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Prevalence of physical conditions and multi-morbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: cross-sectional study

Faculty of Public Health Conference 2018

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What does the evidence tell us?

People with intellectual disabilities have different health needs, shorter life expectancy and other health inequalities compared with the general population

There is likely to be a different pattern of health problems in people with intellectual disabilities due to genetic factors, sedentary lifestyles, diet and poorer access to health care

Most studies on physical health have methodological limitations (e.g. small scale, selected age groups/level of disability), few studies in the UK, no studies looking at certain physical health problems

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What does the evidence tell us?

There is a lack of consistency in reports on the prevalence of **single physical health conditions** in people with intellectual disabilities, due to the differences in methods used and populations studied

Prevalence rates ranged from:

- 18% to 99% for vision problems
- 33% to 50% for gastro-oesophageal reflux disease
- 18% to 84% for untreated dental caries
- 21% to 35% for obesity

Findings are conflicting

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What does the evidence tell us?

Only 5 studies were identified that investigated **multi-morbidity** among adults with intellectual disabilities

Three studies reported high rates of multi-morbidity:

- 71% in 695 older persons (McCarron et al. 2013)
- 80% in 1,047 older persons (Hermans et al. 2014)
- 40.6% in 8,014 adults across of all ages (Cooper et al. 2015)

Two further studies reported lower rates of multi-morbidity:

- 22.9% in 14,751 adults of all ages (vs 13.3% of other people) (Carey et al. 2016)
- 10% in 299 adults aged 16–49 years (vs 5% of other people) (Emerson et al. 2016)

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disabilities

Three studies reported high rates of multi-m

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Two further studies reported lower rates of

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- 10% in 299 adults aged 16–49 years (vs

Further Limitations:

- McCarron et al. (2013) - Relied on proxy reporting of known health conditions out of a list of 12
- Hermans et al. (2014) - included only 20 conditions
- Cooper et al. (2015) - Data extracted electronically from primary care case records on 38 conditions – only included conditions that had previously been presented to the GP
- Carey et al. (2016) - 19 long-term conditions evidenced to be of importance for the general population
- Emerson et al. (2016) - 15 health conditions and focused only on adults with mild intellectual disabilities

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Why is multi-morbidity important?

Multi-morbidity is important as its management is more complex than that of single conditions

Risk of:

- Drug-drug interactions
- Drug-disease interactions
- Disease-disease interactions

Examples:

- Osteoporosis, which can lead to multiple fractures and non-healing of bones, is treated by bisphosphonates, but people with gastro-oesophageal reflux disorder are unlikely to tolerate them
- People with dysphagia may be unable to take medication in tablet form for a wide range of conditions
- Psychotropic drugs, which are commonly prescribed in people with intellectual disabilities, have side effects including: visual disturbance, weight gain, lowered seizure threshold, constipation and ataxia

Health care systems, and care pathways, are focused on management of single conditions

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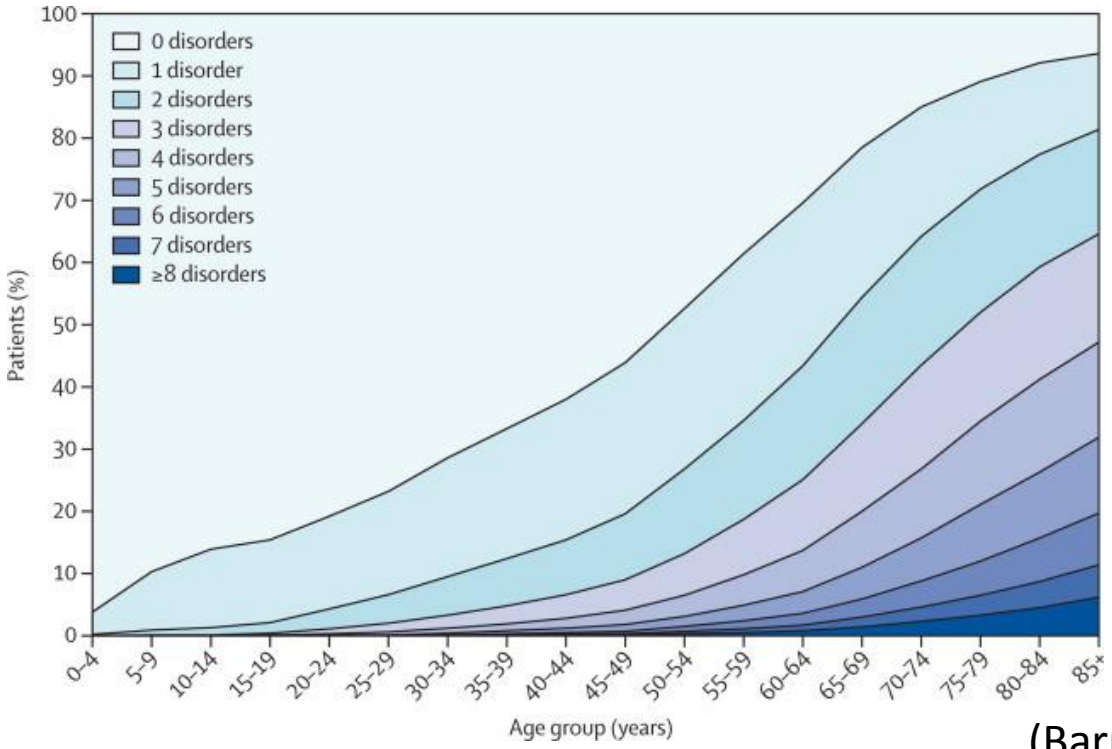
Why is multi-morbidity important?

