oldest old	80+ years	1901-1934	72 977	107



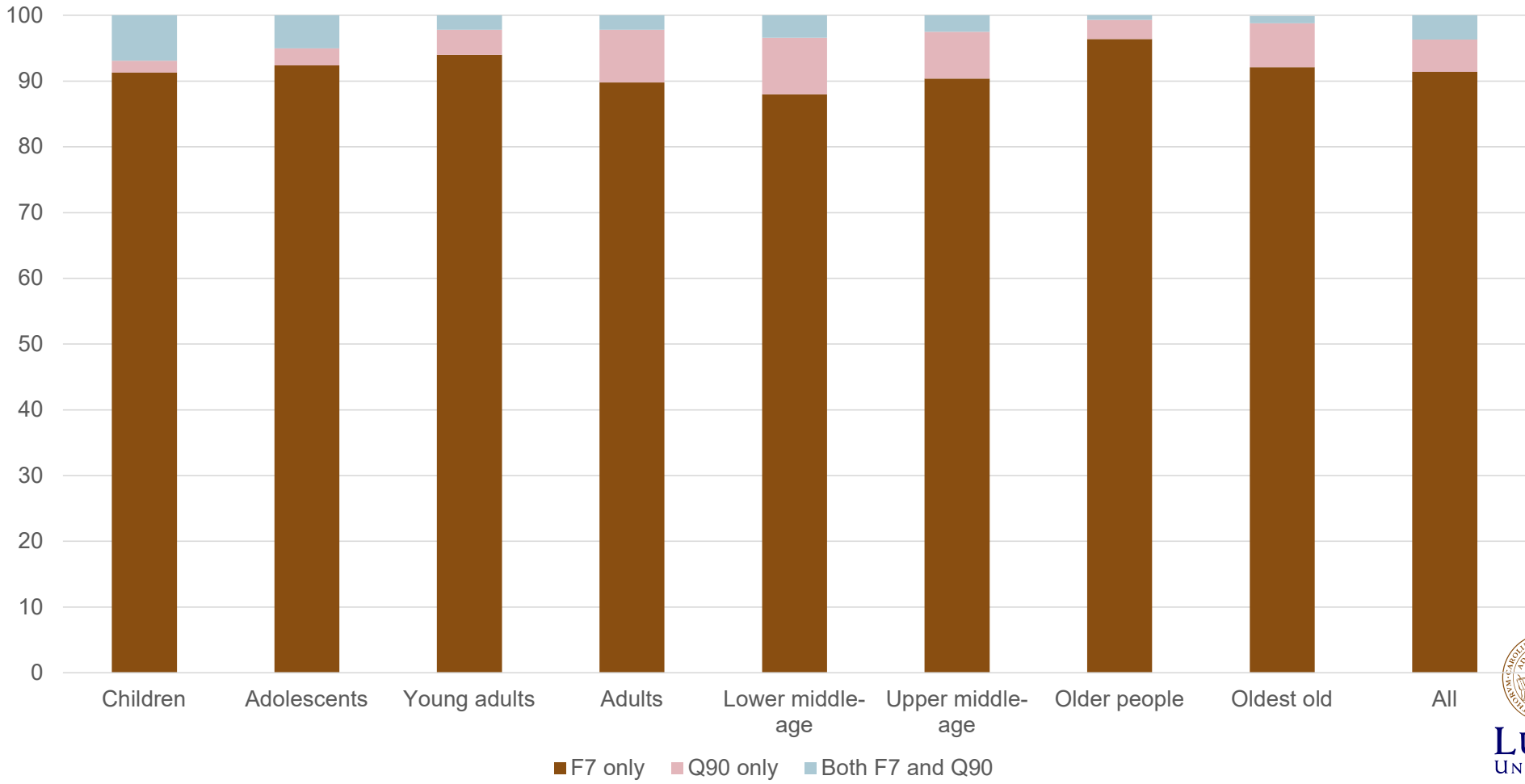
Age distribution