In the general population, awareness has recently been raised on the importance of multi-morbidity, which becomes increasingly prevalent over the age of 50 years



(Barnett et al. 2012)

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Aim and method of project

Aim

To report the physical health conditions of adults with intellectual disabilities, with and without Down syndrome

Method

- Large prospective cohort study
- Adults (aged 16 and over) with intellectual disabilities
- Underwent a comprehensive health assessment

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Aim and method of project

Health Assessment

- 6 nurses reviewed primary care case records
- Comprehensive semi-structured health interviews
- Targeted physical examination – using the C21st Health Check:

  - Height and weight, waist circumference
  - Three recordings of blood pressure, pulse rate, pulse rhythm
  - Communication assessment
  - Oral examination
  - Peak flow
  - Inhaler technique (if used)
  - Feet and nail assessments
  - Urinalysis
  - Vision
  - Hearing

- Phlebotomy Protocol
- Referral Protocol (e.g. referral if any suggestion of possible hearing impairment)
- Findings discussed with one of three GP's who specialised in intellectual disabilities

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Project Aims

We wanted to find out:

1. What are the most common physical health conditions?

2. What is the extent of multi-morbidity for this cohort?

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Results

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Cohort Characteristics

- 1,023 adults consented to take part (65.5%)
- Mean age 43.9 years (range 16 – 83)
- 18.2% Down syndrome (n = 186)
- Mild (38.9%) Moderate (24.2%) Severe (18.9%) Profound (18%)

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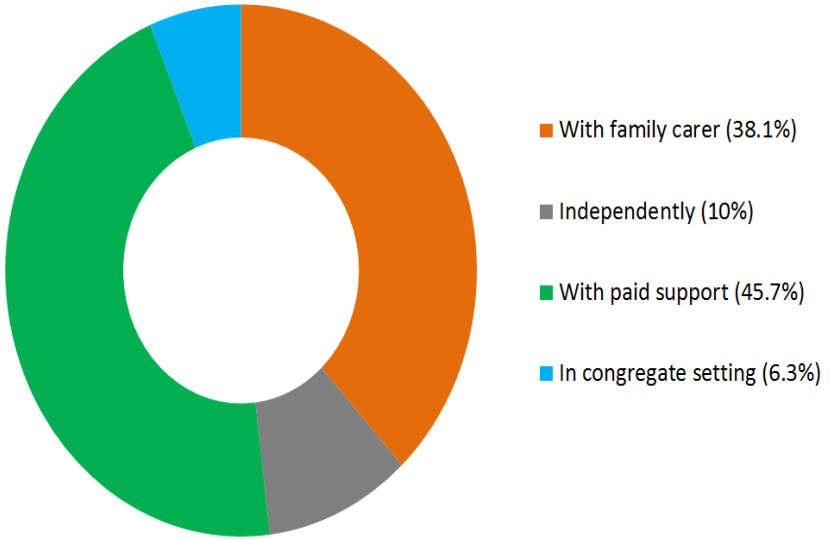
Cohort Characteristics (n = 1,023)

54.9% men

45.1% women



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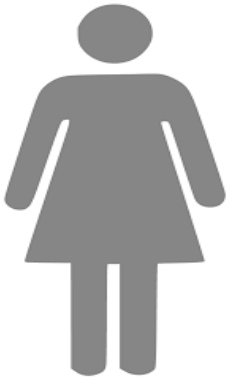
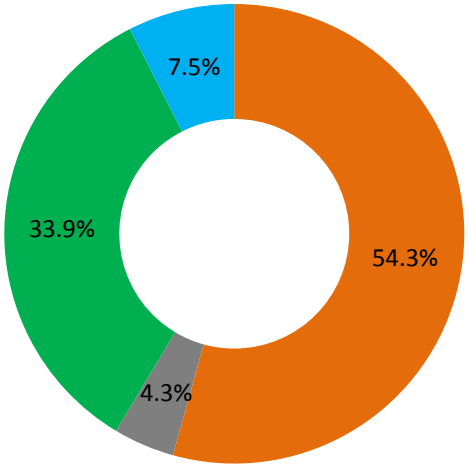
Down Syndrome (n = 186)

51.5% women



48.9% men



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Q1. What are the most common physical health conditions?

	Physical health condition	Whole cohort (n=1,023)	%
1	Vision impairment	481	47
2	Obesity	415	41
3	Epilepsy	349	34.1
4	Constipation	346	33.8
5	Ataxic/gait disorders (e.g. lack of muscle co-ordination)	306	29.9
6	Hearing impairment	276	26.9
7	Nail disorder (e.g. ingrowing nail)	238	23.3
8	Epidermal thickening/xerosis	217	21.2
9	Cerebral palsy and other paralytic syndromes	191	18.7
10	Osteoporosis	189	18.5
11	Fungal infection	167	16.3
12	Hypertension	158	15.4
13	Bone deformity	155	15.1
14	Musculoskeletal pain/dorsalgia	152	14.9
15	Eczema/Dermatitis	149	14.6
16	Gastro-oesophageal reflux disorder	148	14.5
17	Dysphagia	147	14.4
18	Lower respiratory tract infection	134	13
19	Dyspnoea/wheezing	131	12.8
20	Dental/oral	130	12.7

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Painful conditions

	Physical health condition	Whole cohort (n=1,023)	%
1	Vision impairment	481	47
2	Obesity	415	41
3	Epilepsy	349	34.1
4	Constipation	346	33.8
5	Ataxic/gait disorders (e.g. lack of muscle co-ordination)	306	29.9
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18	Lower respiratory tract infection	134	13
19	Dyspnoea/wheezing	131	12.8
20	Dental/oral	130	12.7

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Disabling conditions

	Physical health condition	Whole cohort (n=1,023)	%
1	Vision impairment	481	47
2	Obesity	415	41
3	Epilepsy	349	34.1
4	Constipation	346	33.8
5	Ataxic/gait disorders (e.g. lack of muscle co-ordination)	306	29.9
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19	Dyspnoea/wheezing	131	12.8
20	Dental/oral	130	12.7

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Potentially life threatening and painful/disabling

	Physical health condition	Whole cohort (n=1,023)	%
1	Vision impairment	481	47
2	Obesity	415	41
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4	Constipation	346	33.8
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20	Dental/oral	130	12.7

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Q1. What are the most common physical health conditions?

	Physical health condition	Down syndrome (n = 186)	Without Down syndrome (n = 837)
1	Vision impairment	48.4%	46.7%
2	Obesity	56.5%	37%
3	Epilepsy	13%	38.8%
4	Constipation	24.1%	36%
5	Ataxic/gait disorders (e.g. lack of musc	16.1%	33%
6	Hearing impairment	39.2%	24.2%
7	Nail disorder (e.g. ingrowing nail)	26.9%	22.5%
8	Epidermal thickening/xerosis	37.1%	17.7%
9	Cerebral palsy and other paralytic synd	4.3%	21.9%
10	Osteoporosis	5.9%	21.3%
11	Fungal infection	22.5%	14.9%
12	Hypertension	4.3%	17.9%
13	Bone deformity	14.5%	15.3%
14	Musculoskeletal pain/dorsalgia	17.2%	14.3%
15	Eczema/Dermatitis	20.4%	13.3%
16	Gastro-oesophageal reflux disorder	14%	14.6%
17	Dysphagia	12.9%	14.7%
18	Lower respiratory tract infection	18.3%	11.9%
19	Dyspnoea/wheezing	14.5%	12.4%
20	Dental/oral	15%	12.2%

There are variations with different categories of intellectual disabilities

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Q1. What are the most common physical health conditions?

	Physical health condition	Down Syndrome (n=186)	%
1	Obesity	105	56.5
2	Vision Impairment	90	48.4
3	Hearing Impairment	73	39.2
4	Epidermal thickening/xerosis	69	37.1
5	Nail Disorder (e.g. ingrowing nail)	50	26.9
6	Constipation	45	24.2
7	Thyroid Disease	45	24.2
8	Fungal Infection	42	22.6
9	Eczema/Dermatitis	38	20.4
10	Skin Infection	35	18.8
11	Lower Respiratory Tract Infection	34	18.3
12	Musculoskeletal Pain	32	17.2
13	Ataxic/Gait Disorder	30	16.1
14	Congenital Heart Disease	30	16.1
15	Dental Health	28	15.1
16	Bone Deformity	27	14.5
17	Dyspnoea	27	14.5
18	Gastro-Oesophageal Reflux Disease	26	14
19	Pre Menstrual Tension	25	13.4
20	Epilepsy	24	13

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Comparison with the general population

Adults with intellectual disabilities (n = 1,023) (Kinnear et al. 2018)	Adults in General Population (n = 1,416,364) (Cooper et al. 2015)
Vision impairment	Hypertension
Obesity	Painful Condition
Epilepsy	Asthma
Constipation	Coronary Heart Disease
Ataxic/gait disorders	Irritable bowel
Hearing impairment	Dyspepsia
Nail disorder	Diabetes

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2. What is the extent of multi-morbidity for this cohort?