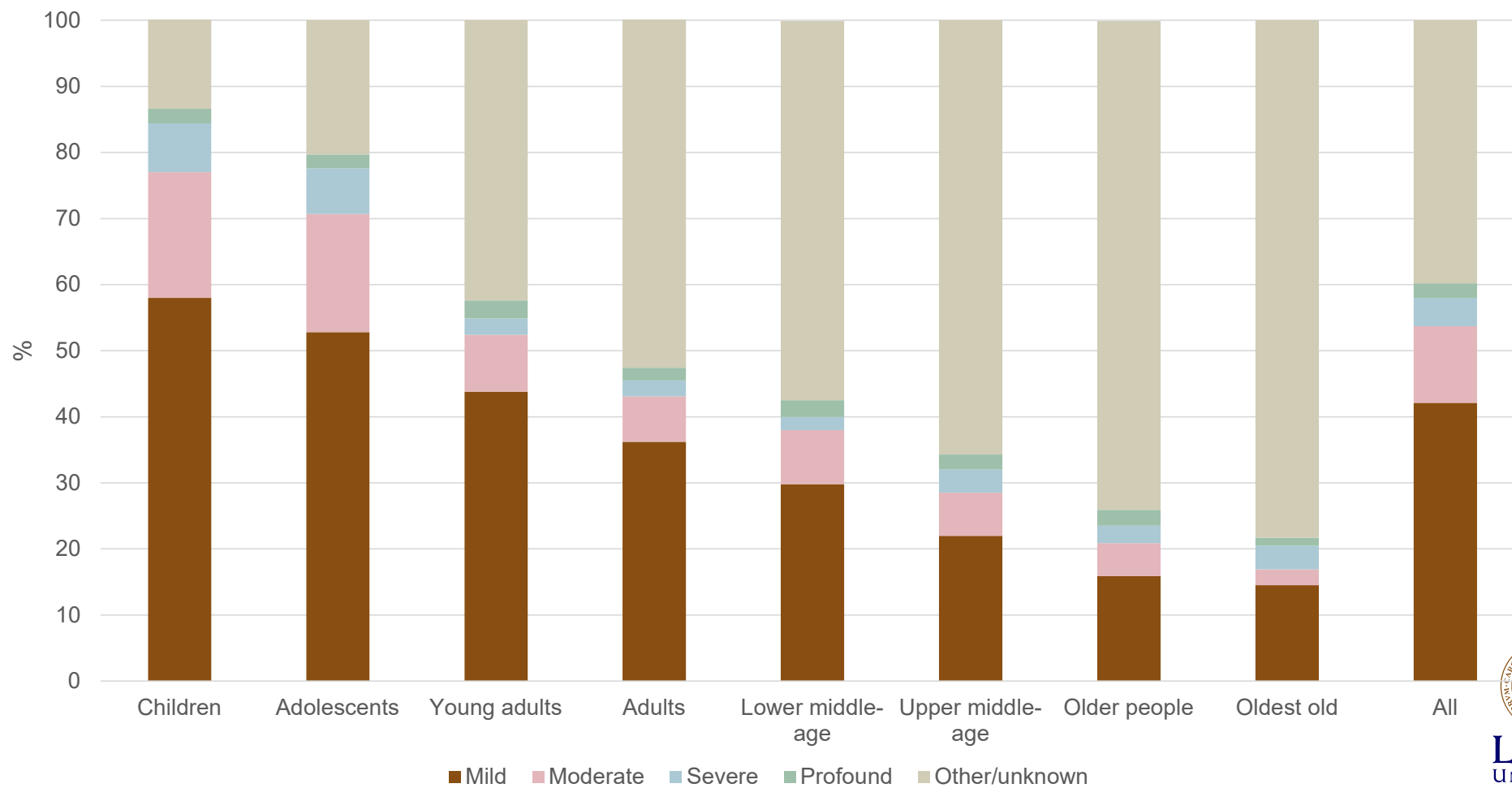
Reason for inclusion in the ID cohort



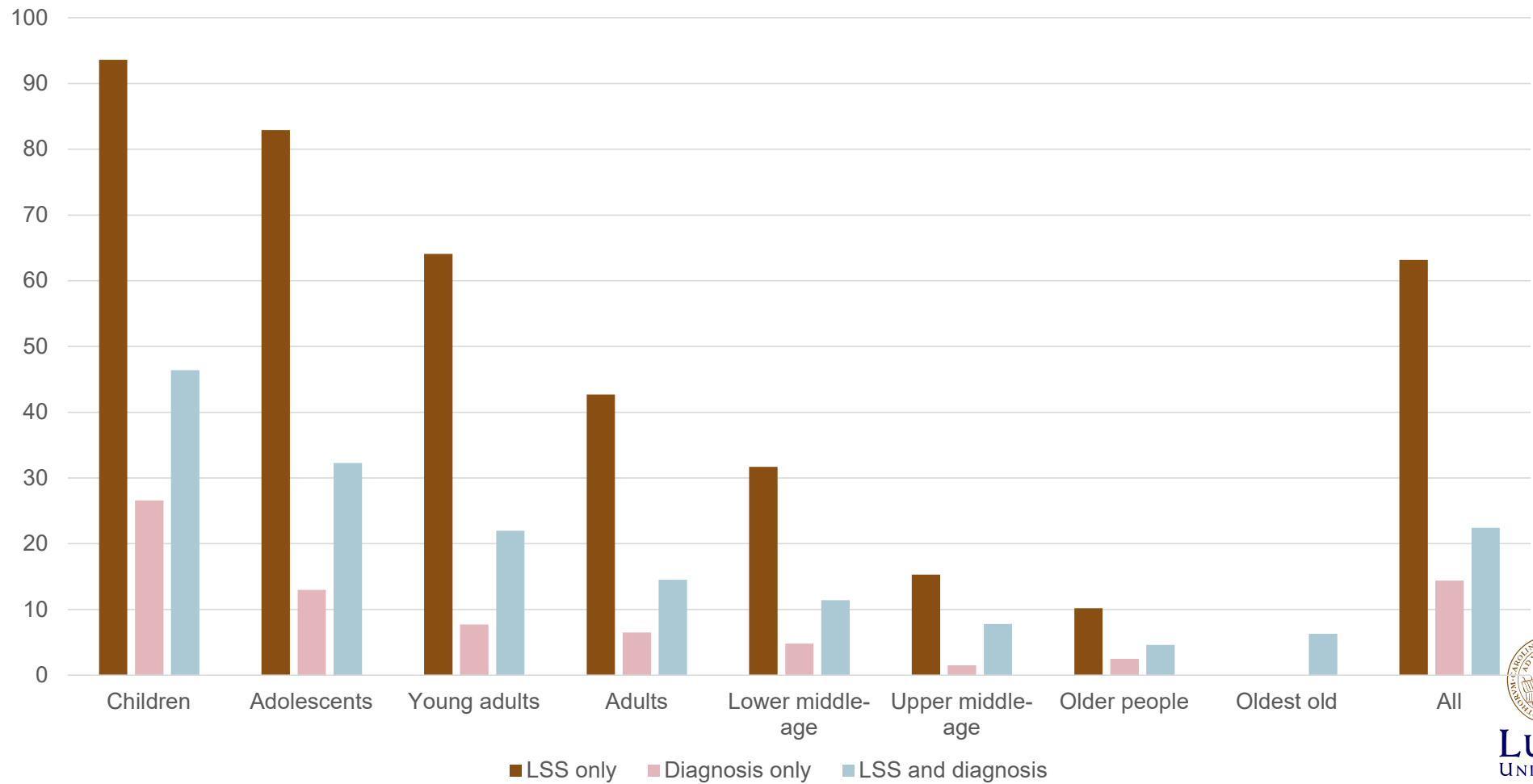
Type of ID



Most severe F7 diagnosis



Concomitant Autism Spectrum Disorder





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