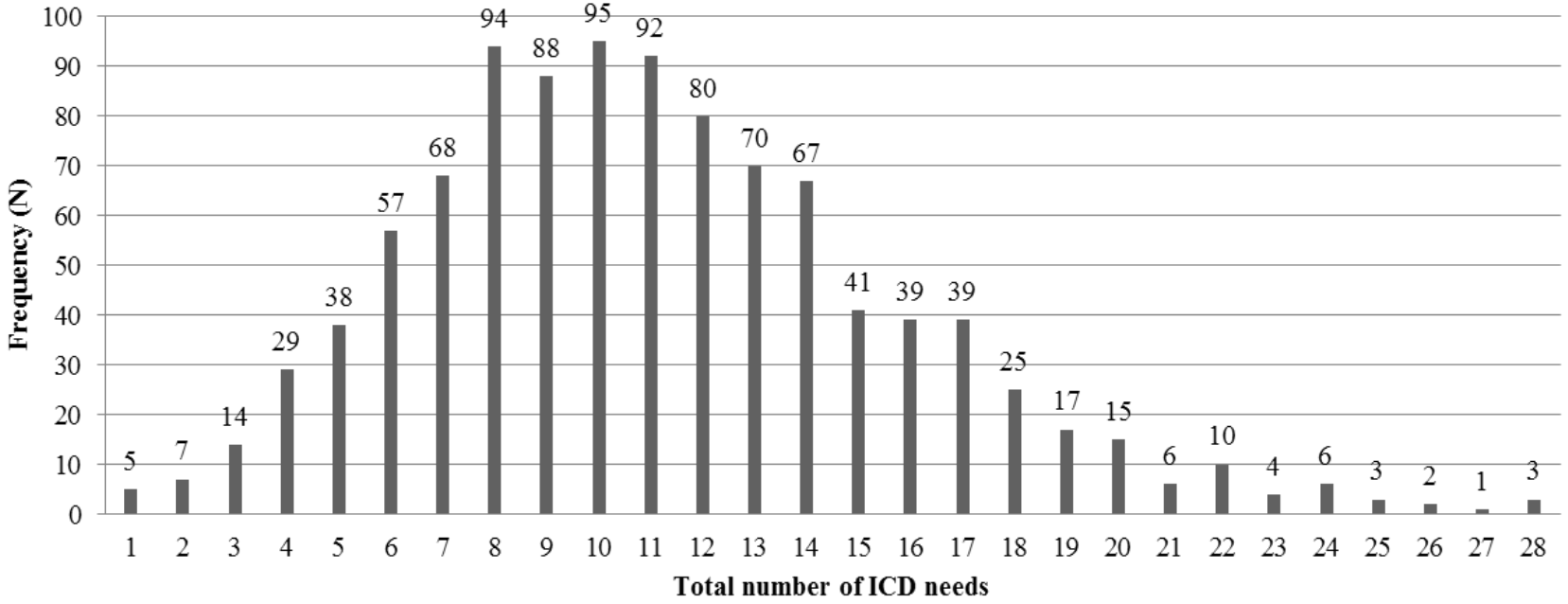

Figure 1. Total number of physical health conditions

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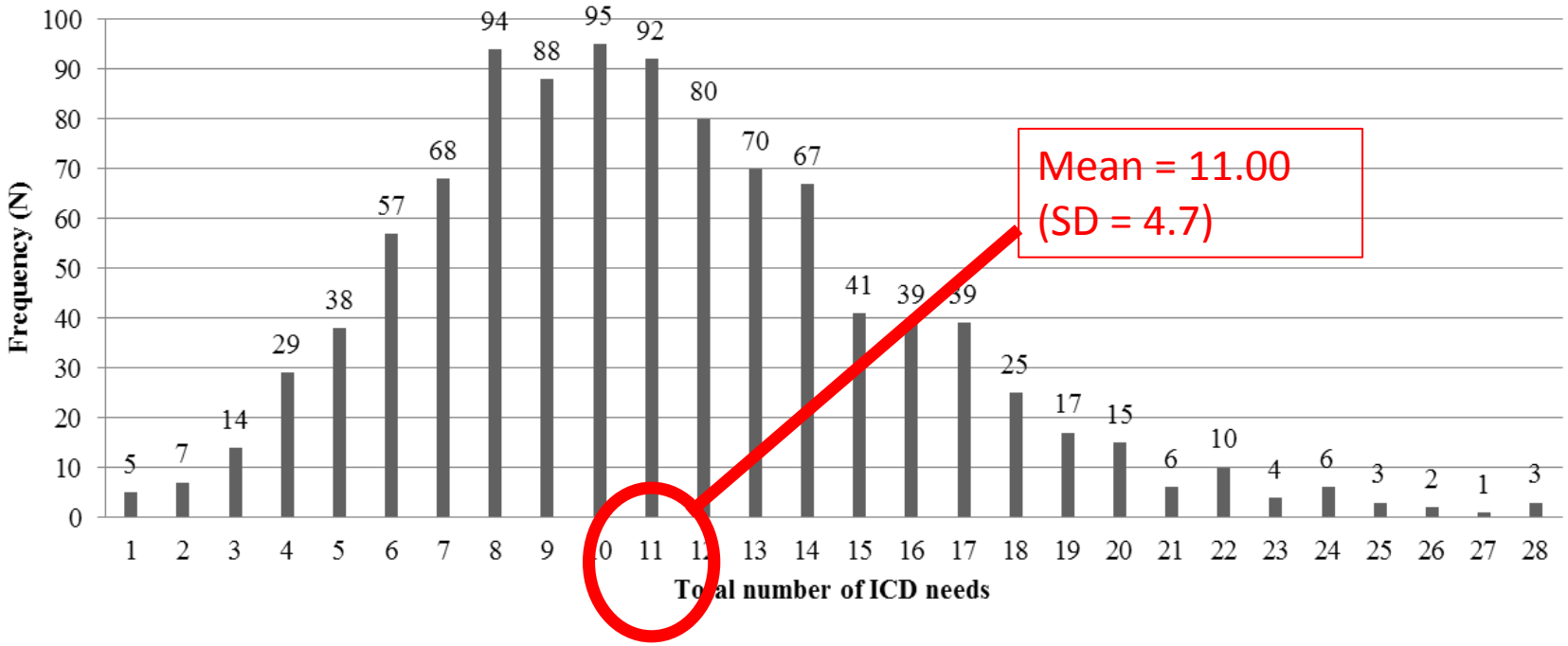
2. What is the extent of multi-morbidity for this cohort?



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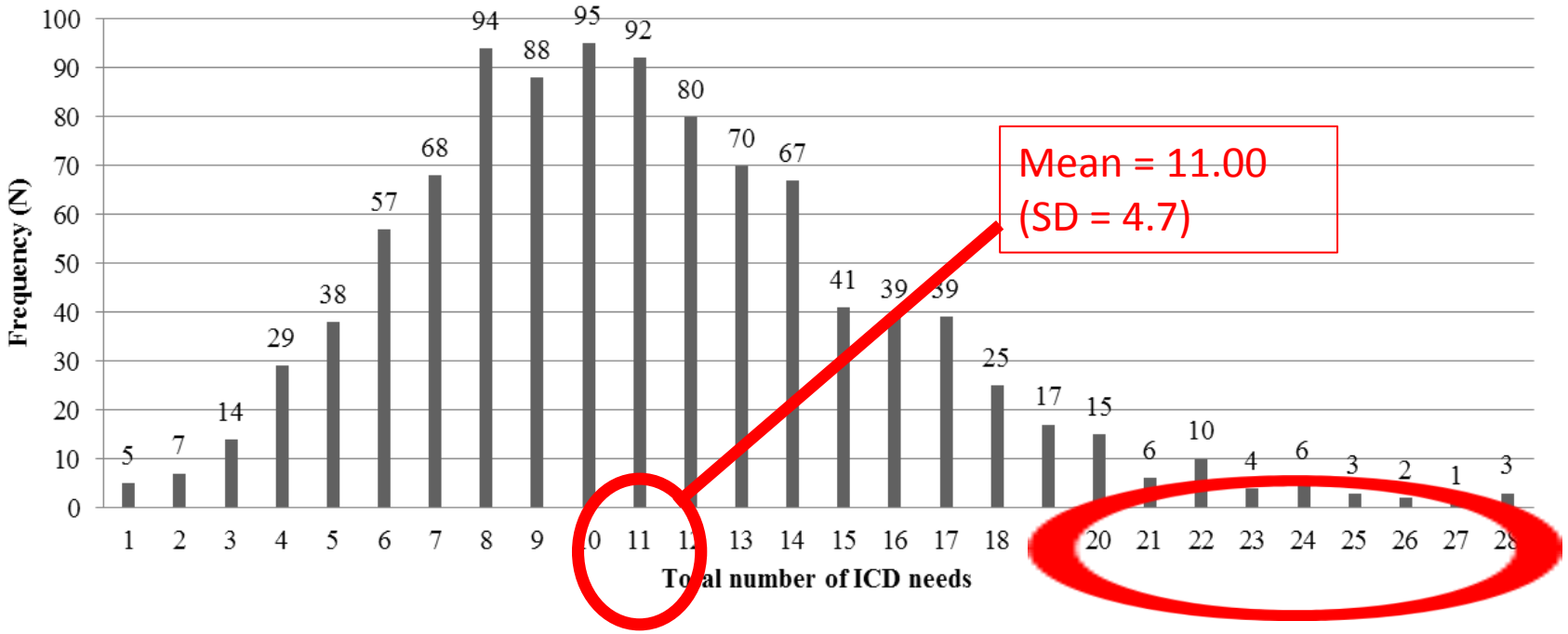

Figure 1. Total number of physical health conditions

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2. What is the extent of multi-morbidity for this cohort?

Mean Age of 43.9 years

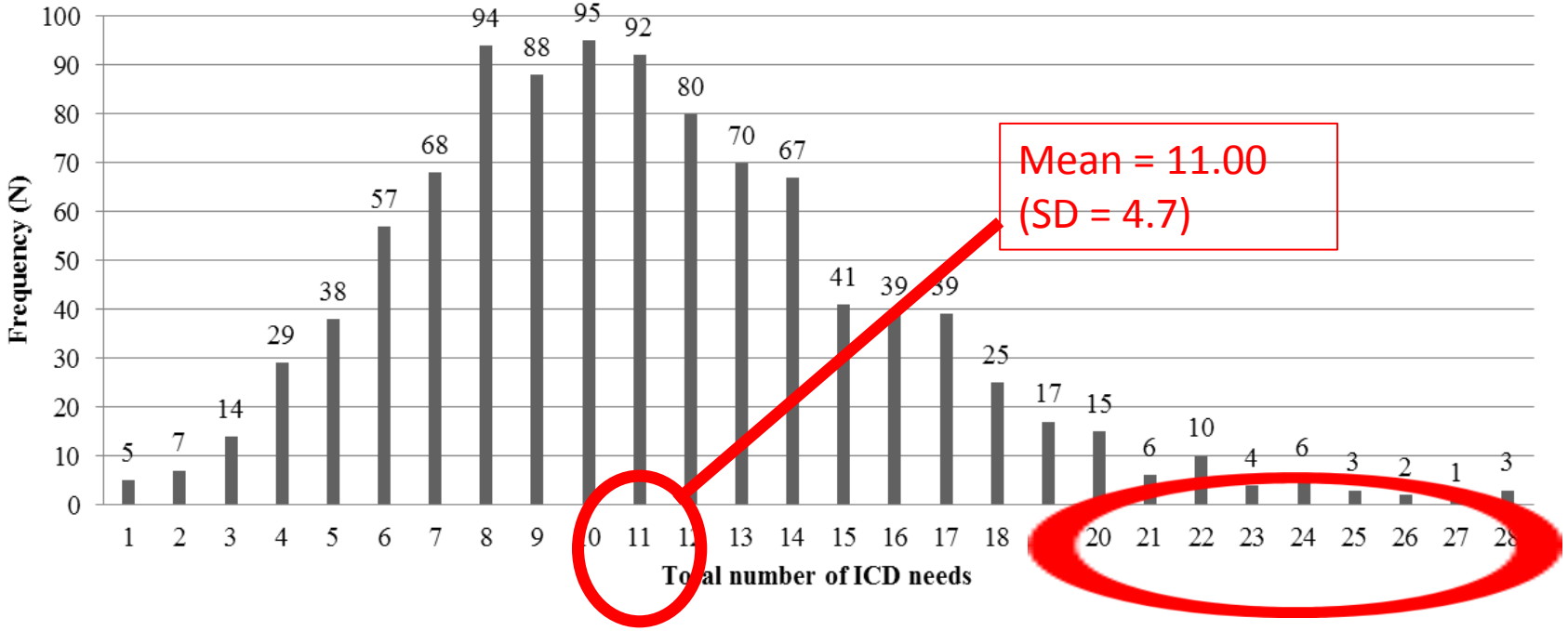

Figure 1. Total number of physical health conditions

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2. What is the extent of multi-morbidity for this cohort?

Mean Age of 43.9 years

- **99.2% of participants had at least one condition**
- **98.7% had two or more conditions**

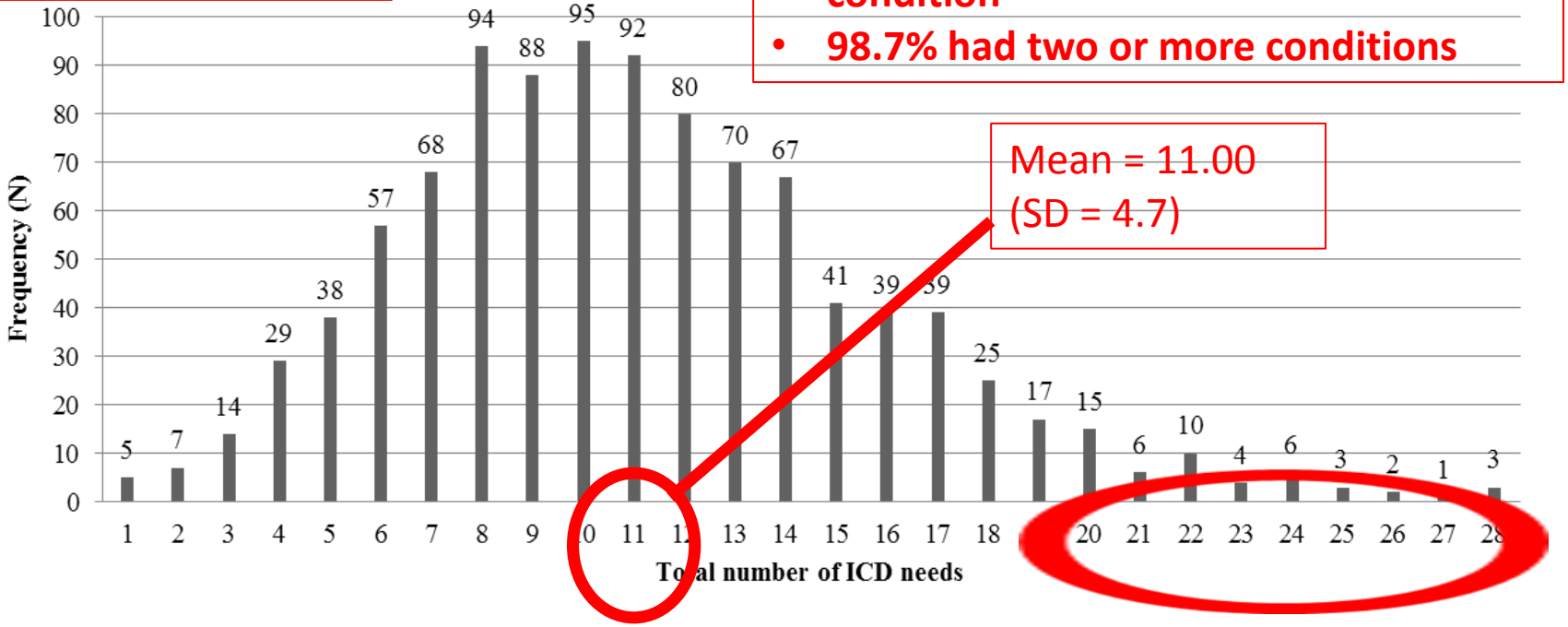

Figure 1. Total number of physical health conditions

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2. What is the extent of multi-morbidity for this cohort?

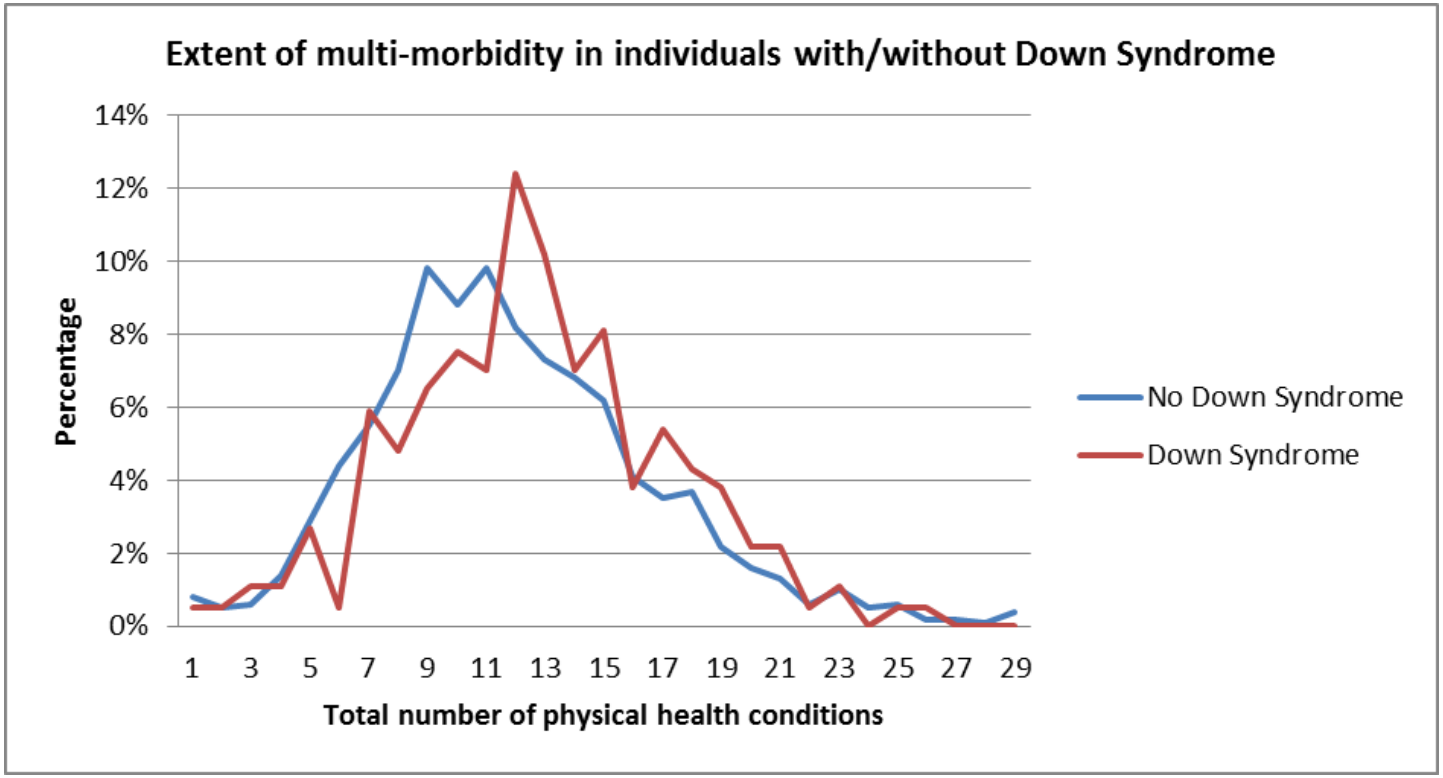

Figure 2. Extent of multi-morbidity in individuals with learning disabilities with and without Down Syndrome

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Conclusions

- This is the first study to report on multi-morbidity in people with intellectual disabilities across the adult lifecourse, in a large population-based sample where each individual had their health comprehensively checked
- Multi-morbidity is important as its management is more complex than that of single conditions and health care services care pathways are organised on single diseases
- The list of most prevalent health conditions in adults with intellectual disabilities differs from that seen in the general population, so the recent work to better understand and address multi-morbidity (Barnett et al. 2012) does not transfer readily to the population with intellectual disabilities
- The extent of multi-morbidity in the adults with Down syndrome was similar to adults with intellectual disabilities without Down syndrome but patterns of disease clusters differ
- Many of these conditions are painful, disabling, and/or life threatening; in the main they are amenable to treatment if high quality care is provided, and multi-morbidity taken account of

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Implications for policy and practice

Our findings are both novel and important, and ultimately have significant implications for service planning and development

- It is vital that healthcare professionals and carers have increased awareness of commonly occurring conditions in adults with intellectual disabilities so that they can identify and report physical health conditions in a timely manner

- Any policy initiatives or guidelines on multi-morbidity need to be relevant throughout all stages of adulthood in people with intellectual disabilities

- Health check programs need to include checks for the most common problems experienced by people with intellectual disabilities

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Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: cross-sectional study

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ABSTRACT

Objectives To investigate the prevalence of multimorbidity in adults with intellectual disabilities with and without Down syndrome.

Design Large, population-based cross-sectional study.

Setting The geographical area of one Health Board, Scotland.

Participants All adults (aged 16+ years) known to general practitioners to have intellectual disabilities and adults receiving services provided or paid by intellectual disabilities health or social work services. 1023/1562 potential participants took part (65.5%); 562 (54.9%) men and 461 (45.1%) women, aged 43.9 years (16–83 years). 186 had Down syndrome and 837 did not.

Main outcome measures The prevalence of International Statistical Classification of Diseases, 10th revision, physical health conditions and multimorbidity detected at a comprehensive health assessment.

Results The mean number of physical health conditions/participant was 11.04, and 98.7% had multimorbidity. The most prevalent conditions are painful and/or disabling and, in some cases, life threatening. The five most prevalent were visual impairment, obesity, epilepsy, constipation and ataxic/gait disorders. The pattern of multimorbidity differs from that seen in the general population and is spread across the entire adult life course. The extent of multimorbidity in the adults with Down syndrome was similar to that of the adults without Down syndrome, while the prevalence of individual conditions differed.

Conclusions This robustly designed study with a large population found an extremely high prevalence of multimorbidity in adults with intellectual disabilities across the entire adult life course. This increases complexity of medical management that secondary healthcare services and medical education are not yet geared towards, as these tend to focus on single conditions. This is in addition to complexity due to limitations in communication and understanding. As the physical conditions within their multimorbidity also differ from that seen in the older general population, urgent attention is needed to develop the care pathways and guidelines that are required to inform and so improve their healthcare.

Strengths and limitations of this study

- This is the first study to have reported on multimorbidity in people with intellectual disabilities across the adult life course, where each individual had their health assessed by trained professionals.
- The health assessments were systematic and detailed.
- The study is large and population based, and the participation rate was high.
- A limitation is that the study was only conducted in one area of Scotland.

INTRODUCTION

People with intellectual disabilities have different health needs, shorter life expectancy and other health inequalities compared with the general population.[1–4] Despite this, there is surprisingly little reported on their prevalence of physical ill health and multimorbidity (two or more conditions in addition to intellectual disabilities), and few studies were population based and conducted on a large scale. Multimorbidity is important as its management is more complex than that of single conditions, with risks of drug–drug interactions, drug–disease interactions and disease–disease interactions. However, healthcare systems, and care pathways, are focused on management of single conditions. In the general population, awareness has recently been raised on the importance of multimorbidity, which becomes increasingly prevalent over the age of 50 years.[5]

Only five studies were identified that investigated multimorbidity among adults with intellectual disabilities. Three studies reported high rates of multimorbidity: 71% in 695 older persons with intellectual disabilities,[6] 80% in 1047 older persons receiving

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